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Theoretical and practical considerations to inform the self-management of physical stroke rehabilitation

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Dedication

I would like to dedicate this dissertation to my beloved grandfather; Mr. Keung Wah Chan, who was my great supporter but passed away following a stroke. This is my motivation to investigate stroke and to find out ways to help stroke survivors to manage their own conditions according to their needs and preferences in order to enable them to live with dignity.

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Abstract

Aim: This study aimed to develop a new stroke exercise manual to promote self-managed rehabilitation with the support of available information and communication technology and a new theoretical foundation for functional physical stroke recovery in the community.

Background: Stroke is the biggest single cause of major disability worldwide and is the single largest cause of adult disability in England. Functional physical recovery continues over a long period of time after stroke, thus, continuous support is essential. Limited resources make it difficult to provide long-term face-to-face services. Hence, there is a need to develop alternative approaches to enable stroke survivors to self-manage their own exercises over the long-term; such as self-managed exercise manual and the use of available information and communication technologies (ICTs). Although the use of physical exercises, self-management concepts and ICTs are shown to be promising for stroke rehabilitation, little was known about integrating them along with educational and technology related theories to empower stroke survivors to manage their own exercise for their continued physical functional rehabilitation in the community.

Methodology & Methods: This is a mixed methods research consisting of 3 parts. The overall design of this research was based on the user-centred design principle and the model of evidence-based clinical decisions. The first part is the foundation phase in which literature related to physical functional stroke rehabilitation, stroke self-management and the use of ICTs for stroke rehabilitation were reviewed. The second part is phase 1 in which semi-structured interviews were conducted with community-dwelling stroke survivors with physical disabilities, their carers, and physiotherapists and occupational therapists who were purposively recruited to identify the components required to develop the manual. It was verified and refined with the interviewees using surveys. The third part is phase 2 in which a survey was conducted with another group of therapists to evaluate the acceptability, suitability, feasibility and safety of using the manual from a professional perspective. Content thematic analysis was used to analyse qualitative data collected from the interviews and questionnaires. Descriptive statistical analysis was used to analyse quantitative data collected in the surveys. A mixed methods matrix was used to integrate and interpret both qualitative and quantitative data.

Findings: In foundation phase, seven types of exercise were identified from the current evidence for physical functional stroke rehabilitation which were included into the design of the new manual in this research project. In phase 1, eight themes were generated from the interviews with 18 stroke survivors and 8 of their carers. Six themes were identified from 7 therapists. Findings were used to support a new theoretical foundation called the “gear model” which consists of self-efficacy theory, adult learning theory (andragogy), self-regulated learning, motor learning theory and technology acceptance model to suggest an integrated conceptual support to the design of the manual. A refinement study was conducted with 15 interviewed stroke survivors and 6 therapists. The results indicate that the manual is understandable and usable. It was evaluated with another group of 7 therapists in phase 2. The results of the evaluation show that the manual is considered to be acceptable, suitable, feasible and safe to be used from a professional perspective. A conceptual framework was established using the themes and selected theories to propose a way to use the manual in clinical practice.

Conclusion: A new stroke exercise manual has been developed to suggest an alternative approach for stroke survivors to manage their own exercise for rehabilitation. Both theoretical and practical considerations were involved in the development process of the manual. Further research is required to examine the impact and value of the manual for stroke rehabilitation. This research has contributed the following new knowledge to the field of community stroke rehabilitation:

1. Integrated theoretical foundation for the self-management of stroke exercises with the support of using available ICTs called “Gear Model”
2. Knowledge about using ICTs that stroke survivors have and wish to use for support
3. Process and components required to individualise a stroke exercise manual with the support of available ICTs to promote self-managed physical functional rehabilitation in the community

Structure of this dissertation

This dissertation reports my studies of developing a new stroke exercise manual to promote self-managed rehabilitation. Ten chapters are included in this document. It begins with background information about the topic areas and the identification of related services and research gaps in chapter one. Then, three literature reviews were conducted and reported in chapter two to provide an overview of the research areas from the related literature, including physical exercise for physical stroke rehabilitation, stroke self-management interventions and the use of technology for stroke rehabilitation.

Then, chapter three goes on to describe the aim, objectives and questions of this research with the understanding about the topic areas from the literature. Chapter four elucidates the methodology and methods adopted to investigate the questions so as to address the aim. Chapter five presents the strategy used to control the quality of the studies.

The findings of interviews with stroke survivors and their carers, and physiotherapists and occupational therapists are reported in chapters six and seven respectively. Then, the information obtained from the stroke survivors and therapists were used to form a prototype programme in chapter eight, in which the refinement process of the programme is reported. In addition, a new theoretical foundation: the “Gear Model”; was created to underpin the programme in the same chapter.

Chapter nine reports the results of the evaluation of the programme with another group of therapists following to the development stage. Finally, chapter ten brings the overall discussion and conclusion of this research together. The above chapters are grouped into the following 5 sections:

Section 1: Introduction and rationale of the research

It includes chapter 1 to provide background information and fundamental concepts about the topic of this research. The rationale of this research was also explored in this section.

Section 2: Foundation phase: preparation stage

Chapter 2, 3, 4 and 5 are categorised in this section to illustrate the preparation stage.

Section 3: Phase 1: development stage

Chapter 6, 7, 8a and 8b are included in this section to present the development process of the programme, in which a refinement stage is involved.

Section 4: Phase 2: evaluation stage

Chapter 9 is presented in this section to describe the professional evaluation of the programme.

Section 5: Discussion and conclusion

Chapter 10 consists of overall discussion, implications, limitations, future research, and philosophical reflection as well as conclusion based on the work of this research.

Abbreviations

ADL/ADLs	Activities in daily living/livings
CCM	Chronic Care Model
DH	Department of Health
FAST	Frenchay Aphasia Screening Test
HBT	Health Behaviours Theory
ICF	International Classification of Functioning, Disability and Health
ICT/ICTs	Information and Communication Technology/Technologies
ISWP	Intercollegiate Stroke Working Party
LTs	Learning Theories
MEBCD	Model for Evidence-Based Clinical Decisions
MLT	Motor Learning Theory
MoCA	Montreal Cognitive Assessment
NAO	National Audit Office
NHS	National Health Services
NICE	National Institute for Health and Clinical Excellence
ONS	Office for National Statistics
OT	Occupational Therapist
PSMrS	Personalised Self-Managed Rehabilitation System
PT	Physiotherapist
RCP	Royal College of Physicians
RMI	Rivermead Mobility Index
SCT	Social Cognitive Theory
SIGN	Scottish Intercollegiate Guidelines Network
SMPRESS	Self-Managed Physical Rehabilitation Exercise programme for Stroke Survivors
SRL	Self-Regulated Learning
TAM	Technology Acceptance Model
UCD	User-Centred Design
UK	United Kingdom
WHO	World Health Organization

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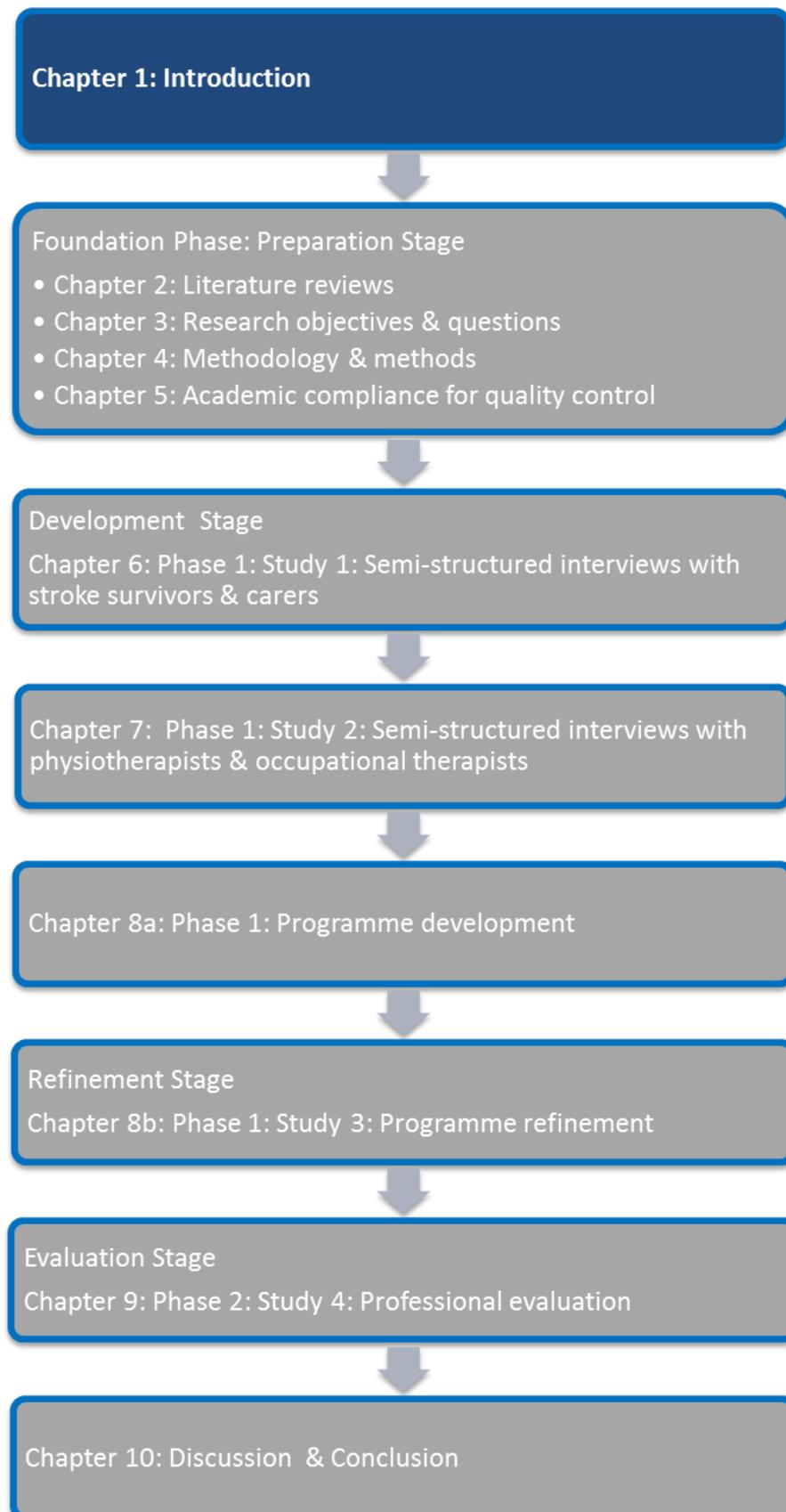
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Section 1: Introduction & rationale of the research



Chapter 1: Introduction

1.1 Background of topic and the research

1.1.1 Background

Stroke is the biggest single cause of major disability worldwide (WHO, 2011a). It has significant impact on stroke survivors' lives and health, society and economy, worldwide and nationwide. Physical consequences of stroke affect individuals over the long-term. World Health Organization (WHO) estimates that about 15 million people suffer a stroke annually worldwide, 5 million of whom are left permanently disabled, placing a burden on family and community (WHO, 2011a). Stroke is the single largest cause of adult disability in England. About 300,000 people live with post-stroke disabilities in England (NAO, 2010a, DH, 2007b, DH, 2004a).

In view of the economic and social burden of stroke, it is important to explore the way to improve the provision of stroke services. Post-stroke conditions directly cost about £2.8 billion to the NHS, and the economy about £2.4 billion for informal care costs, and £1.8 billion income lost to productivity and disability per year (DH, 2007b). The total annual direct cost of stroke in the UK has been estimated to be about £4 billion or 5.5% of the total UK expenditure on health care. The estimated total annual societal costs are about £8.9 billion (Saka et al., 2009). Stroke care costs about £23,315 per patient, and quality-adjusted life years is 2.54 in the UK (NAO, 2010b). Stroke burdens will increase from around 38 in 1990 to 61 million disability-adjusted life years in 2020 worldwide (WHO, 2011a). Hence, managing disabilities post-stroke is an important healthcare focus nationwide and worldwide.

Functional physical consequences post-stroke are common and have significant long-term health related impact for individuals, their carers and society. Therefore, continuous support is needed for ongoing stroke recovery. However, it is costly and difficult to provide direct face-to-face services from physiotherapists and/or occupational therapists for continuous rehabilitation to stroke survivors in the long-term. Longer term physical stroke rehabilitation in the community remains a challenge to clinicians and stroke survivors.

Thus, a new and usable solution is needed for functional physical stroke rehabilitation in the longer-term, which is the core reason to conduct this study.

1.1.2 Research topic

The development and evaluation of a remotely self-managed exercise intervention based on combined theories to support stroke survivors' physical rehabilitation in the community.

1.1.3 Research aim

The purpose of this study was to develop a self-managed exercise intervention with the support of available information and communication technology and theoretical foundation for functional physical stroke rehabilitation in the community.

1.1.4 Research rationale

Post-stroke disability limits stroke survivors' activities and participation. Although stroke-specific physical exercises are safe and effective to improve physical function post-stroke (Hakkennes and Keating, 2005, Ada et al., 2006, Pang et al., 2006, van de Port et al., 2007, Wevers et al., 2009, Brazzelli et al., 2011), it takes a long time for stroke survivors to learn, understand and carry out those exercises.

Stroke survivors have different functional recovery needs due to their different clinical features, personal requirements and goals. Their abilities may change over time. However, it is costly and difficult to provide continuous direct professional services to stroke survivors to modify and practice those specific exercises for continued improvement. It indicates that a practical and sustainable approach is needed to provide specific and personalized support.

The use of physical exercise, self-management support and information and communication technologies (ICTs) are proven to be safe and beneficial for stroke rehabilitation separately (Johansson and Wild, 2011, Brazzelli et al., 2011, Jones and Riazi, 2011). However, little is known about how to enable stroke survivors to

self-manage their own exercise with the use of available ICTs for their physical functional rehabilitation in the community.

Health service gap

Significant proportions of stroke survivors reported unmet health related needs in a recent survey across the UK, including mobility, pain, falls and fatigue. They reported wanting more information for their disability post-stroke (McKevitt et al., 2010). This indicates that stroke survivors' needs are still unmet after they have been discharged from stroke rehabilitation services in the UK.

Stroke recovery continues for many years (DH, 2007b). Thus, ongoing support is required. However, there is insufficient resource to continuously support stroke survivors after their discharge from the National Health Service (NHS) specialist stroke rehabilitation services. Long-term support for stroke survivors to self-manage disabling factors caused by stroke is emphasized in the national stroke strategy (DH, 2007b). Although stroke support groups are available in some areas in the UK, they may not be available in some areas and may not be sustained nor be accessible to every stroke survivor including those with physical disabilities.

Research gaps

Self-management & stroke rehabilitation

Stroke-specific self-management programmes are reported to be safe, feasible, acceptable and effective for stroke recovery, including for physical functions, disability and health (Lennon et al., 2013, Harwood et al., 2012, Cadilhac et al., 2011, Marsden et al., 2010, Jones and Riazi, 2011, Allen et al., 2009, Jones et al., 2009, Huijbregts et al., 2008). However, these programmes involve multiple aspects for stroke. Little is known about self-managing stroke-specific exercises particularly for physical functional rehabilitation with the use of available ICTs. The Health Foundation also argues that one size of self-management does not fit all (Silva, 2011). Hence, it is necessary to develop a self-managed programme particularly to support stroke survivors to manage their own exercises with the use of available ICTs for their ongoing physical rehabilitation.

Theoretical underpinning of self-management & technology for stroke rehabilitation

Although self-efficacy has recently been suggested to be an important construct to support self-management post-stroke from evidence, it is unlikely to be the sole concept in the use of stroke self-management (Jones and Riazi, 2011). Therefore, further development of a theoretical foundation to support the use of self-management post-stroke from the existing stroke self-management interventions. The theoretical base and conceptual framework of self-managing stroke exercises for physical rehabilitation with the use of available ICTs is still unclear, although technologies had been used for that purpose (Mawson et al., 2013, Huijbregts et al., 2010, Taylor et al., 2009, Lai et al., 2004).

Information and communication technologies & stroke rehabilitation

Jones and Riazi (2011) have highlighted the uncertainty regarding the most suitable method to deliver self-management interventions. Since it is costly and difficult to continuously provide direct professional services to stroke survivors in the long-term, alternative and more sustainable methods are needed to provide continuous support instead of relying on a direct service. The use of available ICTs may be a possible solution to provide this continued support to stroke survivors.

Using ICTs is reported to be effective in improving physical functioning and disability, and health outcome post-stroke (Liebermann et al., 2006, Chumbler N.R. et al., 2011, Johansson and Wild, 2011). Therefore, they are proposed in this study.

Although the use of technology has been shown to be a feasible, safe, acceptable and effective alternative to deliver healthcare for stroke rehabilitation (Lai et al., 2004, LaMonte et al., 2008, Huijbregts et al., 2009, Lutz et al., 2009, Taylor et al., 2009), the use of ICTs to deliver stroke-specific physical exercises and self-management services to stroke survivors for functional physical rehabilitation is unclear.

1.2 Definition of stroke

The World Health Organization (WHO) defines stroke as:

“rapidly developing clinical signs of focal (at times global) disturbance of cerebral function, lasting more than 24 hours or leading to death with no apparent cause other than that of vascular origin” (Üstün et al., 2003).

“A stroke is caused by the interruption of the blood supply to the brain, usually because a blood vessel bursts or is blocked by a clot. This cuts off the supply of oxygen and nutrients, causing damage to the brain tissue” (WHO, 2011c).

Since there is no universal definition for “long-term/chronic condition of stroke”, I suggest the following working definition to define the above term in this research.

“A group of multiple incurable health consequences resulted from stroke that will continue after the individual has been discharged from stroke rehabilitation services. Those consequences can limit daily function and participation of the individual in the community.”

1.3 Functional physical consequences of stroke

Stroke causes amongst other things, motor deficits, affecting the control and physical movement of limbs, which limit activities of daily livings (ADLs) (Duncan, 1994, Hankey, 2002, MacWalter and Shirley, 2003, Snell, 2009). Physical impairments post-stroke may limit functional independence and increase healthcare burden. Activity limitation is shown to be strongly associated with stroke and chronic health conditions (Stineman et al., 2011) and is correlated with a high risk of severe mobility disability for ADLs (Guralnik et al., 2001, Volpato et al., 2007).

Post-stroke disability affects stroke survivors for a long time and often permanently. Wolfe et al reported 10-20% stroke survivors still have moderate to severe disability 10 years post-stroke and about 30% stroke survivors were inactive, and their inactivity was found to increase 8 years after stroke (Wolfe et al., 2011). Physical inactivity is associated with an increase in morbidity, mortality and disabilities after

stroke (Kruger et al., 2008). Physical exercises training has long been emphasised for the rehabilitation of motor function after stroke and recommended in guidelines for stroke rehabilitation (NICE, 2013, ISWP, 2012, Dimyan and Cohen, 2011). Impairment and disability of chronic stroke are found to be improved with muscle strengthening; exercise and training aimed to improve physical functioning for chronic stroke recovery (Teixeira-Salmela et al., 1999, Thielman et al., 2004, Pang et al., 2005). Motor functions and recovery of the affected limbs of 'chronic hemiparetic' can be improved with physical trainings (Hanlon, 1996, Schaechter et al., 2002, Cirstea et al., 2006).

It is important to support stroke survivors to continue to manage their own exercises for their functional rehabilitation in the long-term. This is the focus of this research.

1.4 Self-management of long-term conditions

1.4.1 Management of long-term conditions in the UK

Supporting people with long-term conditions to self-manage their chronic conditions is consistent with the health policy and is a key strategy in the UK (DH, 2004b, DH, 2005c, DH, 2005b, DH, 2006c, DH, 2009e). Providing support for self-management is highlighted as an element for the service delivery system in the NHS and social care long term conditions model to empower and inform patients with long-term conditions and to focus health and social care teams (Singh et al., 2006, DH, 2005c, DH, 2006c).

People with long-term conditions are advised to take an active role to manage their own health and care, to live with and prevent worsening of long-term conditions (DH, 2004a, DH, 2005c, DH, 2006c, DH, 2009e, DH, 2007a, DH, 2004b), and long-term supporting systems were suggested for stroke survivors' rehabilitation (DH, 2007b, ISWP, 2012). Hence, information, skills, support networks and technology services are also suggested for patients with long-term conditions in the UK (DH, 2006b).

1.4.2 Definitions of self-management and self-care for health

Defining relevant terms may help to clarify the direction and specific focus of this study.

The term of 'self-management' was first found in the book 'Behavioral contributions to rehabilitation and childhood asthma' written by Thomas Creer et al published in 1976. Creer and colleagues suggested 'self-management' demonstrates the patient is actively participating in the treatment (Lorig and Holman, 2003). Self-management program for health requires patient's participation in the daily management of their chronic illness, based on behavioural and social learning theory (Holroyd et al., 1986).

The use of self-management for chronic conditions is highlighted by the WHO:

"Patients with chronic health problems need care that is coordinated across time and centred on their needs, values and preference. They need self-management skills to ensure the prevention of predictable complications, and they need providers who understand the fundamental difference between episodic illness that is identified and cured, and chronic conditions that require management across many years" (Powell and Gibson Peter, 2002).

There are several definitions of self-management. From the DH, self-management is

"actions people take for themselves, their children and their families to stay fit and maintain good physical and mental health; meet social and psychological needs; prevent illness or accidents; care for minor ailments and long-term conditions; and maintain health and well-being after an acute illness or discharge from hospital" (DH, 2005b).

From the National Institute for Health and Clinical Excellence (NICE), the focus of self-management is to enable sufferers of chronic illness to gain motivation and/or skills needed to improve their condition (Bury et al., 2005).

For this research, self-management for chronic conditions refers to the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and life style changes inherent with living with a chronic disease (Barlow et al., 2002b).

Self-management programmes often include education and training, information provision, early symptom recognition, symptoms management, management of psychosocial consequences, life-style modification (including physical exercise), problem-solving skills, decision making, resource utilization, forming partnership between patient/healthcare providers, or patient-provider relationship, social support, communication, accessing support services, action plans, coping, decision making, goal setting, and self-tailoring (Barlow et al., 2002b, Lorig and Holman, 2003, Bodenheimer et al., 2002a, Jones, 2011).

Self-management for health and chronic condition focuses on the education related to patients' concerns and perceived problems. A self-management programme should be based on patients' perceived problems (Lorig and Holman, 2003). Thus, it is essential to consider the patients' ideas and educational element to develop a self-managed intervention for them.

Since this research is to develop a programme to support stroke survivors to self-manage their own exercises using available ICTs, the following definition of self-management support was used to underpin the concept of supporting stroke survivors to self-manage:

“Self-management support can be viewed in two ways: as a portfolio of techniques and tools that help patients choose healthy behaviours; and a fundamental transformation of the patient-caregivers relationship into a collaborative partnership” (Bodenheimer et al., 2005)

Self-care

Self-care refers to the tasks or actions performed by the individual with chronic conditions for their own health and well-being at home (Clark et al., 1991, DH, 2005b, DH, 2006b, DH, 2009e). It can be defined as:

“the care taken by individuals towards their own health and well being, and includes the care extended to their children, family, friends and others in neighbourhoods and local communities” (DH, 2005b).

The terms “Self-management” and “self-care” are occasionally used interchangeably in some documents of the DH and literature (DH, 2009e, DH, 2004a, DH, 2004b, DH, 2006c). Regarding the concepts, nature and descriptions of “self-management”, “self-management” is more comprehensive and closer to the nature, approach and aim of this research. Thus, it is the preferred term used in this work.

1.4.3 Self-management for chronic conditions and stroke

Evidence indicates self-management works to improve severity of clinical symptoms, daily activities, health status health behaviors, quality of life, patient satisfaction and reduce unnecessary utilization of healthcare resources; including primary care consultations, outpatients and emergency rooms visits and drug expenditure for long-term conditions (DH, 2005b, DH, 2005c, DH, 2006b, DH, 2006c, Silva, 2011).

The use of self-management interventions have shown to be feasible, safe and effective to manage and improve some health conditions and the utilization of healthcare resources in the long-term, including asthma, chronic obstructive pulmonary disease (COPD), arthritis and diabetes (Jones, 2006) and for stroke rehabilitation (Lennon et al., 2013, McKenna et al., 2013, Jones and Riazi, 2011).

Self-management support refers to the provision of information and encouragement to help people maintain greater control by understanding their condition and being able to monitor and take proper action (Silva, 2011). Thus, the intervention to be

developed in this study is intended to support stroke survivors to self-manage; to enable them to help themselves.

Expert Patient Programme

The Expert Patient Programme (EPP) was launched by the NHS in 2002 to enable patients with chronic conditions to manage their health, including post-stroke (NHS, 2010, DH, 2001). It is a generic self-management program developed from Chronic Disease Self-Management Program (CDSMP) from the USA, delivered by trained trainers to support people with chronic conditions. It teaches them to manage chronic conditions using problem solving, decision-making, resource utilisation, development of a patient-professional partnership, and taking action (DH, 2001, NHS, 2010).

However, evidence for the usefulness and effect of EPP is still debatable (Von Korff et al., 2002, Newbould et al., 2006, Griffiths et al., 2007, Wilson et al., 2007, Lorig et al., 2008, Reeves et al., 2008, Richardson et al., 2008, Jacobs, 2009). Problems of using EPP to deliver self-management are highlighted in an analysis, including the dearth of course materials particularly designed for specific chronic condition, lack of clinicians' engagement, and the inability to facilitate collaboration between professional and patient (Vadiee, 2012). High prevalence of patients' refusal for participating in EPP has been reported (Vega et al., 2014). Since EPP is neither stroke-specific nor condition-specific intervention, the use of EPP may not be adequate to satisfy specific needs and conditions for stroke survivors' physical functional recovery. Alternative self-management programmes are needed to address the specific needs of physical stroke rehabilitation in addition to EPP.

1.4.4 Delivery of self-management for stroke

Barriers perceived by patients to participate in self-management service are reported. Most frequently identified barriers include depression, weight problems, difficulty exercising, fatigue, poor physician communication, low family support, pain, and financial problems (Jerant et al., 2005).

An acceptable and feasible delivery system is needed for healthcare services. However, inadequate support affects self-management service delivery. Major barriers affecting ongoing viability of Chronic Diseases Self-Management Program (CDSMP) includes inadequate supported infrastructures for delivery (Bury et al., 2005).

Accessibility may limit users' access to self-management service; particularly for people living in remote or rural areas due to transportation problems and with physical impairments that hinder their mobility. The lack of awareness of the availability of resource, physical symptoms, transportation problems, cost, and lack of insurance coverage are common barriers to accessibility. Participants in Jerant's study were interested in receiving home-delivered support for self-management services (Jerant et al., 2005). With the barriers and uncertainty in delivery of self-management support for physical stroke rehabilitation; the use of ICTs is potential option to be considered.

Elements have been recommended for the self-management of stroke including information provision, support and education about behavior change, acknowledging stroke survivors' beliefs, problem-solving, self-discovery, goal-setting, resource utilization, decision-making, taking action, collaboration, reflection on progress and knowledge (Jones, 2013, Joice, 2012). However, little is known for the components for a remotely supported and self-managed exercise manual for physical functional stroke rehabilitation.

1.5 Management and goals of physical recovery post-stroke

1.5.1 Health policy of stroke management in the UK

Self-management support is needed to manage disabling factors caused by stroke, as emphasized in the national stroke strategy. Thus, the Department of Health (DH) highlighted the vision to expand self-management for stroke survivors (DH, 2007b).

Ensuring people using services and their families are informed and empowered to take control of their care are proposed for high quality stroke services (DH, 2006a). People with long-term neurological conditions living at home should have ongoing

access to rehabilitation, advice and support to meet their continuing and changing needs, increase their independence and autonomy and help them to live as they wish. They need support to manage their own conditions (DH, 2005c, DH, 2006c, DH, 2006a).

1.5.2 Goals of stroke management

It is recommended that stroke rehabilitation goals should be relevant, achievable, and include short as well as long-term targets, with specified and time-bound measurable outcomes to inform treatment (ISWP, 2012).

Goal-setting for stroke survivors should enable individuals to improve or avoid worsening health, maintain desired quality of life (QOL) and live independently in the way they prefer, and facilitate them to participate in ADLs and community. It is suggested that stroke survivors participate in the goal-setting process to identify their personal goals and understand the nature of goal-setting; unless they choose not to or are unable to participate (ISWP, 2012) . Since self-efficacy is closely related to self-management of stroke, greater understanding of the sources of self-efficacy is suggested to ensure that goal-setting is relevant and meaningful to stroke survivors (Jones and Riazi, 2011).

Restoration of motor function has been a key element of stroke rehabilitation (Kalra and Ratan, 2007). Goal-setting for stroke rehabilitation often relate to functioning which has been emphasised in current clinical guidelines (NICE, 2013, ISWP, 2012, Wade, 1999). Although the importance of setting patient-centred goals has been highlighted in the guidelines and policy for stroke (NICE, 2013, ISWP, 2012, DH, 2007b), it is still minimally adopted in stroke rehabilitation services (Rosewilliam et al., 2011). Hence, patient-centred goal-setting for physical functional stroke recovery is a focus in this research.

1.5.3 Stroke pathway in the UK

From the national stroke strategy,

“individuals affected by stroke and their relatives need to receive good-quality, appropriate, tailored and flexible rehabilitation; this will affect long-term recovery and reduce long-term disability“ (DH, 2007b).

However, many stroke survivors may lack continuous health service for their stroke rehabilitation after discharge in some areas of the UK (NAO, 2010). Although 74% stroke survivors in the UK can meet the stroke specialist rehabilitation team, only 55% of hospitals can provide access to specialist community team and offer no further support after discharge (ISWP, 2010). Specific, accessible and continuous healthcare support for stroke survivors' functional physical rehabilitation after their discharge in the UK is not common (DH, 2007b, DH, 2009b, NAO, 2010a, NICE, 2012a, NICE, 2012b).

Despite self-management being proposed in guidelines for stroke rehabilitation (NICE, 2013, ISWP, 2012), little is known about prescribing self-managed exercise manual to stroke survivors with the support of available ICTs in the stroke pathway.

1.6 Technology and stroke care delivery

1.6.1 Introduction

The word “tele” is the Greek for ‘at a distance’ (Brownsell, 2009). Telehealth is generally referred to as the use of equipment to monitor people’s health in their own home (DH, 2009d). It is suggested that it may help to contain costs of healthcare (Klecun-Dabrowska, 2003). Telehealth models are often proposed to monitor patients remotely (Adeogun et al., 2011).

Telehealth may improve healthcare systems and make it more equitable, empower patients and professionals, improve patient compliance with healthcare services, support communication and cooperation between different groups and organizations, enable financial control and clinical governance, provide technical solutions to save money, help to allocate of resources for maintaining and improving health status and QOL of the targeted population, and reduce unnecessary health service utilization. Application of available technology is considered in this study, as it is a readily accessible alternative to support a self-management service in the community.

1.6.2 Definitions of telehealth, telemedicine, telecare, telerehabilitation, ICTs & telestroke

Telehealth and telemedicine often involve the use of electronic transfer of medical and health information between distant sites and participants (Bashshur et al., 2000). They are generally referred to as the use of telecommunications technologies to provide medical information and services (Stradling D.A, 2009). However, there is no known universal definition for related terms. The operational definitions in table 1.6.2 were used for this research.

The concept of applying available ICTs is considered to be involved in the programme of this research. Thus, the term “telerehabilitation” defined in table 1.6.2 reflects the major concept referred to in this study, since the aim of incorporating concepts of using available ICTs into the development of the programme is to support the delivery of community services for stroke rehabilitation.

Table 1.6.2 Working definitions of technology related terms in this research

Terms	Working definitions	Supporting references
Telehealth	Provision of health related services and information using information and telecommunications technologies at a distance	(Fitzmaurice, 1998 , Nickelson, 1998 , Klecun-Dabrowska, 2003 , Brownsell, 2009 , Stroetmann et al., 2010).
Telemedicine	Broadly referred to remote delivery of health care and information. It is generally accepted as the application of telecommunication systems to provide medical information and services	(Bashshur et al., 2000), (Schwamm et al., 2009a , Schwamm et al., 2009b)
Telecare	The use of specific personal assistive device to assist people to live independently “Equipment is provided to support the individuals in their home and tailored to meet their needs”	(DH, 2005a)
Telerehabilitation	A remote delivery of rehabilitation services to people with disabilities and chronic conditions using information and communication technologies at a distance	(Burns et al., 1998 , Winters, 2002 , Lai et al., 2004 , Wakeford et al., 2005 , Piron et al., 2009 , Schwamm et al., 2009b)
Information and Communication Technologies (ICTs)	Under the of telerehabilitation concept, ICTs is referred to technologies providing access to information through telecommunications, with the focus on communication technologies and other communication mediums to receive and provide information and communication delivered remotely over a distance. Commonly available ICTs, include Internet, computer networks, telephone calls, emails, text messaging and videoconferencing.	(Definition used for this research)
Telestroke	General term used to describe the use of telemedicine for various types of medical, healthcare or rehabilitation services, education, consultation, communication or electronic information specifically for stroke; in which various stage of stroke and kinds of technologies are referred; including computer-based, robotic, virtual-reality, web-based and/or telecommunication systems.	(Levine and Gorman, 1999 , Audebert, 2006 , Demaerschak, 2010 , Audebert and Schwamm, 2009 , Rudolph and Levine, 2011)

1.6.3 Health care policy of telehealth for long-term conditions in the UK

Telehealth/telecare are suggested to promote independence and improve QOL of service users and their informal carers (Beale et al., 2010). Telehealth/telecare is promoted in the UK for health and social care systems to enable people to live independently with long-term health conditions (DH, 2005a). Relevant policy is emerging from the UK government to support and direct the use of technology to provide health and social care services in the UK, and is proposed in the stroke strategy (DH, 2007b) for people to live in their own homes for long-term care and support after stroke (DH, 2009a, DH, 2009c, DH, 2010, DH, 2007b, DH, 2005a).

Significant savings to health and social care sectors from telecare services during 2007-2008 in Scotland suggested the allocation of resources to that were effective and generated a significant return on economic investment. Evidence indicated the use of telehealth in the NHS may help NHS to save up to £2 billion annually (West, 2010). However, telehealth services are still under-developed in England, with only around 5000 users of telehealth (Clark and Goodwin, 2010).

1.6.4 Use of technology to deliver stroke rehabilitation

Evidence recommends that greater duration and intensity of rehabilitation can improve outcomes for stroke survivors whilst delivery of healthcare service is often limited. Hence, the use of technologies, especially available information and communication technologies; is considered to be a potential option to deliver support to stroke survivors for their rehabilitation in this research. Telehealth for stroke management may be beneficial for the areas with insufficient neurological health related services to support the long-term post-stroke care needs. Socio-economic benefits from using technology for remote healthcare service delivery include access to healthcare services, cost-effectiveness, healthcare utilization, education, support, to overcome social isolation, improve satisfaction and health outcomes (Jennett et al., 2003).

Positive effects have been reported when using technology to provide interventions for stroke care. Health professionals and participants have been shown to have high levels of satisfaction and acceptance of telerehabilitation interventions for stroke care (Chumbler et al., 2012, Johansson and Wild, 2011).

Although improvements on physical function and disability for stroke survivors from a telerehabilitation intervention directed and delivered by therapists have been reported (Chumbler et al., 2012), little is known about how to support individual stroke survivors to self-manage the exercises determined by themselves with the use of the technologies available to and preferred by them in the way that they like whilst they are the end-users of stroke rehabilitation services.

The resources for face-to-face stroke rehabilitation services are limited. Additionally, stroke support groups may not be available in some areas in the UK or suitable to some stroke survivors including those who have physical disabilities that limit them to go out of their homes. Thus, the idea of using available technologies has been considered to support stroke survivors to continue to manage their own exercises for their physical rehabilitation.

1.7 Theoretical considerations for programme development

This section describes the theoretical considerations for the development of a self-managed physical exercise manual supported with the use of available information and communication technologies for physical functional stroke rehabilitation in the community

1.7.1 Overall theoretical considerations

Theory helps to develop new knowledge by providing motivation and guidance to ask clinical questions, and provide a basis for asking a research question (Portney and Watkins, 2009). It can help to guide the development of interventions, and help to explain the findings when developing an intervention (Rycroft-Malone and Bucknall, 2011). Models are important for rehabilitation which can be used to help to form a framework for research and planning of an intervention, the construct of services, and design of research (Wade and de Jong, 2000).

The following theories underpinned the considerations involved to form the basis for the development of the programme in this research. The details about establishing a new conceptual model for the design of the programme of this research are discussed in the chapter 8a of this thesis. In addition, a conceptual framework is also shown in the chapter 10 suggesting a system to guide the prescription and delivery of the programme.

1.7.1.1 International Classification of Functioning, Disability and Health (ICF) & stroke

With the vision of developing a programme to support stroke survivors' physical rehabilitation for their activity and participation in this research, the ICF model¹ (WHO, 2013) (see figure 1.7.1.1) was considered to frame the design of this functionally oriented programme. The ICF is used to identify physical consequences, functioning, disabilities and peoples' lives in society post-stroke (Geyh et al., 2004, Starrost et al., 2008, Algurén et al., 2010, Lemberg et al., 2010). This is based on biopsychosocial model of disability (Stucki and Melvin, 2007, WHO, 2013).

Body function and body domains are related to activity and participation outcomes after stroke (Skidmore, 2003). Activities and participation is a part of WHO's concept of health and disabilities in the ICF. Self-care is a domain of activity and participation on the ICF core set for stroke (WHO, 2013, WHO, 2011b). Thus the focus of this research is on the management at activity and participation level for physical functioning with the consideration given to the interactions among body structure and functions, and activity and participation; environmental and personal factors.

¹ Two parts are involved in the ICF model: functioning and disability, and contextual factors, in which body functions and body structures, and activities and participation are included in the former part, whilst environmental and personal factors are categorised in the later part. Activity is the execution of a task or action by an individual and participation is the involvement in a life situation. (WHO, 2011c)

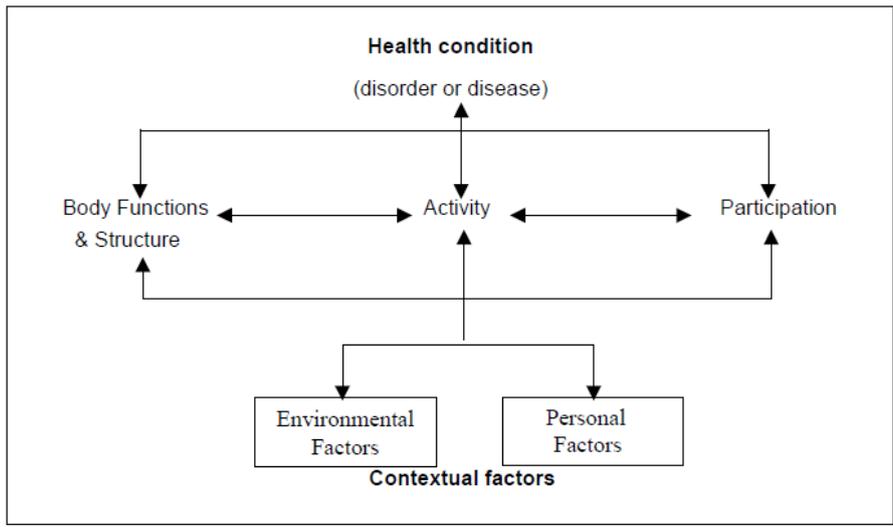


Figure 1.7.1.1: The ICF model² (WHO, 2013)

(Reproduced, with the permission of the publisher, from *How to use the ICF: a practical manual for using the International Classification of Functioning, Disability and Health (ICF)*, Geneva, World Health Organization, 2013 (Box 1, page 7; <http://www.who.int/classifications/drafticfpracticalmanual2.pdf>, accessed 13 Jan 2014)

1.7.1.2 *Chronic Care Model: A conceptual platform*

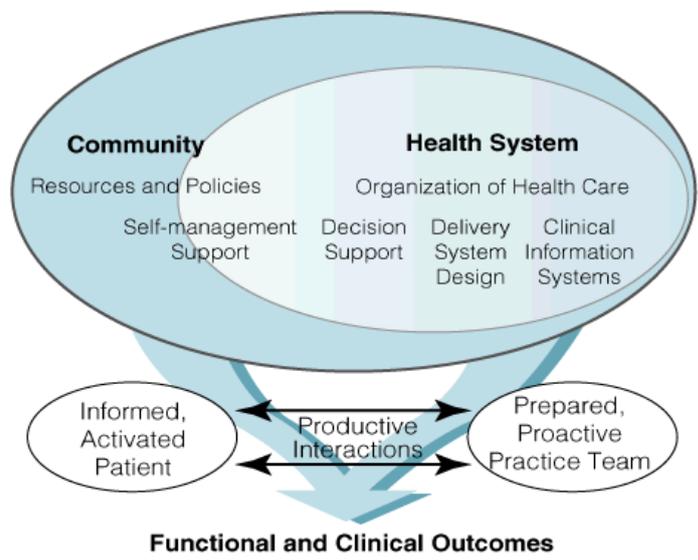


Figure 1.7.1.2 Chronic Care Model (Wagner, 1998) (*Effective Clinical Practice* is the original source of the above figure. Permission is granted to reproduce the above figure from *Effective Clinical Practice*)³

² The permission letter from WHO is attached in the appendix

The overall concept of this research was inspired with the Chronic Care Model (CCM)⁴ (Care, 2011, Wagner, 1998) (figure 1.7.1.2). In view of the CCM, the concepts of self-management support, delivery system design, decision support, clinical information systems, community resources and policies, and health system are connected with each other to manage chronic health conditions (Wagner, 1998, Epping-Jordan et al., 2004, Bodenheimer et al., 2002b, Singh et al., 2006). It has been shown to be possible to adopt the concepts of the CCM in a healthcare intervention to improve stroke survivors' health outcomes after discharge (Allen et al., 2004).

The CCM was considered as a platform connecting the concepts of providing self-management and decision support, designing a delivery system, and organising patient's clinical information for helping stroke survivors with disabilities to self-manage their own exercises in the community in a self-managed exercise manual in this research.

1.7.2 Integrating theories for a joint conceptual support

This section presents an overview of the following theories that were used to develop the programme in this research. Self-efficacy has been shown to be useful and important theory for stroke self-management (Jones, 2008, Jones et al., 2009, Jones and Riazi, 2011). However, I needed to consider whether there is any other theory that can also be used to facilitate the delivery of support for stroke self-management, and theory would be most suitable for supporting the concept of using available technologies for stroke self-management.

I considered incorporating other theories into the development of the programme in this research in addition to the key theory: self-efficacy. This was because relying on one theory may not be adequate to support the broader and complex ambition of

³ The permission letter from the American College of Physicians is attached in the appendix.

⁴ The CCM includes six elements: community, health system, self-management support, delivery system design, decision support and clinical information systems for providing good chronic illness care. Key elements of the CCM are empowering and preparing patients to manage their health via self-management support, delivering high quality care and mobilizing community resources to meet long-term needs in the community

enabling stroke survivors to self-manage their own exercises using available technologies. The following theories were selected due to their features and constructs, relevant evidence, and potential for the topic area of this research. The details about the way they are used are described in the chapter 8a of this thesis.

1.7.2.1 Social cognitive theory

Social cognitive theory (SCT) is a psychological concept of health behaviours theory (HBT) (Painter et al., 2008) which focuses on people's motivation to change behaviour (Weinstein, 1993). I have selected SCT to develop the intervention, since the theoretical basis of most self-management programmes for chronic diseases are often constructed with SCT and self-efficacy (Bodenheimer et al., 2002a, Lorig and Holman, 2003, Jones, 2006). The SCT aims to predict behaviour and its change. The key constructs of SCT include personal characteristics, self-efficacy, expectation, self-regulation, behavioural capacity, emotional coping, observational learning and reinforcement. Self-efficacy and outcome expectancies are central determinants of the motivation of behaviours (Bandura, 1986, Bandura, 1989, Bandura, 1991, Bandura, 1999, Armitage and Conner, 2000, Bandura, 2000, Jensen et al., 2003, Jones and Riazi, 2011).

Self-efficacy

Self-efficacy⁵ is the key concept of social cognitive theory. Self-confidence to perform behaviour is needed to achieve a desired goal, which underpins the philosophy of self-efficacy. Self-efficacy refers to people's beliefs of their own capability to execute a particular behaviour to achieve an expected goal under a certain circumstance (Bandura, 1977, Bandura and Adams, 1977, Bandura, 2000). Perceived self-efficacy can affect people's selection of activities and behaviours (Bandura and Adams, 1977, Bandura, 1977, Bandura, 1993). Self-efficacy beliefs may determine a persons' feelings, thoughts, motivation and behaviour towards their health, which has been commonly been used in self-management interventions for chronic conditions including stroke (Jones and Riazi, 2011).

⁵ Self-efficacy is the primary construct of the SCT (Bandura, 1997). It is shown to be a key element for stroke self-management according to current evidence (Jones and Riazi, 2011, Korpershoek et al., 2011)

The proposed key effectiveness of self-management for chronic conditions is the change in the individual's confidence and belief that they can take control over their life despite their disease (DH, 2001). This is central to the core value and function of self-efficacy.

Evidence indicates improved self-efficacy is associated with improved health behaviours and clinical outcomes (Silva, 2011). Self-efficacy may be associated with patient empowerment, with patients accepting responsibility to manage their own condition and being encouraged to solve their own problems based on information (Bodenheimer et al., 2002a).

Self-efficacy has been proven to be beneficial and the key element for stroke self-management (Jones and Riazi, 2011, Korpershoek et al., 2011). Therefore, it was used as a core theory which underpins the design of the programme in this research to facilitate stroke survivors' competence to self-manage. The concepts of four common sources of self-efficacy: mastery experiences, vicarious experiences (modelling), verbal persuasion (social persuasion) and physiological feedback (Jones, 2011, Lorig and Holman, 2003, Bandura, 1997a, Bandura, 1997b). They were involved in the programme development, which are detailed in chapter 8a.

1.7.2.2 Learning theories

Stroke rehabilitation programmes extend what patients can do for themselves for health and functional status and encourage them to be independent and self-reliant. Longer term stroke rehabilitation should aim at educating stroke survivors to maximise their functional abilities for daily activities (Aziz, 2010). Functional stroke recovery is deemed as a learning process (Gelber et al., 1995, Kwakkel et al., 1999), and self-management support often involves education. Educational theory has been suggested as a basis for later stage in stroke rehabilitation (Young and Forster, 2007). Neuroplasticity is important for brain recovery and the rehabilitation of motor function after stroke, in which learning is crucial (Dimyan and Cohen, 2011, Langhorne et al., 2011, Cramer and Riley, 2008, Ivanco and Greenough, 2000).

Current self-management interventions have a more educational focus (Jones, 2011). However, stroke survivors may not have been able to learn to self-manage by trial and error (Jones et al., 2013b). This raises a question about how can we help them to learn to self-manage to enable them to take control over their own rehabilitation. Therefore, a group of educational theories were adopted to generate a new conceptual support to educate stroke survivors to learn how to self-manage their own exercises for physical functional rehabilitation during the development of the programme in this research.

Knowles' adult learning theory (Andragogy)

The intervention in this research is planned to be developed for adult stroke survivors. Thus, educational concepts for adult learners are needed to address their learning needs. Andragogy refers to adult learning principles (Knowles, 1973, Hough, 1984). It suggests adults are independent and self-directing, have accumulated experience as a rich resource for learning, value learning via integrating the demands of their everyday life, become ready to learn when they need to know or do somethings, more interested in immediate and problem centred approach and more internally motivated to learn (Knowles, 1973, David and Patel, 1995, Kaufman, 2003, Smith, 2004, Green and Ellis, 1997). Andragogy have been used to form the intervention and enable stroke survivors to learn for their functional recovery needs.

Self-regulated learning

Self-regulation can be defined as the process for a person attempts to control personal, behavioural and environmental factors to attain and maintain personal goals (Schunk and Zimmerman, 2012, Maes and Karoly, 2005, Zimmerman, 1990). It is closely related to self-efficacy. Self-efficacy belief is regarded as an important determinant of human self-regulation as people's beliefs about their capabilities may influence the choices they make, their aspirations, the amount of effort they mobilise, and how long they persevere in the face of difficulties (Ayotte et al., 2010, Zimmerman, 2000, Bandura, 1991, Bandura and Jourden, 1991, Schunk, 1989). Therefore, self-regulation concept is relevant to self-management in this study. Self-regulated learning (SRL) is the way for learners to master their own learning, via

actions and processes directed at acquisition of information or skills. Zimmerman suggested that self-regulated learners plan, set goals, organize, self-monitor and self-evaluate during acquisition in their learning (Schunk and Zimmerman, 2012, Zimmerman, 2002, Clark and Zimmerman, 1990, Zimmerman, 1990). Self-regulatory behaviour has been suggested to be directly related to physical activity (Ayotte et al., 2010). This is in line with the vision of enabling stroke survivors to take control over the management of their own rehabilitation exercises in this research. Hence, SRL was used to support the programme to facilitate stroke survivors to regulate the process to learn to self-manage their own exercises.

Self-regulated learning often involves metacognitive, motivational, and behavioural processes to acquire knowledge and skills including goal-setting, planning, learning strategies, self-reinforcement, self-recording, and self-instruction (Schunk and Zimmerman, 2012, Pintrich, 2000, Zimmerman, 2000, Clark and Zimmerman, 1990, Schunk, 1990, Zimmerman, 1990). In particular, the SRL process and components proposed by Zimmerman were adopted in this research out of other existing SRL models since that is goal-oriented and self-generated by nature.

According to Zimmerman's model for SRL, learning environmental influences, personal (self) influences and behavioural influences are suggested determining factors to SRL of which task analysis, self-motivation, self-control, self-observation⁶, self-judgement⁷, and self-reaction⁸ are involved throughout SRL process. In view of personal influence of Zimmerman's model, person's self-efficacy beliefs determine the individual's learning. Self-observation, self-judgement and self-reaction are proposed to be factors influencing the individual's behaviours in SRL process (Schunk and Zimmerman, 2012, Puustinen and Pulkkinen, 2001, Clark and Zimmerman, 1990). Therefore, this model is in line with the vision of helping stroke survivors to learn to take control over the management of their own programmes for

⁶ Self-observation refers to explicit attempts to perceive one's own behaviour (Clark and Zimmerman, 1990)

⁷ Self-judgement involves using criteria to assess the situation or problem (Clark and Zimmerman, 1990).

⁸ Self-reaction refers to the responses to self-observations and self-judgement about the individual's own behaviour and the impact of that behaviour the one's immediate environment (Clark and Zimmerman, 1990).

the goal of physical functional rehabilitation. The details about using the concepts of SRL to develop the programme are described in the chapter 8a of this thesis.

Motor learning therapy

Motor learning theory (MLT) was considered to facilitate and understand the process of self-managing physical exercises using the developed programme for the purpose of functional stroke recovery. Motor learning is a theory about the skill acquisition and modification of motor movement for stroke rehabilitation. It involves the analysis and training of specific tasks (Graham et al., 2009, Carr and Shepherd, 1989). Schmidt proposed motor learning as a set of processes correlated with practice or experience causing relatively permanent changes in the capabilities of responding (Schmidt, 2008, Schmidt, 1991).

Based on the mechanisms of neuroplasticity, the recovery of motor functions can be improved via motor learning poststroke. The motor learning process may happen through functional reorganization in cortical areas of the brain (Subramanian et al., 2010). Skill acquisition, motor adaptation and decision making to determine correct movement are included in motor learning processes (Krakauer, 2006). The improvement of functional motor performance is suggested as the focus of exercise training for functional skills after stroke (Shepherd, 2001), whilst motor relearning programme was found to be effective to improve functional skills for stroke recovery (Chan et al., 2006).

The focus of motor relearning is on the active participation of the stroke survivor with guidance and feedback for movement correction (Van Vliet and Wulf, 2006, Sparkes, 2000). Evidence indicates that repetitive task-specific training is beneficial for the improvement of motor function recovery after stroke, of which the provision of feedback on performance is recommended for task-specific practice (Langhorne et al., 2011, Langhorne et al., 2009a). Feedback can provide information on the improvement of movement and is suggested as an important factor for motor learning after stroke. It can be classified into either extrinsic or intrinsic. Intrinsic feedback is to provide sensory information whilst performing movement tasks. Extrinsic feedback is provided from external environment via the provision of information about the knowledge of performance (KP) and the knowledge of results

(KR)⁹. Evidence suggests that the provision of extrinsic feedback could improve motor learning and recovery poststroke (Subramanian et al., 2010, Cirstea et al., 2006, Van Vliet and Wulf, 2006).

The provision of information about movement performance may help in motor learning after stroke (Orrell et al., 2006). Hence, it is important to identify the practical ways to provide optimal feedback and information to facilitate the process of motor learning for continued functional recovery of stroke survivors. However, how motor relearning effects the longer term after stroke remains unclear (Langhammer and Stanghelle, 2003). Thus, it is necessary to discover how to transfer and maintain the effect of motor learning for continued stroke recovery. The details about using the MLT to formulate the programme of this research are described in chapter 8a.

1.7.2.3 Technology acceptance model

The use of available information and communication technologies (ICTs) include: DVDs, mobile phones, emails, and videoconference etc.; are considered to be involved to provide support to stroke survivors to self-manage their own exercises in this research. However, it is important to consider how the users of those technologies think when incorporating the idea of using ICTs in order to motivate them to use them. Thus, it is necessary to consider the users' view in using available ICTs for the purpose of self-managing exercises.

Based on the principle of User-Centred Design (UCD), which is an approach generally referred to underpinning philosophy and methods focusing on designing incorporating users throughout the development process to design technologies systems (Gould and Lewis, 1985, Abras et al., 2004); it is necessary to explore how

⁹ Knowledge of performance (KP) refers to extrinsic feedback on the nature of the movement pattern used to achieve the goal of the movement with the concern of how the person moved. The KP focuses on the timing and frequency of information delivered to the learner. Knowledge of results (KR) is the goal-related extrinsic feedback with the focus on the outcomes of the movement BROWN, V. A., GROOTJANS, J., RITCHIE, J., TOWNSEND, M. & VERRINDER, G. (2007) Jackie Green and Jane South, LENNON, S., MCKENNA, S. & JONES, F. (2013) Self-management programmes for people post stroke: a systematic review. *Clinical Rehabilitation*, 27, 867-878

users think in order to develop the intervention using technologies. UCD has recently been suggested to develop interactive health technologies for patients and used to design assistive technology for stroke survivors (Ma et al., 2007, Dabbs et al., 2009). Hence, concepts about users' behaviours, acceptance and willingness in using ICTs are considered to support an acceptable and usable intervention in this study.

Fred Davis proposed the Technology Acceptance Model (TAM) to analyse why users accept or reject information technology (Davis, 1985, Venkatesh, 2000, Venkatesh and Davis, 2000). It is selected as the underpinning model to provide a basis to understand how to incorporate ICTs into a self-managed programme to support stroke survivors to manage their own exercises in this research. Key beliefs in TAM¹⁰ are "perceived usefulness" (PU) and "perceived ease of use" (PEOU). These are relevant to the understanding and explanation of users' underlying psychology, internal beliefs, behaviours, intentions, and attitudes and acceptance towards using technology (Silvestre et al., 2009, Davis, 1985, Davis, 1989, Davis et al., 1989, Davis, 1993) (see figure 1.7.2.3).

With regards to the value of the UCD, it was essential to understand users' acceptance and perception toward selecting and using available ICTs to develop a usable intervention as the focus of this study was to develop an acceptable and usable intervention for actual practice. Thus, TAM is a fundamental principle underpinning the idea of using available ICTs to support stroke survivors, who are the users; into this research.

¹⁰ The PU and PEOU are key determinants of user's intention to adopt technology. The PU concerns the degree to which a person believes that using the new system will facilitate the user to complete his/her tasks. The PEOU is the extent to which the user believes that using the system will be free of effort. Both factors can influence user's attitude and intention towards using a system

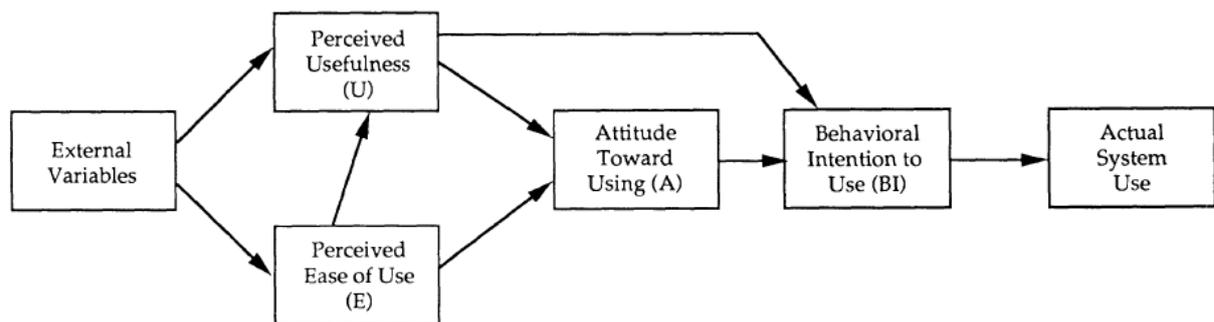


Figure 1.7.2.3 Technology Acceptance Model (TAM).

(Davis et al., 1989)

(Reprinted by permission, Fred D. Davis, Richard P. Bagozzi and Paul R. Warshaw, User acceptance of computer technology: a comparison of two theoretical models, *Management Science*, volume 35, number 8, Aug 1989. Copyright 1989, the Institute for Operations Research and the Management Sciences, 5521 Research Park Drive, Suite 200, Catonsville, Maryland 21228 USA.)¹¹

The TAM is proven to be useful to help to understand and explain users' behaviours in implementation of information technology (Legris et al., 2003). The TAM focuses on system design features and is suggested to be used as a guide to design efforts (Taylor and Todd, 1995). Technologies have been used to provide stroke rehabilitation in recent studies (Johansson and Wild, 2011, Parker et al., 2013, Mawson et al., 2013). However, little is known about using the concepts of TAM to facilitate the delivery of community stroke rehabilitation services using appropriate and available ICTs. The details about using the concepts of TAM for the development of the programme are described in the chapter 8a of this thesis.

1.7.3 National and clinical guidelines for stroke rehabilitation

Clinical guidelines provide a source of information about the management of clinical conditions that can assist practitioner and patient to discuss different options for treatment and benefit and risk that interventions may have (Herber, 2005).

Therefore, current stroke specific guidelines were referred to develop the programme so as to promote the decision-making process between therapist and stroke survivor whilst using the programme. The use of guidelines may also ensure the contents of the programme matched the current widely accepted standard for stroke

¹¹ The permission letter from INFORMS is attached in the appendix

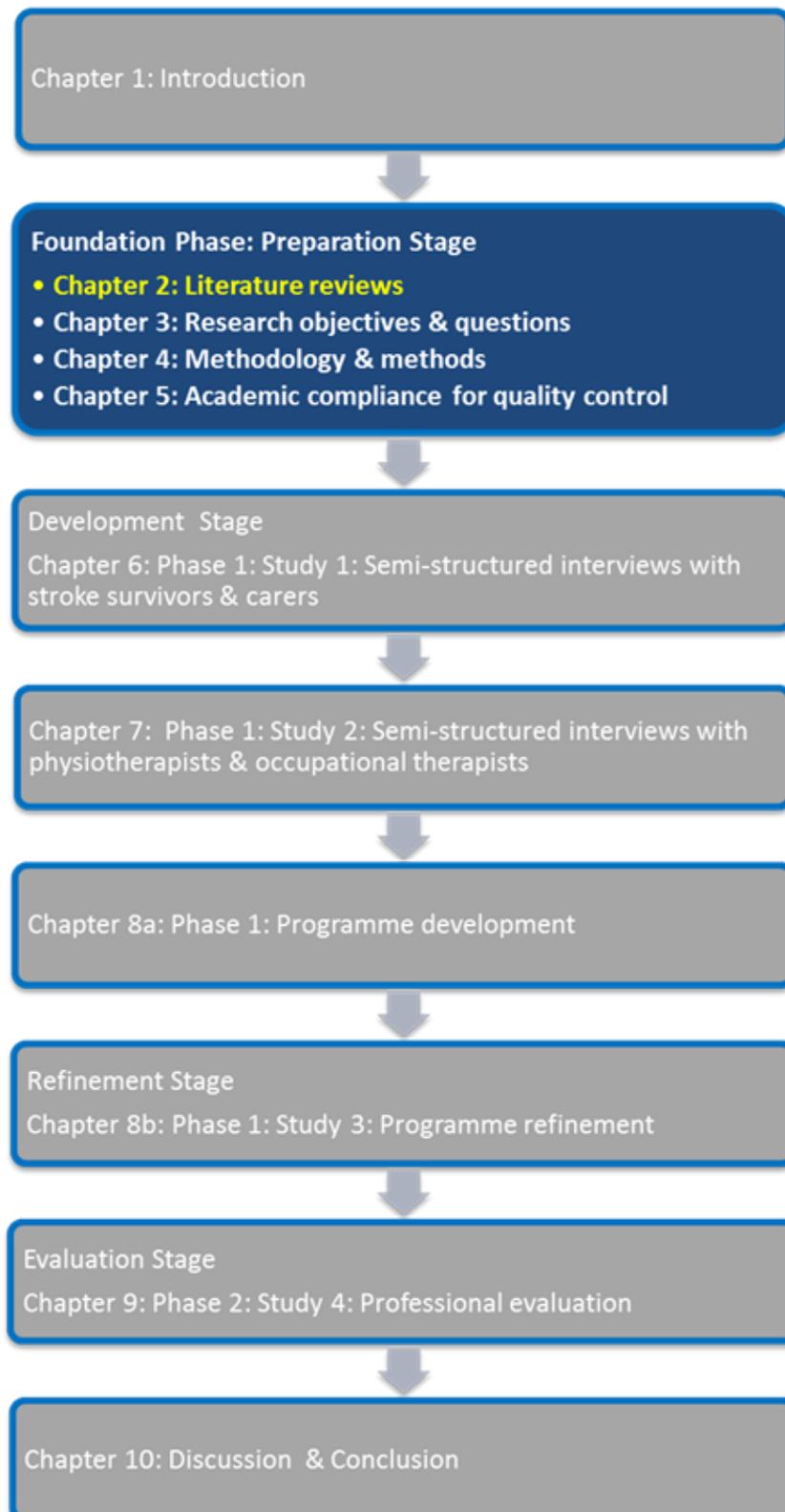
rehabilitation. The selected guidelines included Royal College of Physicians (RCP) national clinical guideline for stroke (4th edition) (ISWP, 2012), National Institute for Health and Care Excellence (NICE) stroke rehabilitation: long-term rehabilitation after stroke (NICE, 2013), Scottish Intercollegiate Guidelines Network (SIGN) management of patients with stroke: rehabilitation, prevention and management of complications, and discharge planning (SIGN, 2010).

Although stroke-specific exercise recommendations and dosages exist in the above guidelines, many stroke survivors may not be able to attend a supervised exercise session or manage their own exercises. To assist them to achieve the recommendations to benefit from practising exercises, it is crucial to support the individuals in their self-practice.

1.8 Summary

This chapter describes background information related to this research. Terms specific to this research are defined with an overview of the related information, theories and guidelines. The next chapter presents my further understanding from the literature in the areas of physical exercises for stroke recovery, stroke self-management and the use of technology to deliver stroke rehabilitation services.

Section 2: Foundation phase: preparation stage



Chapter 2: Literature reviews

2.1 Introduction

Evidence is emerging to support the value of self-management, physical exercise and the use of technology for stroke rehabilitation. Three literature reviews were conducted to explore the information required to inform this research.

Aim

This chapter aimed to obtain an overview of the literature in the areas of physical exercise for physical functional stroke rehabilitation, stroke self-management, and the use of information and communication technologies (ICTs) to support stroke survivors to self-manage their rehabilitation. The purpose of exploring what is known in the above areas was to provide background knowledge to shape this research.

Objectives

The following issues were explored in the three literature reviews to prepare for the development of the programme in this research:

1. What information is there related to physical exercise for physical functional stroke rehabilitation in relevant literature?
2. What are the common components of existing stroke self-management programmes according to related evidence?
3. What is the evidence about using information and communication technologies for the delivery of stroke self-management interventions?

2.1.1 Search strategy and methods

The following strategy was used to search available literature in each focused areas.

Literature searches were conducted in the following electronic databases (latest updates in August 2014): EMBASE, MEDLINE® In-Process & Other Non-Indexed

Citations and Ovid MEDLINE® , PubMed, AMED (Allied and Complementary Medicine via OVID), PsycINFO, CINAHL (via EBSCO), Science Citation Index Expanded (SCI-EXPANDED); Social Sciences Citation Index (SSCI); Arts & Humanities Citation Index (A&HCI); Conference Proceedings Citation Index- Science (CPCI-S); Conference Proceedings Citation Index- Social Science & Humanities (CPCI-SSH) via Web of Science, Physiotherapy Evidence Database (PEDro), Cochrane Stroke Group Trials Register, the Cochrane Database of Systematic Reviews, the Cochrane Central Register of Controlled Trials (CENTRAL), NHS Centre for Reviews and Dissemination (CRD) and Google scholar. The reference lists of the identified systematic review papers and guidelines for stroke were also searched.

Keyword and medical subject headings (MeSH terms) searches were used to search for relevant papers for each topic. The combinations of the terms were used.

Selection criteria

Papers were included if the studies conducted on or relevant to stroke survivors, published in English, relevant to self-management intervention for stroke, the use of ICTs for stroke, and physical exercise for stroke rehabilitation. There were no restriction placed on study design and method, sample size and components within the intervention, comparison, assessment and outcome measure. There was no restriction placed on the age, gender and race of the population, type and severity of stroke and location of provision. This allowed me to thoroughly understand the field of the topic under review.

Papers were excluded if the studies focused on general chronic disease or condition, management of chronic disease or condition other than stroke, purely on medical or surgical or nursing care, acute stroke care; poorly described study design, method, results and outcome measures; insufficient information, non-human, and irrelevant to stroke, self-management, physical exercise/activity and functional physical rehabilitation.

Procedures

The abstracts of the identified articles were screened with the above criteria. Then, I used Critical Appraisal Skills Programme (CASP)¹² (CASP, 2013, Singh, 2013) to check the selected papers to understand whether the papers contain necessary and relevant information required for each review topic. The CASP checklists were used according to the nature of the identified papers including systematic review, randomised controlled trial, case control, qualitative and cohort study.

The papers which could not fulfil the criteria of the screening questions of CASP were excluded. For instance, the following screening questions were used for randomised controlled trial articles; “Did the trial address a clearly focused issue?”. “Were all of the patients who entered the trial properly accounted for at its conclusion?”. The papers were included when the answers of the above questions were “Yes”. Descriptive papers suggesting procedures of benefits were selected to provide context and clarity in addition to the papers chosen using the above process. The following figure 2.1 illustrates the procedures used.

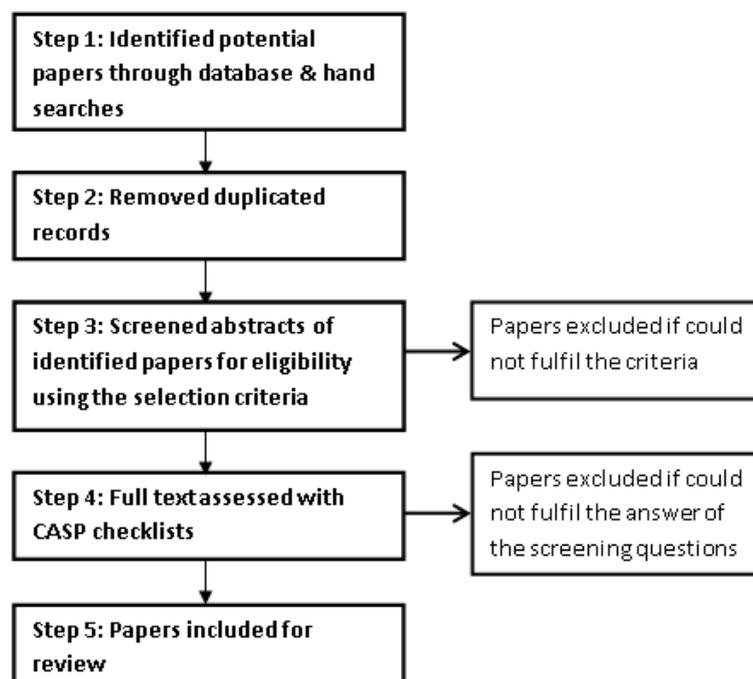


Figure 2.1: Flow diagram of literature review steps

¹² The Critical Appraisal Skills Programme (CASP) is a non profit making entity and is part of Better Value Healthcare which is based in Oxford. The programme has developed workshops and tools for critical appraisal covering a wide range of research. The CASP checklists are critical appraisal tools designed to be used when reading research (CASP, 2013, Singh, 2013)

The results of the literature were summarised using a narrative approach since it is considered to be a flexible way to summarise diverse literature to understand the subject matter (Dixon-Woods et al., 2004). This was to gain a broader understanding of evidence and information about physical exercises, self-management and the use of ICTs for physical functional stroke rehabilitation.

2.2a Review topic 1: Review of research evidence of physical exercise for physical functional stroke rehabilitation

2.2a.1 Introduction

Stroke survivors may have impaired physical function and disability. The importance of physical exercise has been emphasized in the updated national clinical guideline for stroke rehabilitation (ISWP, 2012 and NICE, 2013). The aim of this review was to obtain an overview about the effects of physical exercise for physical functional stroke rehabilitation from the current studies to inform the design of an exercise manual for physical functional stroke rehabilitation.

Objectives

- to identify the common exercise studied for physical functional stroke rehabilitation
- to explore the effects of the exercise for physical functional stroke rehabilitation
- to determine the types of physical exercise needed for the design of an exercise manual for physical functional stroke rehabilitation

2.2a.2 Methods

2.2a.2.1 Identification of studies

Search strategy

Four steps were used to identify and select relevant literature for this review; 1) identification via the electronic databases stated in the previous section 2) first screening of titles, 3) eligibility screening of abstracts 4) full-text sift. Literature related to the aim of this review was searched via the selected electronic databases.

In addition, hand searching of the key journals of stroke and existing stroke exercise guidelines, manuals and recommendations were performed to identify potentially relevant literature related this topic. Studies focused on drug trials or without full-text and irrelevant to the study aim were excluded at the eligibility screening stage. In view of the validity of evidence, randomised controlled trials and systematic reviews were selected as they are the essence for the evidence based practice movement (Walker, 2003, Rycroft-Malone, 2006, Berwick, 2005).

Search terms

The following key words were used for searching the available evidence on the electronic database. Medical subject headings (MeSH) were used when searched on PubMed and MEDLINE databases. In addition, boolean operators were used. The search terms were combined using “AND” to identify specific papers. The terms “physical active\$” and “exercise\$” were combined using “OR” to explore the potential relevant papers.

- Stroke.mp
- Physical.mp
- Exercise\$.mp
- Physical activ\$.mp
- Rehab\$.mp
- Function\$.mp

2.2a.2.2 Selection criteria

Studies were included if they met the following selection criteria:

- Studies involved stroke survivors with physical disabilities
- Studies evaluated the effects of physical exercise/activity for physical functional stroke rehabilitation
- Studies involved the measurement of outcome related to physical functioning
- Studies published in English
- Studies conducted with human subjects

- Randomised controlled trials or systematic reviews
- Availability of full text

Eligibility criteria and basic screening questions were adopted from the CASP checklist for randomized controlled trials to select related RCT studies. The questions are “Did the trial address a clearly focused issue?” and “was the assignment of patients to treatments randomized?”. Studies that were non-randomized controlled trials were excluded. The basic screening questions of the CASP systematic review checklist was used for the selection of valid review papers, including “Did the review address a clearly focused question?” and “Did the authors look for the right type of papers?”. This was to ensure the accuracy of the selected evidence and to identify the most relevant articles to obtain a wealth of information.

Additional exclusion criteria were used to screen full-texts to obtain more focus literature. Exclusion criteria for full texts included:

- 1) The application of robotics / electronic devices studies
- 2) Focus of the studies were not specific to stroke-specific physical exercise/activity for the rehabilitation of physical functioning after stroke, including studies about post-stroke behavioural and psychosocial issues
- 3) Single case reports, due to possible influence from multiple treatments and comorbidities

2.2a.2.3 Data extraction

A data extraction form was designed to assist the process of synthesizing information from the included studies. It is attached in appendix 12

2.2a.2.4 Quality assessment

Methodologic aspects of the included trials were appraised using the checklist recommended by the Centre for Review and Dissemination (Centre for Reviews and Dissemination, 2009) (table 2.2a). This was to obtain further understanding about the effects of the exercises via checking the contents and the quality of the studies.

Table 2.2a Checklist for assessing quality of randomised controlled trials from the Centre for Review and Dissemination (CRD)

No	Topic	Checklist item
1	Randomisation	Was the assignment to the treatment groups really random?
2	Blinding of participants	Was the randomisation of participants blinded?
3	Follow-up	Was relatively complete follow-up achieved?
4	Analysis of withdrawal	Were the outcomes of people who withdrew described and included in the analysis?
5	Blinding of outcome assessors	Were those assessing outcomes blind to the treatment allocation?
6	Baseline	Were the control and treatment groups comparable at entry?
7	Identical except intervention	Were the groups treated identically other than for the named interventions?

2.2a.3 Results

2.2a.3.1 Search results

A total of 925 potentially relevant papers were identified from the databases and hand-searching of key related journals and reference lists of related systematic reviews. After filtering out the duplicated studies, there were 882 potentially relevant literature retrieved. Then, 284 abstracts were sifted for eligibility screening.

Subsequently, 193 full texts were further assessed. Of which 126 articles were excluded because they did not meet the inclusion criteria. A total of 67 literatures were included for review: 49 trials and 10 reviews, and 8 guidelines and manuals. The flow diagram of study selection process is shown in figure 2.2a.1 below.

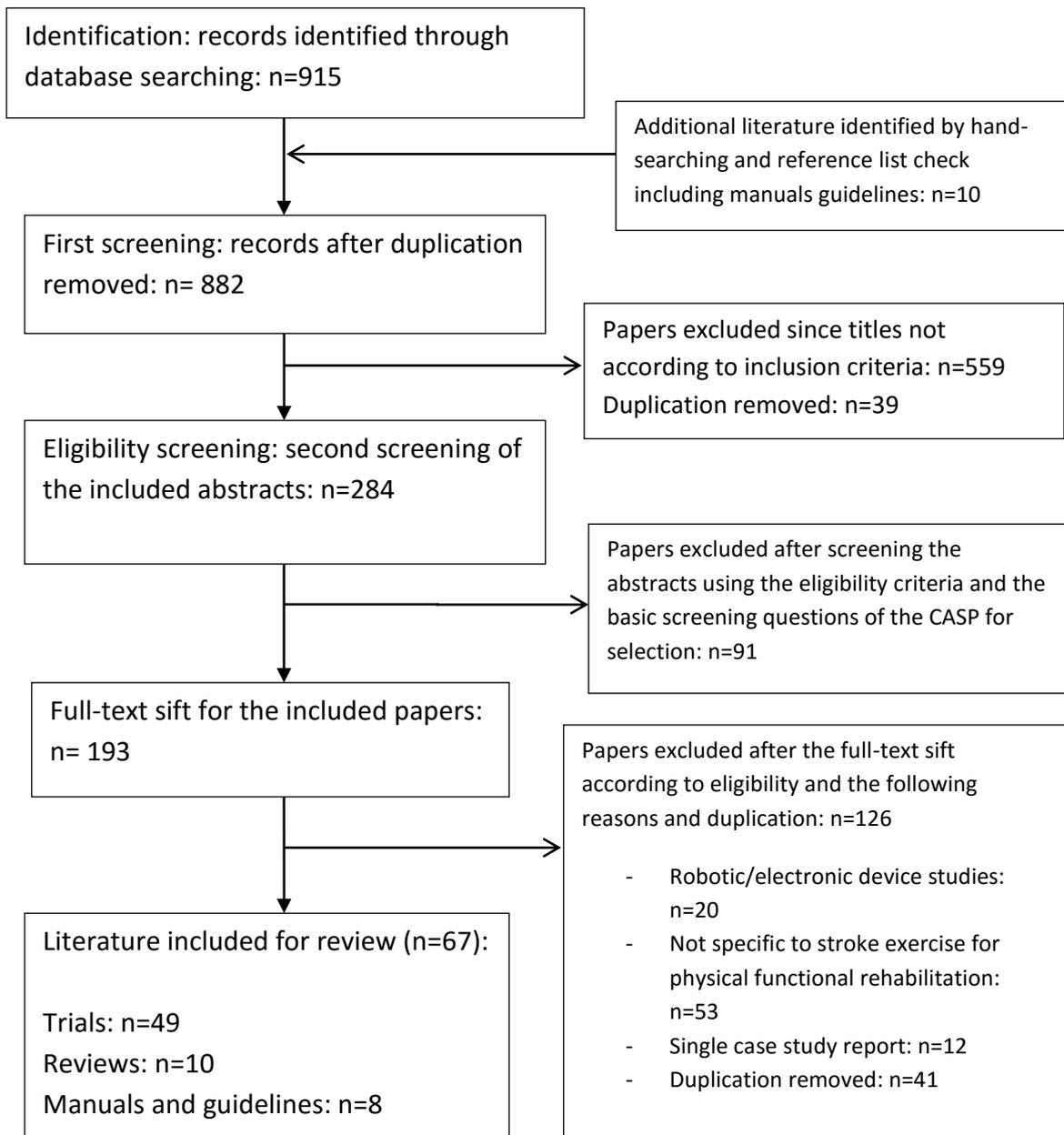


Figure 2.2a.1: Flow diagram of study selection process

2.2a.3.2 Types of exercise interventions

Randomised controlled trials

Total of 7 types of exercises were identified in the included 49 randomised controlled studies involving a total of 3114 participants. Of which, mobilizing (n=3), aerobic (n=3), walking (n=15), strengthening (n=8), balance (n=3), and combined aerobic and strengthening exercises (n=2), as well as combined task-oriented functional movements (n=15) were reviewed after full text sift. The summaries of the reviewed trials are shown in tables 2.2a.1 -2.2a.5 in appendix 13

Systematic reviews

A total of 10 systematic reviews which included 177 studies were included in this review. Reviews of aerobic (n=3), strengthening (n=2), combined aerobic and strengthening (n=2) and balance (n=1) exercises, as well as combined task-oriented functional movements training (n=2) were identified. The summary of the included reviews is shown in table 2.2a.6 in appendix 14.

Of the reviews about aerobic trainings, two indicate the positive effects of aerobic exercises but one concludes no additional benefit. Both of the 2 reviews on strengthening exercise manuals report an increase in strength. Of the 2 reviews that report on mixed aerobic and strengthening training, one indicates the improvement in gait using mixed training (van de Port et al, 2007), whilst the other only shows a positive effect from aerobic training on walking function, but is uncertain about the strengthening part in the mixed trainings (Saunders et al, 2013). In general, positive effects were concluded from the studies about balance exercise and combined task-oriented functional movement training.

Stroke exercise manuals and guidelines

The information from the 8 identified stroke exercise manuals and guidelines are summarized and discussed in the next review 2.2b.

2.2a.3.3 Outcome measures

The effects of exercises are generally positive in different aspects of functional recovery after stroke. However, the effectiveness of different exercises is varied

whilst different outcome measures were used in the studies. Most of the studies used physical specific scales to measure the outcomes and changes in physical functioning. However, the outcome measures are relatively high in heterogeneity. A wide range of outcome measure tools were adopted in the same type of exercise intervention in the studies. The frequently used measurement tool for aerobic exercise is 6-minutes-walk test (6MWT). For walking exercise, Berg's balance scale (BBS), 6MWT, walking speed, functional ambulation category (FAC) score and Fugl-Meyer Assessment (FMA) were frequently reported.

A variety of tools were used in the studies of strengthening, mobility, balance, combined aerobic and strengthening, and combined task-oriented functional movement training. For instance, Upper extremity performance test, shoulder flexion and handgrip strength, hip muscle strength, sit-to-stand, FMA, 6MWT, electromyogram (EMG), Timed-Up-and-Go (TUG), Rivermead Motor Index (RMI) and Functional Independence Measure (FIM) were reported in strengthening exercise programmes (da Silva et al., 2015, Kim et al., 2015, Lee et al., 2013, Lee and Kang., 2013, Mead et al., 2007). For mobility exercise, motor assessment scale, joint angles, forced vital capacity were used (Cho et al., 2015, Tseng et al., 2007, McClellan and Ada., 2004). For balance training, trunk impairment scale, Brunel balance assessment and BBS were used in different studies (Karthikbabu et al., 2011, Fu-Ling et al., 2010, Verheyden et al., 2009). For combined aerobic and strengthening programmes, 6MWT, gait velocities, maximal VO₂ stress test and Biodex strength assessment were used (Lee et al., 2008, Carr and Jones., 2003). For combined task-oriented functional movement training, Barthel Index, BBS, 6MWT, Motor Assessment Scale, 2-minute step test, walking speed, FMA, Stroke Impact Scale, TUG, sit-to-stand, action research arm test, and grip strength were used in different programmes (Langhammer et al., 2014, Taylor-Piliae et al., 2014, Schmid et al., 2014, Mayor et al., 2013, Wu et al., 2013, Holmgren et al., 2010, Wolf et al., 2010, Dromerick et al., 2009, Hart et al., 2004, Duncan et al., 2003, Page et al., 2002, Dean et al., 2000) Details about different outcome measures used in different studies are reported in table 2.2a.2 in appendix 13.

2.2a.3.4 Quality assessment of the trials

The quality of the trials is varied. Random allocation was reported in all of the included studies. In view of blinding methods, only 3 trials reported the blinding of participants and 23 trials reported the blinding of assessors, of which 3 are double blinded studies with blinding to both patients and assessors.

There are only twelve studies reported complete follow-up of the participants after intervention. There are only thirteen studies reported on the analysis of intention-to-treat (the analysis of withdrawal). Forty-four trials consisted of comparable intervention and non-intervention groups at baseline. Twelve–three trials did not report equivalent treatment other than the targeted interventions. The details of the results of the quality assessment are in table 2.2a.7 in appendix 15.

2.2a.4 Discussion

Studies included in this review suggest 7 common and beneficial types of exercises for the design of a physical exercise manual for physical functional stroke rehabilitation. Of the 49 exercise interventions in the trials, most of them are walking (n=15), task-oriented functional movements (n=15), and strengthening exercises (n=8). Mobility (n=3), aerobic (n=3) balance (n=3) exercise interventions were also reported in the trials. A combined aerobic and strengthening exercise programme (n=1) was also identified.

In general, physical exercise has been shown to be safe and beneficial for physical functional recovery and daily activities after stroke. Evidence indicates that exercises can improve strength and range of motion of the affected limbs and aerobic capacity in daily functional activities (Ada et al., 2006, Pang et al., 2006, van de Port et al., 2007).

2.2a.4.1 Effects of exercises for physical functional stroke rehabilitation

Mobility exercise

In the 3 trials of mobility exercises, a total of 97 participants were involved. The improvements in joint mobility, functional activities, and cardiorespiratory functions have been reported in code 1-3 in appendix 13. Thus, mobility exercise should be

considered in an exercise manual for functional stroke recovery. Investigations about the relationships between this and other types of exercises are needed as this is not clear in the evidence. There is no systematic review on the mobility exercise for functional stroke recovery. How much should the users do to gain the functional benefits from this and other exercises? Since there were relatively fewer trials and participants involved in the studies about the effects of mobility exercises, it is inadequate to only rely on this kind of exercise alone for promoting physical functional stroke recovery.

Aerobic (Cardiorespiratory) exercise

Most of the trials are aerobic exercises, including walking. A total of 1538 stroke survivors were involved in those 18 trials (aerobic: n=198, walking: n=1340). Three relevant systematic reviews were identified. Aerobic exercises are generally shown to be effective to improve lower functions, general mobility status, strength, balance and aerobic capacity for physical functioning for stroke survivors in code 4-21 in appendix 13. Aerobic and walking capacities are found to be associated and decreased in stroke survivors (Tseng et al., 2007), both of which can adversely affect physical function and ADLs. A systematic review reported strong evidence supporting the use of cardiorespiratory (aerobic) training to improve stroke survivors' functional capacity in stair-climbing and walking (van de Port et al., 2007). Improvement in sensorimotor function is significantly related to the improved aerobic capacity (Potempa et al., 1995). Evidence supports aerobic training for increase in walking speed, endurance and independence post-stroke. Saunders and colleagues suggest that it is beneficial to incorporate aerobic exercises into stroke rehabilitation (Saunders et al, 2013).

Cardiorespiratory capacity and walking ability of chronic stroke survivors have been shown to be effectively improved with aerobic exercises in code 4-21 in appendix 13. Although Meek et al (2003) reported that aerobic exercise is not better than no exercise, other evidence supports this exercise is safe and beneficial for aerobic capacity improvement of stroke survivors with mild and moderate stroke (Pang et al., 2006, Stoller et al., 2012). The different conclusions may result from the use of different search strategies and selection criteria in different reviews. Whilst there is an amount of evidence indicating the benefits of using aerobic exercises for

functional recovery, helping stroke survivors to continue to practice to maintain the effects remains a challenge.

Walking

Walking is the most common type of aerobic exercises reported in the trials. The evidence indicates that walking improves physical function, especially lower limbs control, gait pattern and walking speed in code 7-21 in appendix 13.

Strengthening exercise

There are a total of 8 trials about strengthening training, in which 342 participants were involved in code 22-29 in appendix 13. Two related systematic reviews were reported. The number of strengthening exercise studies were less than that of aerobic training. Also, the sample sizes of strengthening trials were relatively smaller than that of aerobic training. Strengthening exercises have been found to be safe and effective for the improvement of both muscular power and activity, which are both beneficial in stroke rehabilitation (Ada et al., 2006). However, progressive resistance strengthening exercises were found to be not effective when compared with the same exercises given without resistance (Moreland et al., 2003). However, there are 2 systematic reviews (Morris et al, 2004, Ada et al, 2006) and 7 interventions provided positive reports towards the effects of strengthening exercise for physical functional stroke recovery. This may be related to the intrinsic factors from the contexts in that particular intervention. Nevertheless, the trend of the effect of strengthening exercises remains positive based on different sources of evidence, especially when it is being done with aerobic exercises together.

Combined aerobic and strengthening exercises

Two trials which involved 92 participants studied interventions consisting of both aerobic and strengthening exercises in code 33-34 in appendix 13. Two related systematic reviews were found. Evidence supports aerobic exercise and strength training as being beneficial for recovery of physical function after stroke. Saunders and colleagues evaluated the evidence for the effects of strength training, cardiorespiratory training, and mixed training programs on gait training. They suggested that exercise interventions focusing on cardiorespiratory training resulted

in the improvement of scores for maximum speed and ability for walking (Saunders et al, 2013). It has been reported that the combination of strengthening and aerobic exercises is beneficial for improving the gait performance of chronic stroke survivors. Whilst positive effects of aerobic exercises for upper and lower limbs functions and strength have been reported, the combination of aerobic and strengthening exercises has found to provide larger improvement (Carr and Jones, 2003).

Balance exercise

Three trials that involved 95 participants were identified in code 30-32 in appendix 13. One related systematic review was found. Effects of balance exercise have shown to be positive in the improvements of balance control, muscle strength, walking speed and endurance according to the 3 identified trials and the systematic review (Sorinola et al, 2014). Multiple elements are often involved in balance training. The evidence reflects the potential connections between balance and other kind of exercises for the benefits of functional improvements. Thus, balance exercise should be used with other exercises to optimize the potential effects for physical recovery.

Combined task-oriented functional movement

Fifteen trials which involved 918 stroke survivors were reported. Two related systematic reviews were found. Positive findings have been reported in different combinations of exercises for task-oriented functional training in code 35-49 in appendix 13. The combination of multiple types of exercises has been identified. For instance, Duncan and colleagues reported positive effects in an exercise programme designed to improve strength, balance, and endurance and the use of the affected extremity (Duncan et al., 2003). Mixing multiple exercises may help to gain the distinct benefits from various exercises to address multiple needs in physical functioning of the individuals.

Constraint-induced movement therapy (CIMT) is a distinct group of combined task-specific exercise training used for physical functional stroke rehabilitation in the trials. It incorporates repeated and structured paretic upper limb practice for functional goals and realistic tasks. Although improvements for the functions of the affected upper limb for stroke survivors have been reported using CIMT (Dromerick et al., 2009, Wolf et al., 2010), the studies have not characterized subjects in terms of

impairment severity. Little is known about how to tailor the contents of an exercise manual to the individual stroke survivors' needs and abilities in task-oriented functional training.

From the studies included in this overview, there is insufficient evidence to conclude a single type of exercise is superior. The features of the identified exercises are different. Hence, different exercises may contribute specific effects towards promoting physical recovery. The inclusion of multiple types of exercise is needed instead of only adhering to a certain type of training to gain distinct beneficial effects from different exercises, since positive effects from a type of exercise may help to improve multiple functions. For instance, cardiorespiratory capacities of stroke survivors were improved with resistance exercises to inspiratory muscles in code 23 and 26 in appendix 13. Hence, it may be helpful to include multiple types of exercise in an exercise intervention to maximize the potential for physical functional recovery.

2.2a.4.2. Study quality

The quality of the included trials should be considered when drawing conclusions about the effects of different exercises. However, the quality of the studies is varied. Methodologic variation was identified in the existing studies which may influence the direct application of the exercise interventions reported in the evidence. The poorly designed studies may have potentially biased estimates of the effects.

Randomisation

Randomised controlled trials are selected for this review with the concern about the quality of evidence. Whilst excluding non-randomised trials may protect against the inclusion of studies with potential allocation bias, the inclusion of randomised trials may not guarantee the protection of bias. Different kinds of bias may affect the estimate of the effects of exercise including selection bias. This may affect decisions for the design the exercise manual. The findings of the literature reveal that various sources of biases may exist in the available studies which may affect the interpretation of the effects of different types of exercise. For instance, a homogenous sample of high functioning independently ambulatory subjects with stroke was selected to receive close and open kinetic chain strengthening exercise (Lee et al., 2013). Some studies have relatively small sample sizes for the

intervention group. There were 6 subjects (Cho et al., 2015, Thielman et al., 2004, Dean et al., 2000) allocated in the experimental group which involved studies about mobility, strengthening and combined task-oriented functional movements trainings. This may limit the use of the information from those trials to the greater population of stroke survivors who often have different levels of physical impairments and disabilities, although positive effects were reported.

Blinding methods

Blinding methods used in the evidence may influence the interpretation of results which can affect the decision-making of exercise prescription based on the effects of exercise training reported in the evidence. Blinding to the assessors may help to protect against measurement bias. However, measurement bias may occur in the measurement process whilst the assessors were not blinded in 26 trials (code 1, 4-7, 12, 14-16, 19, 23-26, 28, 34-38, 40, 43, 45, 46, 48, 49) in appendix 15. Except the 3 balance studies, other types of exercise intervention include studies without blinding to the assessors. It is uncertain about the potential influence from the assessors to the findings reported in those studies as they know the allocation of the groups. The potential assessors' bias may be a concern especially when the measurement procedures are relatively subjective. For instance, subjectivity may be involved in the use of Berg Balance Scale (BBS). However, the assessors in some studies were not blinded during measurement (code 12, 14 and 36). Although the blinding of assessors was reported in the rest of other 23 studies, it may not be used for the measurement of self-reported outcomes adopted in some trials unless the participants are blinded. However, there are 26 studies did not report both blinding to assessors and participants whilst self-reported outcome measure tools were used in those studies. For instance, subjectivity is involved in using Stroke Impact Scale (SIS); however, no blinding to the participants in the study reported by Wolf and colleagues when they used this self-reported measurement tool (Wolf et al., 2010).

The blinding of participants provides a way to control placebo effects in intervention (Herber et al., 2011). Placebo effect may influence the determination of the effects of an intervention. However, the majority of the trials did not report blinding to the participants (n=46). Although it may be difficult to blind the participants while their active participation and understanding about what to do are often needed in exercise

intervention, it remains unclear about the potential influence to the self-reported outcome measures due to the lack of blinding to the participants in those studies.

Outcome measures

A variety of outcomes were measured in the included studies. Whilst using a wide range of outcomes measures may help to understand the effects of exercises for physical functioning from different perspectives, the features of the findings and the contexts in which they were collected are heterogeneous. It is difficult to draw a quantitative conclusion via the direct comparison of the data measured with a wide range of different scales even among similar trials. This may influence decision-making for selecting exercises for individualised prescription. It would be beneficial to focus on a smaller number of robust, specific, and standardized outcome measures in a common dataset to enable future comparisons between trials to understand the effects of exercises for physical functioning.

Failure to report information on other treatments including medications, loss to follow-up and the analysis of withdrawal (intention-to-treat analysis) may have affected the quality of the outcomes, since reactions from other interventions may influence the overall understanding about the effects of exercise training.

Different measurement tools have distinct items for assessment, monitoring and evaluation. This may make direct comparison of the outcomes of exercise training difficult. It may be helpful to use appropriate outcome measures with particular relevance to patients, their carers, and clinicians to understand the effects of exercise to determine suitable exercise prescription in practice. Thus, in addition to collecting quantitative findings, it may be helpful to collect qualitative data to further understand the outcomes of training. This may provide more in-depth understanding of the effects of exercise to the individuals.

Future research will require proper methods and design to optimize the understanding of the effects of exercise for physical functional stroke recovery. It will be important to address the methodological issues including allocation and blinding methods, and the use of appropriate outcome measures. Despite the considerable heterogeneity in the studies, the evidence indicates that the outcomes of exercise trainings are generally effective for physical functional recovery.

2.2a.5 Implications

The evidence implies that physical exercises are generally effective for the recovery of physical functions after stroke. However, no stroke is the same and the impact on stroke survivors is devastating and multifaceted (Walker et al., 2013). The included evidence is based on selected populations. Therefore, no individual exercise recipe is likely to be applicable to all stroke survivors as they often have various functional needs. It remains a challenge to provide patient-tailored exercise prescriptions using the evidence. Intervention aimed at improving disability should include exercises specific to the disability. In addition, the development processes of the reported stroke exercise programmes are often unclear. Are the contents of the interventions preferred by the researchers alone? Hence, research is needed to meet the challenge of designing a personalised exercise manual to tailor the individual survivors' health conditions, abilities and preferences for physical functional recovery.

Research is needed to explore how to support individual stroke survivors to continue to manage their own exercises. Mead and colleagues highlighted that the benefits of exercise training were not retained in longer term (Mead et al., 2007). Whilst various effects of stroke exercise have been reported, there was little information about how to enable stroke survivors to keep managing their own exercises for the long-term retention of benefits in the identified studies. Is there any underpinning concept or factors that may help to drive stroke survivors to keep managing the exercise prescribed to them in the longer term?

Furthermore, the review on existing stroke exercise manuals and related guidelines is needed in addition to the review of trials and systematic reviews. Considering to methodologic variations in the available studies, it may not be adequate to only follow the research findings in the included studies to decide what exercise to be prescribed in practice. Reviewing the manuals and guidelines may provide information about what exercise components are clinically acceptable in current practice. Integrating the information from research evidence, existing manuals and guidelines may help to determine the appropriate types of exercise to be used to design an evidence-based and practical stroke exercise manual. This may help to translate the evidence into practice for the provision of appropriate stroke exercise.

Using two different sources of research evidence may offer a relatively comprehensive understanding about the effects of exercise for functional stroke rehabilitation from relevant evidence in this single study. However, they are different levels of evidence containing different features and information. This made the direct appraisal and combination of the findings difficult, which subsequently limits drawing a combined conclusion to synthesise the clinically useful exercise components to be used for this research project. Hence, to ensure the inclusion of clinically relevant and important exercises in line with current acceptable clinical standard for stroke rehabilitation, the review on existing stroke exercise manuals and guidelines was needed. This may enable the manual to be developed. This is detailed in review 2.2b.

2.2a.6 Limitations

This overview focuses on the evidence of randomised controlled trials and systematic reviews which are least likely to provide biased estimates of effect. However, the non-randomised trials, including case-control and case studies, and general discussion papers were excluded which may also provide useful information from other sources of evidence.

Reviewing the systematic reviews may provide summarized information about the effects of a particular type of exercise, however, this may not allow for drawing conclusions from the results of the original studies, and the details of the individual studies in those papers are not sifted. Different methods, including search strategies and selection criteria were adopted in different systematic reviews. This may lead to different conclusions about the effects of exercises for physical rehabilitation such as the reports of aerobic exercises in different reviews. Hence, whilst the concerns previously discussed, the findings of both trials and systematic reviews were compared and analysed together to determine the effects of exercises using different sources of relevant evidence.

The information in this review is limited with the availability of evidence from the selected databases. The use of relatively comprehensive searching approach may help to identify relevant reviews and trials to obtain a relatively informative knowledge from the available evidence. However, potentially relevant evidence

published using the languages other than English and in other electronic databases might not be included.

Despite the still gaps and shortcomings in the evidence, I believe that this overview does provide a relatively specific and informative summary from relevant evidence about the effects of exercise for physical functional stroke rehabilitation.

2.2a.7 Conclusion

This overview provides a basis on which to inform the development of a new stroke exercise manual using related evidence. Seven types of exercise including aerobic, walking, strengthening, mobility, balance, combined aerobic and strengthening, and combined task-oriented functional movement training are commonly used in the studies.

Evidence shows the trend of positive effects of the above exercises for promoting physical functional stroke recovery, although the degree of effectiveness of each exercise, as well as the quality of the trials are varied. Therefore, these exercises should be considered in the design of an exercise manual for physical functional stroke rehabilitation. Multiple types of exercise should be included in the design of the manual since no single type of exercise has been shown to be superior for functional stroke recovery.

Research is needed to systematically connect the features of exercises towards building a personalized and self-managed exercise manual using the information from the evidence to support the continued physical functional stroke recovery.

2.2b Review of stroke exercise manuals

2.2b.1 Introduction

The value of regular exercises for the maintenance and improvement of function and activities of daily living of stroke survivors has been highlighted (Langhammer and Lindmark, 2012, Langhammer et al., 2007). Evidence indicates a positive trend of effects of exercise for physical functional stroke rehabilitation in the previous section. This section aims to obtain an overview of the available stroke exercise manuals and related guidance to determine the exercises needed for the design of a new stroke exercise manual intended for self-managed exercise for rehabilitation.

Objectives

- to review the available stroke exercise manuals and related guidance
- to determine important components for the design of a new stroke exercise manual

2.2b.2 Methods

The search strategy and selection criteria of this review were the same as that reported in review 2.2a. The identified stroke exercise manuals and guidelines were put together for further analysis in this section. The manuals and guidelines are included if their contents are stroke-specific, functionally relevant, comprehensive, and supported with related evidence.

The contents and recommendations in the manuals and guidelines were summarised into table 2.2b.3 below. The identified exercises in the manuals and guidelines were cross-checked with the findings of review 2.2a before being used to synthesize a summary of components for a new stroke exercise manual in table 2.2b.4. The types of exercise included in table 2.2b.4 were used to inform the development of a new stroke exercise manual which is detailed in chapter 8a.

2.2b.3 Results

A total of 8 manuals and guidelines were identified and reviewed.

The following 4 manuals were identified:

- STroke: A Randomised Trial of Exercise or Relaxation (STARTER) programme (Saunders and Mead 2013)
- Graded Repetitive Arm Supplementary Program (GRASP): A home-work based program to improve arm and hand function in people living with stroke (Eng and Harris 2012)
- Best Practice Guidance for the Development of Exercise after Stroke Services in Community Settings (Best et al., 2010)
- Physical activity in the Prevention and Treatment of Disease: Stroke (Grimby et al., 2010)

The following 4 guidelines were identified:

- Physical Activity and Exercise recommendations for Stroke Survivors: A Statement for Healthcare Professionals From the American Heart Association/American Stroke Association (Billinger et al., 2014)
- ACSM's guidelines for exercise testing and prescription (9th edition) (ACSM 2014)
- National clinical guideline for stroke (4th edition) (ISWP 2012)
- US Department of Veterans Affairs and Department of Defence (VA/DoD) clinical practice guideline for the management of stroke rehabilitation (MSRWG 2010)

The information in the above 8 manuals and guidelines are summarised in Table 2.2b.3 below. The manuals provide different exercise programmes for stroke rehabilitation. The guidelines suggest the elements for the design of stroke exercise programmes from related evidence for clinical practice. In view of the diverse information, contents and recommendations of these manuals and guidelines were cross-checked with the findings reported in the previous section to generate an integrated and evidence-based overview about the important components.

Table 2.2b.3 Summary of exercise from stroke exercise manuals and related guidelines

Manual (n=4)			
Code no.	Manual	Mode of exercise	Recommended contents & exercise prescription
3.1	STroke: A Randomised Trial of Exercise or Relaxation (STARTER) programme (Saunders and Mead 2013)	Warm-up (15 to 20 minutes)	<ul style="list-style-type: none"> - Seated march/arm marching - Sit-to-stand - Mobility exercises for major joints - Pulse raising activity - Stretches - Transition to circuit area
		Cardiorespiratory training (Cardiovascular endurance component)	<ul style="list-style-type: none"> - Cycling ergometry - Ball lift and lower - Shuttle walking (10 metres between chairs) - Wall press (press-ups in standing) - Sit-to-stand - Knee-to-hand (standing) - Step-up - Transition to seated area - Stair climbing / descending - Endurance training ended with a graded cool-down and standing stretches
		Resistance training (Strengthening)	<ul style="list-style-type: none"> - Pole raise - Triceps strengthener - Upper back strengthener - Sit-to-stand - Resistance training ended with a gentle cool-down and flexibility exercises lasting 10-15 minutes
		Cool down	<ul style="list-style-type: none"> - Stretches as warm up
		Summary of training	<p>Training type: mixed cardiorespiratory and resistance Programme: 12 weeks Frequency: 3 days/ week Intensity: RPE 13-16 (6-20 scale) Duration: 15 mins (week 1) increasing to 40 mins (week 12) Specificity: task-related components; stair ascending/ descending, chair rising and walking Progression: Cycling intensity, exercise duration, repetition numbers, task complexity, resistance</p>
3.2	Graded Repetitive Arm Supplementary Program (GRASP) (Eng and Harris 2012)	Multiple arm and hand exercises	<p>Arm and hand exercise programme includes range-of motion and stretching exercises, functional strengthening, weight bearing, trunk control, gross and fine motor skills including repetitive paretic arm practice, and repetitive bilateral arm tasks</p> <ul style="list-style-type: none"> - range of motion and stretching upper limbs - strengthening of the arm and hand (small wrist weight, theraputty, hand gripper) - weight bearing through hand e.g. while sitting, lean forward on hands on table and perform a partial push-up

Continue Table 2.2b.3

			<ul style="list-style-type: none"> - trunk control to facilitate arm reaching - repetitive paretic arm practice include various fine and gross motor tasks (eg, blocks, Lego, pegs) - repetitive bilateral arm tasks include folding towels or clothes, doing buttons and zippers, and bilateral arm strengthening exercises using theraband <ul style="list-style-type: none"> - 1 hour of exercise prescribed by an occupational therapist / physiotherapist - 7 days/week - divide the exercise up into 2-30 minute sessions - check off the exercise completed on a log sheet every day <p>Equipment: 3 books (level 1, 2, 3) and a bag of equipment consists of hand gripper, theraputty, light weight, tennis ball, clothes pegs, lego pieces, plastic jar and lid, hand towel, paper clips, beanbag, and target board (a plastic sheet)</p>
3.3	Best Practice Guidance for the Development of Exercise after Stroke Services in Community Settings (Best et al., 2010)	Warm up (15 to 20 minutes)	<ul style="list-style-type: none"> -Enhance circulation, mobility and to become familiar with basic movement patterns that will be utilised in the training session <ol style="list-style-type: none"> 1. Posture check 2. Circulation booster: march 3. Shoulder rolls mobiliser 4. Circulation booster: march 5. Side bend mobiliser 6. Circulation booster- march 7. Trunk twists mobiliser 8. Circulation booster: march 9. Ankle mobiliser 10. Circulation booster 11. Stretches (normal range of movement and posture check; gentle)
		Training section	<p><u>Cardiovascular/ Aerobic Training:</u></p> <ol style="list-style-type: none"> 1. Bike 2. Ball raise 3. Shuttle walk 4. Wall press 5. Step up 6. Knee to hand <p>Squat or Sit to Stand: Optional</p> <p><u>Functional Strength/Resistance Training:</u></p> <ol style="list-style-type: none"> 1. Upper back strengthener 2. Sit to stand leg strengthener 3. Back of arm strengthener 4. Pole lift from chair

Continue Table 2.2b.3

		Cool down	<ol style="list-style-type: none"> 1. Circulation lower/ re-warm 2. Flexibility stretches: <ol style="list-style-type: none"> a. Calf muscles b. Chest muscles c. Back of thigh muscles d. Side of trunk muscles
		Recommended duration, intensity & frequency	<p>The overall duration of the session will be one hour.</p> <p>The total duration of the aerobic/cardiac exercise training should increase from 15 minutes (week one) to 40 minutes by week 12</p> <p>The intensity of exercise should aim to be moderate as opposed to low</p> <p>The frequency of the session should be three times per week</p>
3.4	<p>Physical activity in the Prevention and Treatment of Disease: Stroke</p> <p>(Grimby et al., 2010)</p>	Aerobic training	<p><u>Activity</u></p> <ul style="list-style-type: none"> • Walking • Nordic pole walking • Circuit training • Ergometer bicycle training • Arm/leg cycling • Walking on treadmill • Step training • Water exercises • Dancing • Wheelchair driving <p><u>Intensity</u></p> <ul style="list-style-type: none"> • 60–80% max HR • 12–15 RPE • Slightly to moderately out of breath <p><u>Frequency (times/week)</u></p> <ul style="list-style-type: none"> • 2–5 <p><u>Duration</u></p> <ul style="list-style-type: none"> • 10–60 min./session, 4–6 months –throughout life

Continue Table 2.2b.3

		<p>Strength training</p>	<p><u>Activity</u></p> <ul style="list-style-type: none"> • Weight lifting machines, e.g. leg press • Eccentric/concentric training • Isokinetic training • Functional training <p><u>Intensity</u></p> <p>Start with 50%, increase to 70–80% of RM, 12–13 RPE</p> <p><u>Frequency (times/week)</u></p> <ul style="list-style-type: none"> • 1–3 • Increase: increase load, not number of repetitions <p><u>Duration</u></p> <ul style="list-style-type: none"> • 1–3 sets of 7–10 repetitions, 10–12 weeks
		<p>Muscular endurance training</p>	<p><u>Activity</u></p> <ul style="list-style-type: none"> • Circuit training • Sequence training • Walking/moving <p><u>Intensity</u></p> <ul style="list-style-type: none"> • 30–50% of 1 RM, 9–11 RPE <p><u>Frequency (times/week)</u></p> <ul style="list-style-type: none"> • 1–5 <p><u>Duration</u></p> <ul style="list-style-type: none"> • 3 sets of 25–50 repetitions
		<p>Functional training</p>	<p><u>Activity</u></p> <ul style="list-style-type: none"> • Balance and coordination training <p><u>Intensity</u></p> <ul style="list-style-type: none"> • Increase level of intensity <p><u>Frequency (times/week)</u></p> <ul style="list-style-type: none"> • 1–3

Continue Table 2.2b.3

		Flexibility	<u>Activity</u> <ul style="list-style-type: none"> • Warm up • Cool down • Stretching <u>Frequency (times/week)</u> With every type of training
			intensity of the training should be adapted to the individual and relevant symptoms

Continue Table 2.2b.3

Guideline (n=4)			
Code no.	Guideline	Mode of exercise	Recommended contents & exercise prescription
3.5	Physical Activity and Exercise recommendations for Stroke Survivors: A Statement for Healthcare Professionals From the American Heart Association/American Stroke Association (Billinger et al., 2014)	Aerobic	<ul style="list-style-type: none"> • Large-muscle activities (eg, walking, graded walking, stationary cycle ergometry, arm ergometry, arm-leg ergometry, functional activities seated exercises, if appropriate) <p><u>Prescriptive guidelines</u></p> <ul style="list-style-type: none"> • 40%–70% Vo₂ (oxygen uptake) reserve or heart rate (HR) reserve; 55%–80% HR max; (Rating of Perceived Exertion, RPE) 11–14 (Rating of Perceived Exertion = subjective perceived level of exertion according to the Borg scale 6–20) • 3–5 days/week • 20–60 mins/session (or multiple 10-min sessions) • 5–10 mins of warm-up and cool-down activities • Complement with pedometers to increase lifestyle physical activity
		Muscular strength/endurance	<ul style="list-style-type: none"> • Resistance training of upper limb extremities, trunk using free weights, weight-bearing partial weight-bearing activities, elastic bands, spring coils, pulleys • Circuit training • Functional mobility <p><u>Prescriptive guidelines</u></p> <ul style="list-style-type: none"> • 1–3 sets of 10–15 repetitions of 8–10 exercises involving the major muscle groups at 50%–80% of 1 repetition maximum (RM) • 2–3 days/week • Resistance gradually increased over time as tolerance permits
		Flexibility	<ul style="list-style-type: none"> • Stretching (trunk, upper and lower extremities) <p><u>Prescriptive guidelines</u></p> <ul style="list-style-type: none"> • Static stretches: hold for 10–30 seconds • 2–3 days/week (before or after aerobic or strength training)

Continue Table 2.2b.3

		Neuromuscular	<ul style="list-style-type: none"> • Balance and coordination activities • Tai chi • Yoga • Recreational activities using paddles/sport balls to challenge hand-eye coordination • Active-play video gaming and interactive computer games <p><u>Prescriptive guidelines</u></p> <ul style="list-style-type: none"> • Use as a complement to aerobic, muscular strength/endurance training, and stretching activities • 2–3 days/week
3.6	American College of Sports Medicine: ACSM’s guidelines for exercise testing and prescription (9th edition) (ACSM, 2013)		<p>Standard stroke care during initial 3-6 months postevent period focuses on basic mobility function and recovery of activity in daily living.</p> <p>Exercise interventions that go beyond the early subacute period are needed to optimize functional capacity for the long term</p>
3.7	National clinical guideline for stroke (4th edition) (ISWP 2012)		<p><u>Royal College of Physicians Recommendations</u></p> <ul style="list-style-type: none"> - Clinicians with the relevant skills and training in the diagnosis, assessment and management of movement in people with stroke should regularly monitor and treat people with movement difficulties until they are able to maintain or progress function either independently or with assistance from others (for example rehabilitation assistants, carers, fitness instructors) - After stroke, patients should participate in exercise with the aim of improving aerobic fitness and/or muscle strength unless there are contraindications -Task-orientated exercises should be used as components of exercise programmes
3.8	US VA/DoD clinical practice guideline for the management of stroke rehabilitation (MSRWG, 2010)		<p><u>Recommendations:</u></p> <ul style="list-style-type: none"> - Cardiovascular exercise and strengthening should be included for motor recovery - Strong evidence that task-specific training improves motor recovery - Consider using strength training - Consider active and passive range of motion prolonged stretching programme - Provide balance training programme to patients with balance impairments - Consider using treadmill for gait training with other task specific practice and exercise training - Practice of functional tasks for upper limb functional recovery

Two stages are included in some of the manuals and guidelines: pre-exercise assessment and exercise sessions. A pre-exercise assessment session has been recommended in some of the guidelines (Billinger et al., 2014, Best et al., 2010, Grimby et al., 2010). Pre exercise assessments consist of medical and activity history, physical examination, exercise tests, contraindications, risk assessment, and information provision are involved. This is to obtain an overview of the stroke survivor’s impairments to tailor the exercise manual to each patient.

The exercise session is often divided into 3 sub-sections: warm-up, training and cool down. Exercises ranging from stretching, aerobic, muscular strengthening, balance, coordination and task-oriented functional training have been recommended. Table 2.2b.4 summaries the components suggested for a stroke exercise manual.

Table 2.2b.4 Components for a stroke exercise manual

Stage	Section	Mode	Recommendation
Pre-exercise assessment session	<ul style="list-style-type: none"> • Introduction • Basic base-line assessment • Individual exercise program design • Exercise testing & individual exercise prescription • Information provision 		<ul style="list-style-type: none"> • General and stroke related medical history • Medication relevant to exercise restriction • Physical health status, blood pressure, heart rate, motor control, balance, gait, functional abilities, visuospatial problems, cognition and communication • Risk assessment
Exercise session	Warm up (15-20mins)	Flexibility exercises (include stretching and mobilising exercises)	<ul style="list-style-type: none"> • Before each aerobic and strength training • Include circulation booster; march • 2-3 days/week • Hold each stretch for 10-30 seconds
	Training section	Aerobic training	<ul style="list-style-type: none"> • Include walking, stepping, sit to stand, stair-climbing, cycling • 2-5 days/week • 10-60 mins/session (multiple 10 mins sessions) • RPE: 11-16 (6-20 scale) • Gradually increase from 15 minutes • Intensity: 40-70% heart rate reserve/ 55-80% HRmax
		Resistance (strengthening) training	<ul style="list-style-type: none"> • upper and lower limbs functional trainings: sit-to-stand, stair-climbing, resistance and free weights • 1-3 days/week • 8-10 exercises • 7-15 repetitions

			<ul style="list-style-type: none"> • 1-3 sets • 50-80% 1 RM (repetition maximum) • RPE: 12-13 (6-20 scale) • Major muscle groups
		Muscular endurance training	<ul style="list-style-type: none"> • include: circuit training, walking • 1-3 sets • 25-50 repetitions • 1-5 times/week • 30-50% 1RM • RPE: 9-11 (6-20 scale)
		Neuromuscular training	<ul style="list-style-type: none"> • Balance and coordination trainings • Such as steadily paced lateral stepping • 1-3 days/week • Include tai chi, yoga etc.
		Task-oriented functional exercise training	<ul style="list-style-type: none"> • such as constraint-induced movements therapy (CIMT), tai chi, yoga, recreational activities & functional movement training
	Cool down (10-20 minutes)	Flexibility exercises (include stretching and mobilising exercises)	<ul style="list-style-type: none"> • After each type of training • Hold each stretch for 10-30 seconds • Include circulation exercise

2.2b.4 Discussion

This review informed a set of exercise components for the development of a new stroke exercise manual for self-managed exercise from the elements recommended in 8 available manuals and related guidelines for stroke exercise. This review has identified 7 types of selected exercise adopted in current stroke exercise manuals and guidelines: stretching, mobilizing, aerobic, strengthening (include resistance and endurance), balance, coordination, and task-oriented functional exercise training.

The 7 types of exercise identified in the manuals and guidelines were cross-checked with the findings reported in review 2.2a in order to understand whether the exercise suggested in these manuals and guidelines are beneficial for physical functional stroke recovery. Also, this may help to ensure the design of the new exercise manual is up to current acceptable clinical standard for evidence-based practice. Since each of the manuals and guidelines has its own characteristics, method and formulated recommendations, several manuals and guidelines were referred in order to gain a comprehensive overview to develop the manual.

Although evidence showing physical exercises are beneficial for functional stroke recovery, the most optimal contents and prescription for functional stroke recovery

has not been determined in the evidence. No single type of exercise has been found to be superior. This may be because different contents, dosages and methods were used in different studies. Thus, multiple types of exercise are included to design the exercise manual in this study based on the evidence, guidelines and other manuals.

In addition to the understanding of the effects of different exercises in the previous section, it is helpful to review the evidence together with relevant guidelines to ensure the inclusion of clinically relevant information for exercise prescription. For instance, flexibility exercises including stretches have been found in the manuals and guidelines. However, it has not been reported in the identified randomised controlled trials. Thus, reviewing current manuals and guidelines may help to partly compensate the limitation from only relying on systematic reviews and randomised controlled trials in the previous overview whilst some useful information may not be included in the studies. Hence, the existing manuals and guidelines were reviewed in this section to obtain a relatively comprehensive understanding about clinically acceptable stroke exercise to design a new manual for practice.

The present evidence, manuals and guidelines provide broad indicative guidance for exercise prescription. However, physical activity goals and exercise prescription for stroke survivors are recommended to be customised for the individual to maximize long-term adherence according to the recent guideline (Billinger et al., 2014). With regards to the complexity of clinical practice, clinical decision on exercise prescription should neither be based on outcomes reported in studies nor recommendations in guidelines alone.

Contextual issues from service users' and providers' perspectives should also be taken into account to determine contents for the design of a practical exercise manual. Individual decisions of exercise prescription should rely on the integration of information from relevant evidence, guidelines, individual therapists' judgement, and individual stroke survivors' needs and abilities at different stages of recovery. This may promote the translation of the knowledge from evidence into practice. Question remains about whether the components in the manuals, guidelines and the studies reflect the user's and the provider's preferences and needs for physical functional rehabilitation, or not.

In addition, it is noted that a systematic approach to decide patient-centred exercise prescription for physical functional stroke rehabilitation may be lacking. Whilst the current exercise manuals and guidelines have described the components and offered a relative standard approach for exercise prescription, they do not guide the clinicians through the process to identify the individual's physical functional rehabilitation needs to determine specific exercise towards achieving individual survivor's functional goals of recovery. There is no two stroke survivors present in exactly the same way due to different pathologies, comorbidities, personal health conditions, functional abilities, needs and goals. The current guidelines indicate the importance of deciding stroke exercises according to individual's needs for physical functioning. Given the consideration of personal variations after stroke, it will be inappropriate to adhering to the information given in the manuals and guideline alone.

2.2b.5 Implications

This review suggests that research to determine how to personalise the prescription to address individual functional rehabilitation needs after stroke is warranted. With the variations among the information in the manuals and related studies, it remains unclear about factors influencing the design of a tailor-made and functional oriented exercise manual for individual survivors' ongoing physical functional recovery.

Evidence has been accumulating on the functional gains from exercises. However, there is no evidence that improvements are sustained once training has ended (French et al., 2007). Supporting stroke survivors to regularly practice their own exercises remains a challenge, although positive effects of exercises have been reported. While trials and systematic reviews provide relatively high-quality source of information and the existing manuals and guidelines suggest the contents for prescribing stroke exercise, little is known about factors and practical ways to support stroke survivors to continue to practise the exercise components suggested in the current manuals and guidelines for their ongoing recovery.

Although different exercise interventions have been reported, little is known from therapists' and patients' perspectives about designing a personalized exercise manual to support stroke survivors' ongoing functioning recovery. Instead of rigidly

following the information of the current manuals and guidelines, and related studies; it is necessary to identify the viewpoints of users and providers to determine the most suitable way to customise exercise prescription for the best interests of the individual survivors. Research is needed to explore their perspectives since they are the providers and the end users of exercise intervention to be developed. This may help to understand how to facilitate stroke survivors to continue to practice their own exercises to benefit from the positive effects stated in the evidence.

Whichever types of exercise are chosen, stroke survivors and clinicians should decide the contents of an exercise intervention according to individuals' abilities to address personal needs. Thus, studies are warranted to determine the ways and components preferred by stroke survivors and clinical therapists to individualise the contents of each exercise manual so as to better address the rehabilitation needs and expectations of each stroke survivor. This may help to provide a realistic and patient-centred exercise prescription in practice. These were investigated and reported in chapter 6 and 7.

2.2b.6 Conclusion

This review provides a set of evidence-informed exercise components to inform the design of a new stroke exercise manual for physical stroke rehabilitation. Seven types of exercise were identified from 8 manuals and guidelines about exercise for physical stroke rehabilitation. Findings from this review inform the exercise components for the development of the manual for this research project. The details about the development of the manual are provided in chapter 8a.

Information from guidelines and research evidence should be integrated with professional judgement and patients' preferences to design a tailor-made, practical and evidence-based exercise manual for stroke survivors to use. This may facilitate the translation of knowledge from evidence into practice. Research is needed to incorporate the information of the overviews of the relevant evidence, manuals and guidelines, and clinicians' and patients' views to design a new exercise manual aimed at self-managed exercise for the long term rehabilitation after stroke.

2.3 Review topic 2: Stroke and self-management

This section focuses on the evidence about self-management for stroke.

2.3.1 Search terms

1. stroke.mp./stroke
2. (self management or self-management).mp

2.3.2 Search results

285 potentially relevant references were identified and screened for their eligibility in which 101 duplications were identified and removed. 184 articles were included for further screening. After further abstract checking, 160 records were excluded; in which 12 were not specific to application of self-management for stroke, 5 were robotic studies focusing on using of specific computer software or device, 20 were conceptual or discussion papers without an actual intervention, 123 were irrelevant to self-management interventions for stroke survivors or with insufficient information or focusing on the effects of specific medications. Thus, 24 articles were included and analysed. 16 stroke-specific self-management programmes were identified from the 24 articles which were further analysed.

2.3.3 Summary of findings

Evidence of self-management interventions for stroke

The background information and key findings research evidence of stroke self-management interventions extracted from the 24 articles were summarised in table 2.3.1 below. This was to gain an overall understanding about the field of stroke self-management programmes from the literature.

Please note that for the ease of reading and reference the literature has been given a code number in the table which is referred to in the rest of this section in this chapter.

Table 2.3.1: Summary of the evidence of self-management interventions for stroke

Reference code	Author, Year & Country	Study design & Setting (Sample size)	Aim of study	Key findings
A1	(Lo et al., 2014) Australia	Systematic review (N=3)	Systematic review	Inconclusive evidence about the effectiveness of theory-based stroke self-management programs on community-dwelling stroke survivors' recovery. Potential benefits in improving stroke survivors' quality of life and self-efficacy.
A2	(McKenna et al., 2013) UK	RCT Single blinded 2 groups (Total: N=25) Intervention group: (N=12) Control group: (N=13) Setting: Community	Evaluate the feasibility of delivery Compare with usual rehabilitation	Participants received the programme have greater change in self-efficacy, functional activity, social integration & quality of life over 6-week intervention period. Stroke survivors showed less declined in mood & quality of life at 3-month follow-up. Professionals found the programme acceptable Questions remain regarding the feasibility of delivering the programme
A3	(Lennon et al, 2013) UK	Systematic review (N=15)	Systematic review	Significant treatment effects Optimal timing, content, and mode of delivering self-management interventions post-stroke remains to be determined. Information provision, goal-setting, problem solving, and promotion of self-efficacy are common self-management interventions for stroke survivors
A4	(Harwood et al., 2012) New Zealand	RCT Parallel groups (Total: N= 172) DVD –based intervention (N= 48) “Take Charge Session” (TCS) (N=46) DVD + TCS ((N=39) Control (N= 39) Setting: Community	Test 2 novel community interventions	An intervention promoting self-directed rehabilitation improved health related quality of life & reduced dependence & strain on carers Participants allocated to TCS were less likely to have a mRS > 2 (i.e. fewer participants dependent on others for activities of daily living) & their carers had better CSI scores
A5	(Jones and Riazi, 2011) UK	Systematic review (N= 22)	Systematic review Self-efficacy for stroke self-management	Self-efficacy is correlated with various outcomes measured post-stroke Optimal format of delivering self-management interventions for stroke survivors is not clear

(continue table 2.3.1)

Reference code	Author, Year & Country	Study design & Setting (Sample size)	Aim of study	Key findings
A6	(Cadilhac et al., 2011) Australia	RCT Single blind Treatment groups : Stroke-specific self-management program (SSMP), N=48 Generic chronic condition self-management program , N=47 Standard care group (control), N=48 Setting: Urban community	Evaluate if SSMP was safe and feasible	SSMP & Generic self-management programs were safe & feasible SSMP is more feasible than generic program
A7	(Huijbregts et al., 2010) Canada	RCT Mixed methods Cross over trial Intervention group: MOST (via videoconference) Control group: waiting list control (WLC) Setting: Urban & rural community	Determine the efficacy of combined videoconference and face-to-face delivery for participation and well-being	Increased in GAS & SIS participation, greater improved RNL & SIS participation for participants in rural sites. Increased confidence & assumption of responsibility for health behaviour change & favourable reception of videoconferencing
A8	(Marsden et al., 2010) Australia	RCT Single blind Cross-over trial (Community-dwelling chronic stroke survivors N=25) (Carers N=17) Setting: Rural outpatient	Explore feasibility of a group programme Determine maintenance of benefits at 12 weeks post intervention	Insufficient participant to show statistical significance High attendance was reported.

(continue table 2.3.1)

Reference code	Author, Year & Country	Study design & Setting (Sample size)	Aim of study	Key findings
A9	(Cadilhac D, 2010) Australia	RCT Single blind (Stroke specific self-management program ; SSMP N=48) (Generic self-management program; GCDP N= 47) (Standard care; SC N=48) Sett: not provided	Determine either stroke specific self-management program safe & feasible compared to standard care or generic self-management program	SSMP is feasible and safe SSMP benefits over GCDP are uncertain
A10	(Hoffmann S, 2010) Australia	Quasi-experimental Setting: Not provided	Explore alternative models	Potential to use peer support models Structured education program shown positive shifts in hei-Q
A11	(Allen et al., 2009) USA	RCT Total: N=380 Intervention group: N=190 Control group: N=190 Setting: Community	Test a comprehensive postdischarge care management intervention	Postdischarge care management was not more effective than organised stroke department care Significant effect of the intervention has been shown in stroke knowledge and lifestyle domain
A12	(Huijbregts et al., 2009) Canada	Quasi-experimental Mixed methods (Telehealth group, Stroke N= 10, Care partner N= 6) (Control group, Stroke N=8, Care partner N=2) Setting: Community	Evaluate the feasibility & efficacy of telehealth stroke self-management programme	High attendance rates for people with stroke and care partners. Feasible to deliver MOST programmes via videoconferencing method to provide self-management programmes to stroke survivors. For efficacy, significant improvement in BBS No significant difference in other outcome measures. Videoconference decreased sense of isolation to their participants. Associated with well-being improvement for person with stroke & their care partners

(continue table 2.3.1)

Reference code	Author, Year & Country	Study design & Setting (Sample size)	Aim of study	Key findings
A13	(Jones et al., 2009) UK	Multiple-participant 2-phase single subject design (N=10) Setting: Community	Examine the effects of a self-management workbook intervention	Significant improvements in SSSQ & RLCS
A14	(Lutz et al., 2009b) USA	Quasi-experimental Mixed methods (Stroke N=18) (Caregivers N=14) Setting: Home-based	Implement a stroke-specific, care coordination home telehealth programme	Positive for depression at least once Caregivers reported significant burden Feasible to implement a post-stroke home-telehealth programme. Need to develop home-telehealth programmes that are easy to understand to provide stroke-related information to meet post-stroke needs.
A15	(Taylor et al., 2009) Canada	Quasi-experimental Mixed methods (Urban centre group, N=7 stroke plus N=7 caregivers and N=2 facilitators) (Rural group, N=5 stroke plus N=5 caregivers) Setting: Urban & rural communities	Explore the feasibility of videoconference delivery	Videoconferencing is feasible to deliver self-management program to people with stroke in rural areas. Participants improved awareness of stroke, social support, coping ability and decreased loneliness. Improvements in goal attainment, mood, balance, balance confidence and walking endurance
A16	(Damush et al., 2008) USA	RCT Protocol Setting: Not provided	Develop stroke self-management programme	Potential to decrease prevalence of post stroke depression & improve health related QOL for stroke survivors
A17	(Huijbregts et al., 2008a)	Prospective, longitudinal cohort For participant with stroke (MOST group N=18) (LWS group N=12) For care partner (MOST group N=7) (LWS group N=9) Setting: Community	Evaluate and compare a new self-management programme with land and water exercise & a standard education programme	Significantly improved RNL & ABC scale for MOST group. All short-term personal goals achieved in MOST group

(continue table 2.3.1)

Reference code	Author, Year & Country	Study design & Setting (Sample size)	Aim of study	Key findings
A18	(Johnston et al., 2007)	RCT Intervention group: a workbook-based intervention, N=103 (stroke survivors & caregivers) Normal care (control group), N=100 Setting: Community	Examine if an intervention could enhance control cognitions	Intervention group: significantly better disability recovery. Only psychological improvement was confidence in recovery. Large proportion of intervention participants did not complete the workbook tasks. The success was modest.
A19	(Kendall et al., 2007b)	Longitudinal RCT (Intervention N=58) (Control N=42) Setting: Community (Metropolitan & suburban areas)	Examine the utility of CDSMP course for psychosocial recovery	No significant difference; no impact on self-efficacy; failed to influence outcomes including mood & social participation
A20	(Allen et al., 2004)	RCT (Intervention group N=190) (Control group N=190) Setting: Community	Describe and test theoretical basis for an interdisciplinary post-stroke care management model	Significant positive effect

(continue table 2.3.1)

Reference code	Author, Year & Country	Study design & Setting (Sample size)	Aim of study	Key findings
A21	(Kang et al., 2004) Korea	Quasi-experimental (Experimental group N=38) (Control group N=37) Setting: Not provided	Evaluate the effect of an East-West self-help program	Effective in improving functional abilities & self-management ability Score of rehabilitation self-efficacy , BADL, IADL, amount of use & quality of movement of affected upper limb, grip power increased significantly Blood cholesterol level s decreased significantly
A22	(Lai et al., 2004) Hong Kong	Quasi-experimental Mixed methods (Stroke N=21) Setting: Community	Evaluate feasibility, efficacy & acceptability	Significant improvements BBS, SSES & knowledge test scores & all subscales of SF36. Shown feasibility, efficacy & high level of acceptance
A23	(Allen et al., 2002) USA	RCT Total: N=96 Intervention group: N=47 Control group (Usual care): N=46 Setting: Community	Test the effectiveness of interdisciplinary postdischarge care management	Postdischarge care management was not more effective than organised stroke department care Intervention significantly improved the profile of health & prevention for stroke / TIA patients 3 months postdischarge Each domain shoed a positive effect of the intervention.
A24	(Frank et al., 2000) UK	RCT Intervention & control groups (wait list) (Total: N=39) Setting: Community	Evaluate the effects of a workbook intervention	No intervention effect. Patients could achieve improvements in function in both groups. Improvements in function were associated with increases in control cognitions Interventions that enhance patients belief in control are likely beneficial

Feasibility and safety

In general, stroke specific self-management approaches are shown to be possible, acceptable, beneficial, effective and safe for stroke rehabilitation. They are reported to have significant positive health impact on the individuals' health status and recovery after stroke (McKenna et al., 2013, Cadilhac et al., 2011, Jones and Riazi, 2011, Cadilhac D, 2010, Huijbregts et al., 2009, Jones et al., 2009, Taylor et al., 2009, Huijbregts et al., 2008, Lai et al., 2004). No adverse effect has been reported (see figure 2.3.1). This indicates that it is generally possible and safe to provide stroke self-management interventions to stroke survivors for community rehabilitation.

Although 62.5% (Code A1, 7, 12-15, 17-18, 21-22 in figure 2.3.1) of the programmes reported significant improvement for the rehabilitation and health status of the stroke survivors, 18.8% (Code A6, 19 and 24) reported no change whereas A8, 16 and 20 had uncertain results). This may be associated with different content, design, theoretical base, delivery method and subjects, and outcome measures used in the studies of different interventions.

Significant improvements were reported for balance ability of stroke survivors participating in many self-management programmes. Additionally, self-management interventions for stroke survivors were found to be beneficial to improve physical function, participation and reintegration to ADLs (see figure 2.3.1).

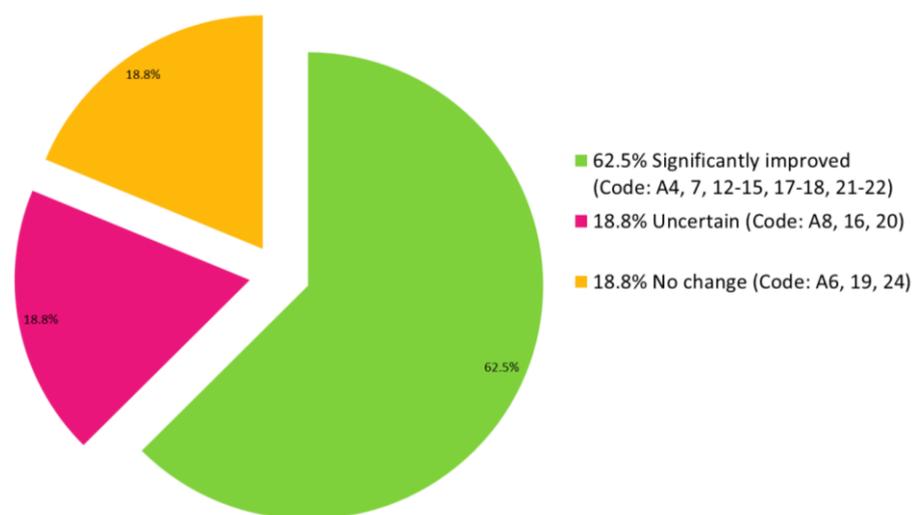


Figure 2.3.1: Health impact of the existing stroke-specific self-management programmes

Stage of post-stroke

The stage of post-stroke of the participants described in this literature ranges from less than 3 months to over 18 months. However, 37.5% (Code A8, 12, 18-21 in figure 2.3.2) identified studies have not specified the stage of post-stroke of their participants. From these studies, the provision of stroke self-management interventions appears possible, acceptable and safe whether delivered in the initial or relatively later stage post-stroke whilst no adverse effect has been reported so far. Therefore, the literature indicates that self-managed interventions may be helpful for the rehabilitation of stroke survivors across different stages after the onset of stroke.

However, further work is needed to explore which stage of post-stroke is the most suitable to implement a stroke self-management programme. This may help to provide practical guidance for the delivery of stroke self-management in practice (see figure 2.3.2).

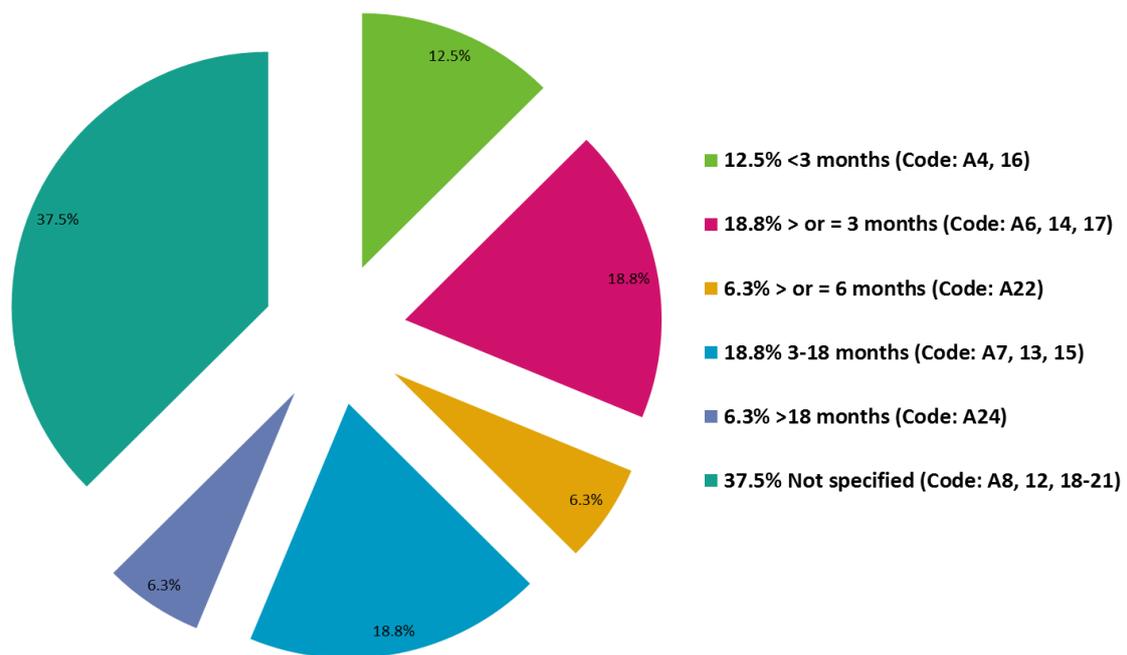


Figure 2.3.2: Stage of post-stroke of the existing programmes

Self-efficacy

Stroke survivors were reported with significant improved self-efficacy associated with a stroke-specific self-management programme (Jones et al., 2009) (see code A13 in table 2.3.1). Self-efficacy is suggested to be an important variable associated with health outcomes, including physical function post-stroke. Jones and Riazi (2011) report that self-management programmes based on self-efficacy principles were beneficial for stroke survivors' health and recovery. Self-efficacy has been found to be an important factor associated with physical functioning outcome, health and ADL in stroke self-management programmes (see code A2, 1.3, 1.5 in table 2.3.1).

Although more evidence is required to understand the feasibility, acceptability, effectiveness and efficacy of theory-based stroke self-management programmes, studies suggest the potential benefits of theory-based self-management programmes for the improvement of quality of life and self-efficacy of community-dwelling stroke survivors (Lo et al., 2014, Lennon et al., 2013, Jones and Riazi, 2011).

Therefore, the literature indicates that self-efficacy is a key factor to be considered when developing a self-managed intervention for stroke rehabilitation.

Features about study design and outcome measures of stroke self-management interventions

Table 2.3.2 summarises information about the study design and outcome measures of the evidence of stroke self-management interventions. This helps to explain the common design and components contained in existing similar interventions and to inform the possible approaches to design studies and develop the programme in this research project.

Table 2.3.2: Features about study design and outcome measures of stroke self-management interventions

Reference code	Types of study population Individual /group	Types of intervention & Duration	Outcome measures
A1	Systematic review	Systematic review	Primary outcomes included health-related quality of life & self-management behaviors. Secondary outcomes included physical (activities of daily living), psychological (self-efficacy, depressive symptoms), & social outcomes (community reintegration, perceived social support).
A2	Stroke survivors in community stroke team or within 4 weeks of commencing rehabilitation with the team Individual	Intervention group: One session of up to one hour per week over 6 weeks in addition to their usual rehabilitation Control group: Usual care only	Feasibility: Participant recruitment & retention, participant adherence to the programme Suitability of outcome measures: Assess suitability of the selected outcome measures Quality of life: Changes of EuroQol (EQ-5D), Stroke specific quality of life scale, self-efficacy scale, stroke self-efficacy questionnaire Functional activity: Barthel Index, Nottingham Extended Activities of Daily Living Community integration: Subjective Index of Physical and Social Outcome Application & fidelity of the programme by community stroke team Acceptability of the programme to stroke survivors, carers & community stroke team
A3	Systematic review	Systematic review	Disability, confidence in recovery, the stroke specific quality of life (sub-scales of family roles and fine motor tasks), and physical component scale of short form SF-36

(continue table 2.3.2)

Reference code	Types of study population Individual /group	Types of intervention & Duration	Outcome measures
A4	Within 3 months of a new stroke Individual	4 groups DVD: “inspirational” DVD was an 80-min professionally produced DVD about stroke & stroke recovery using inspirational stories of 4 Maori & Pacific people & their families. Messages include potential for good outcomes, overcoming adversity, personal & family roles & their contribution to recovery, encouraging meaningful activity & participation for stroke survivors, & where to access resources for them TCS: 80-min individualised assessment with a structured risk factor & activities of daily living assessment designed to engage the patient & their family in the process of recovery, facilitating a process where they identified for themselves areas where they could make progress & set personal goals Control: Written material about stroke for people & their families, covering diagnosis, consequences, risk factors, secondary prevention & recovery after stroke Follow up 12 months after randomisation (N=139) DVD & TCS: 80-min Control: 30 mins	Physical Component Summary (PCS) & Mental Component Summary (MCS) of Short-form 36 (SF-36), Frenchay Activities Index (FAI), Caregiver Strain Index (CSI), Barthel Index (BI), modified Rankin Score (mRS)
A5	Systematic review	Systematic review	Quality of life, perceived health status, depression, ADL & physical functionings
A6	≥ 3 months after confirmed stroke Group	SSMP: -Only by health professionals & peer leaders skilled in stroke & trained -Provide targeted stroke-specific information each week -Revisits information to ensure retention of learning & skills -Topics included: Introduction, sharing stroke journey, how does stroke make you feel? attitudes to stroke recovery, leisure activities, social support and financial matters, working with health professionals, learning to be stroke safe for life and where to from here? -8-week intervention -2.5 hours <u>Generic:</u> 11 generic programs performed by up to 8 different Stanford-trained leaders Not included more than one-third of stroke survivors Topics: use of medicines, communicating effectively with family & friends & nutrition. -6 week intervention -2.5 hours <u>Standard care:</u> usual care only to information and education provided by hospital team or local general practitioner	Feasibility: levels of participation & included numbers of randomized participants had intention to participate / accessed a program/completed the program with >50% attendance

(continue table 2.3.2)

Reference code	Types of study population Individual /group	Types of intervention & Duration	Outcome measures
A7	3-18 months post stroke Group	MOST (via videoconference) -Each session with information exchange on specific topic; followed by exercises -Topics included same as "MOST" 18, 2-hour sessions	Participation domain of the Stroke Impact Scale (SIS), Reintegration to Normal Living index (RNL), Goal Attainment Scaling (GAS), Geriatric Depression Scale (GDS) Post intervention focus groups & interviews
A8	Community-dwelling chronic adult stroke survivors discharged from all therapy programmes for at least 4 weeks & their carers Group	Community Living After Stroke for survivors and carers (CLASSiC) programme. Conducted by an rural-based stroke specific multidisciplinary team with different healthcare professionals 1 hour physical activity, 1 hour education by presentations, group discussions & group activities Weekly 2.5 hour group session for 7 weeks	SIS, Health Impact Scale (HIS), 6-minute walk test (6MWT), timed up and go (TUG), Caregiver strain index (CSI)
A9	Stroke survivors Mean age: 69 59% female Group & individual	SSMP: 8 weeks SC: not specified GCDP: 6 weeks	Primary outcomes: recruitment, participation and participant safety Secondary outcomes: positive & active engagement in life (Health education impact questionnaire), quality of life, mood (irritability, depression and anxiety scale) between baseline and 6 months from recruitment
A10	Stroke survivors Group	2 services models delivery; structured stroke education program delivered at 8 sites based on Stanford model, another less formal model with 6 peer support groups delivered self-management activities targeted to needs 8 week	Health education impact questionnaire (hei-Q)

(continue table 2.3.2)

Reference code	Types of study population Individual /group	Types of intervention & Duration	Outcome measures
A11	Stroke survivors confirmed on ischemic stroke & discharged to home within 8 weeks Individual	2 groups Postdischarge care (Intervention group): Advanced-practice nurse (APN) provided care management to patients. In-home assessment within 1 week of discharge. Standard education & intervention protocols for stroke & common poststroke complications were implemented during home visit. Results of home assessment reviewed by an interdisciplinary poststroke consultation team mainly geriatrician, community-based general internist, stroke clinical nurse specialist, APN-care manager, & physical therapist; to develop patient care plans 6 months	5 domains: neuromotor function (National Institutes of Health Stroke Scale, NIHSS; Timed Up and Go test, ambulation & transfer), institution time or death (days spent hospitalised or in a nursing home during 6 months follow-up period and death), quality of life (stroke-specific quality of life scale), management of risk (blood pressure, total serum cholesterol, hemoglobin A1c, medication appropriateness, Center for Epidemiological Studies of Depression; CES-D scale, self-reported falls & incontinence) & stroke knowledge & lifestyle
A12	Nil Group	Telehealth Moving on after stroke (MOST) intervention was delivered via videoconferencing & related systems with study participants & local facilitator in a centre, the second facilitator in remote area attended the group via videoconference. Modified MOST delivered by trained health professional facilitators 1 hour land-based exercises, 1 hour discussion to enhance self-confidence, well-being, successful community participation via sharing knowledge, problem solving and self-management skills in a supportive environment with others with stroke 9-weeks with 2 sessions per week that last 2 hours per session	Measured at baseline & within 2 weeks after programme completion Outcomes measured: RNL, Stroke-adapted sickness impact profile (SA-SIP 30), Geriatric Depression Scale (GDS-15), Berg Balance Scale (BBS), Chedoke-McMaster Stroke Assessment-Activity Inventory (CMSA-AI), GAS, perceived program benefits, feasibility Data collected via instruments, focus group, reflection logs & attendance rates
A13	12 weeks to 18 months after first stroke 7 men, 3 women, mean age 61.5 years Individual	Individualized self-management workbook based on self-efficacy principles, sections to increase mastery, vicarious experience & feedback 4 weeks	Visual inspection for 14 weeks Measured 14 times ; included: Stroke self-efficacy questionnaire (SSSQ), general self-efficacy scale (GSES), recovery locus of control scale (RLCS), Rivermead mobility index (RMI), Rivermead activities of daily living scale (RADLS), subjective index of physical and social outcome (SIPSO) and hospital anxiety & depression scale (HADS)

(continue table 2.3.2)

Reference code	Types of study population Individual /group	Types of intervention & Duration	Outcome measures
A14	at least 3 months Individual	Participants were provided with an in-home messaging device Stroke related questions & their recovery & management needs & information about signs, symptoms & risk factors & answered stroke specific outcome measures. Data collected & transmitted via home telephone line with web-based programme connected with care coordinators (nurses) to review. Instruments used to measure stroke-related outcomes 14 days.	Physical impairment, depression, fall prevalence, near falls and fear of falling, and burden level among informal caregivers were assessed. Patient Health Questionnaire (PHQ-2), SIS, Brief Burden Interview (BI), questions related to falls, medication administration, Zarit-12 Caregiver Burden Interview, questions of service needs, information of stroke prevention and management and qualitative interviews were used. Interview and survey were used.
A15	3-18 months, not receiving any long-term care, rehabilitation Group	Two groups received same self-management program via videoconference; one group in urban centre, the other in rural area 9 weeks, 2 sessions per week, 2-hours per session	Measured at pre-, post- and 3-months after interventions Goal attainment, balance, mood, participation and walking endurance logs, surveys, focus groups & interviews.
A16	Stroke survivors prior hospital discharge & caregivers Group & individual	6 sessions delivered by 2 case managers half in person (3 sessions) & half by telephone (3 sessions) Self-management skills, goal setting to for behaviour change, negotiation of behaviour planning & problem-solving 12 weeks begin at hospital discharge	Primary outcome; depression Secondary outcome; Patient self-efficacy & stroke specific QOL
A17	30 stroke survivors (average 68 years, 2 years post-stroke) 16 care partners Group	MOST program based on self-management; includes 17 times 2-hours, group-based sessions, in which 1 hour discussion of weekly topics, short-term goal setting, and problem solving , 1 hour exercise, including land & water exercises 2/ week for 8 weeks.	Assessed at baseline, program completion & 3-months follow-up RNL, Activity-specific balance confidence (ABC) scale, exercise participation, goal attainment program delivery costs & focus groups

(continue table 2.3.2)

Reference code	Types of study population Individual /group	Types of intervention & Duration	Outcome measures
A18	Discharged following acute stroke & caregivers Individual	<p>Intervention group:</p> <p>By a workbook implementer to promote patients & their carers being in control, to increase perceived control by providing information, teaching coping skills & guiding self-management tasks</p> <p>-First intervention, implementer presented workbook & instructed participants to use -Second contact, implementer answered questions, provided encouragement & offered more information about stroke risk factors in following week -Third & forth contacts, delivered by telephone at weekly intervals, implementer monitored goals & achievements & continued to provide encouragement -Last contact, a home visit in the fifth week, quizzes and tasks, dairy days & set goals -Content included information about stroke & recovery, guidance on coping skills, self-management instruction, cognitive behavioural therapy techniques by activities for patients to attain coping skills to encourage self-management with task materials & for goal setting, dairy sheets & audio relaxation cassette tape described simple body relaxation & breathing exercises 5 weeks</p>	<p>Primary outcome;</p> <p>Disability/activity limitation with Barthel index & Observer Assessed Disability (OAD), Recovery from disability with OAD & Barthel index, emotional distress with Hospital Anxiety & Depression Scale (HADS), Satisfaction with scales from 0 to 10, perceived control over recovery with Recovery Locus of Control Scale (RLOC), confidence in recovery with ratings from 0 to 10, clinical assessments with Orgogozo index, National Institutes of Health Stroke Scale (NIH), numbers of previous stroke, comorbidity & length of hospital stay, cognitive impairment with Information & Orientation section of the Clifton Assessment Procedures for the Elderly (CAPE) & Mental Status Questionnaire (MSQ), carer measure with physical functioning scale of Short Form 36 (SF36),</p>
A19	100 stroke victims, male, n=67, female, n=33, average age of sample was 65.96 years, range between 25 and 82 years. Spouse invited to participate (n=69), adult child (n=25), friend (n=4) & sibling (n=2) Group	<p>CDSMP, 2 hours each week.</p> <p>2 trained health professionals facilitated the courses Both continued standard post-discharge rehabilitation 7 weeks for each group, 18-months for 8 groups</p>	<p>Data collected by telephone 4 times over 12 months post-stroke.</p> <p>Self-efficacy scale & SSQOL scale</p>
A20	Nil Individual	<p>Intervention :of elements of chronic illness care models with organizational leadership, incentives, resources for providers, delivery system redesign in advanced practice nurse functions, clinical information systems, community linkages, self-management support & decision support for primary care physicians</p>	<p>Not specified</p>

(continue table 2.3.2)

Reference code	Types of study population Individual /group	Types of intervention & Duration	Outcome measures
A21	Nil Group	Experimental group participated in self-help group program of 6 sessions, 2 per week Program consists of health education of stroke, exercise, oriental nursing interventions, and therapeutic recreation 6 weeks	Score of rehabilitation self-efficacy , Basic ADL, IADL, amount of use & quality of movement of affected upper limbs, grip power , blood cholesterol level
A22	least 6 months post-stroke; able to walk independently no cognitive function impairment, significant communication barriers or uncompensated cardiac or pulmonary insufficiency Group	Programme delivered by a physiotherapist via a videoconference system to participants in a community centre, with a non-professional assistant included to facilitate the programme. Intervention included education, exercise, social support. Education topic included: Pathophysiology of stroke, signs & symptoms, medical management, rehabilitation pathways, identification & modification of risk factors, psychosocial impact, community support, home & environmental safety Exercise: improve strength & balance exercise logbook was given 8-week, 1 session per week, 1.5 hours per session, including 30 minutes for exercise session	Primary outcomes: at baseline & after programme completion ; including BBS, Medical Outcomes Study 36-item Short Form (SF-36), State Self-Esteem Scale (SSES) & Stroke knowledge test. Secondary outcomes: only assessed at the baseline upon recruitment to define baseline functional and clinical status of participants; including GDS-15 (15 items Short form of GDS), Elderly Mobility Scale (EMS), Lawton Instrumental Activities of Daily Living Scale (Lawton IADL) Outcomes measured by a physiotherapist & a research assistant in interviews & focus groups

(continue table 2.3.2)

Reference code	Types of study population Individual /group	Types of intervention & Duration	Outcome measures
A23	<p>Stroke survivors diagnosed with ischemic stroke or TIA, Rankin score <3</p> <p>At the discharge from acute stroke unit to home or short-term rehabilitation (< 1 month postdischarge) Individual</p>	<p>2 groups</p> <p>Postdischarge care (Intervention group):</p> <p>Advanced-practice nurse (APN) contacts patient by phone within 3-7 days of discharge to home. Then perform biopsychosocial assessment in patient's home within 1 month postdischarge. APN reports assessment findings to the poststroke consultation team to discuss home assessment findings.</p> <p>Interdisciplinary team mainly geriatrician, stroke clinical nurse specialist, APN-care manager. To develop individualised treatment plan. APN follows up and implements the plan.</p> <p>3 months postdischarge 4 hours on assessments, care plan development & follow-up.</p>	<p>5 domains: neuromotor function (National Institutes of Health Stroke Scale, NIHSS; Timed Up and Go test, ambulation & transfer), institution time or death (days spent hospitalised or in a nursing home during 6 months follow-up period and death), quality of life (stroke-specific quality of life scale), management of risk (blood pressure, total serum cholesterol, hemoglobin A1c, medication appropriateness, Center for Epidemiological Studies of Depression; CES-D scale, self-reported falls & incontinence) & stroke knowledge & lifestyle</p>
A24	<p>Stroke within 2 previous years</p> <p>Individual</p>	<p>Intervention: designed to increase perceptions of control by giving information, enhancing coping resources, and rehearsing planning & problem-solving skills</p> <p>Workbook used.</p> <p>1 month;</p> <p>Second visit was arranged for 1 week later when questions were answered. Over the next 3 weeks, patients, their carers worked independently of the researcher on the workbook & telephoned weekly for questions and progress</p>	<p>Functional Limitation Profile (FLP), Hospital Anxiety and Depression Scale (HADS), Recovery Locus of Control Scale (RLOC), Perceived Health Competence Scale (PHCS), 10-point ratings of usefulness & intelligibility of the workbook</p>

Study design

The review of the designs of the studies reported in the literature helped me to reflect on the possible way to construct this research. Mixed methods designs were often reported in the studies of self-management programmes (see table 2.3.2). These indicated that it may be preferable and workable to adopt a mixed methods approach to investigate the issues of stroke-specific self-management interventions. This approach allows the collection of explanatory information to explore and interpret which results are important for the developmental stage of a new intervention.

Most interventions reported in the literature were community-based and found that these interventions were workable and acceptable in practice (see table 2.3.2). Therefore, it appears that the research for developing a community-based and self-managed intervention for helping stroke survivors to manage their rehabilitation is possible and acceptable in the field.

Outcome measures

Multiple outcome measurement tools were used in the identified studies. The adoption of diverse types of tools may be due to the generic nature of the contents in the most of the existing programmes which contain a wide range of components, different study designs, and aims, and features of the interventions. These are summarized in table 2.3.3. Outcome measure tools including self-efficacy, physical impairment, disability, functional activities, psychosocial, goal attainment and well-being were used.

Most studies used multiple types of outcomes to evaluate the effect of the interventions. This indicates that the majority of the existing stroke self-management interventions generally focus on how to help stroke survivors to manage their multiple consequences and needs for stroke rehabilitation. Further work is needed to explore how to enhance stroke survivors' ability to manage specific health related consequences from stroke; such as their physical functional rehabilitation for activity and participation in the community. This may enable the clinicians to identify more tailor-made methods to address their specific type of needs in more in-depth way.

Table 2.3.3: Summary of types of outcome measures used in the existing studies of stroke self-management programmes

Type of outcome measures	Total frequency	Percentage %	Reference code
Self-efficacy	6	13.3	A12, 13, 17, 19, 21
Disability	5	11.1	A8, 12, 15, 18, 22
Functional activities in daily living	5	11.1	A4, 7, 8, 17, 21
Quality of life	4	8.9	A4, 16, 19, 22
Goal attainment	3	6.7	A7, 15, 17
Psychosocial	3	6.7	A13, 15, 18
Well-being	3	6.7	A12, 15, 22
Mood/emotion	3	6.7	A14, 15, 16
Overall stroke impact	3	6.7	A7, 8, 21
Participation	2	4.4	A6, 7
Self-management abilities	2	4.4	A8, 21
Physical impairment	2	4.4	A14, 21
Attendance	2	4.4	A6, 20
Cognitive	1	2.2	A22
Problem-solving	1	2.2	A15

The measurement tools related to physical mobility and functions were often used in the studies including 6-minute walk test (6MWT), timed up and go (TUG), Berg balance scale (BBS), Chedoke-McMaster stroke assessment activity inventory (CMSA-AI), Rivermead activities of daily living scale (RADLS), subjective index of physical and social outcome (SIPSO), Barthel index (BI), observer assessed disability (OAD), activity-specific balance confidence (ABC) scale, elderly mobility scale (EMS), Lawton instrumental activities of daily living scale (Lawton IADL), National Institutes of Health Stroke scale (NIHSS), physical component summary (PCS) and physical functioning scale of short form 36 (SF36) (see table 2.3.3). Therefore, it indicates that the impact on stroke survivors' self-efficacy, disability and functional physical stroke rehabilitation from participating in stroke self-management interventions are regarded important in some studies.

Stroke self-efficacy questionnaire (SSSQ) and general self-efficacy questionnaire (GSES) have been used to measure the change of stroke survivors' self-confidence as a result of using the programmes in some studies. This may reflect that self-efficacy is considered to be a necessary element to be included in a self-managed intervention for stroke rehabilitation.

In view of measuring the quality of life aspect, stroke specific quality of life scale (SSQOL) and EuroQol (EQ-5D) have been reported in some studies. Thus, a self-managed programme may have certain impact on stroke survivors' quality of life in their rehabilitation process.

The outcome measures should be selected and evaluated based on the particular focus of the intervention and the included components to reflect health impact on the target areas to understand the effect from using the intervention. However, the effectiveness of current self-management interventions for physical functional recovery of stroke remains inconclusive due to insufficient data in the literature. This is also associated with the problems from using different tools for outcome measures in different studies which make it difficult to directly compare the effect of different programmes to the same domain to determine the effectiveness of using self-managed programmes for physical stroke rehabilitation.

Characteristics of existing self-management programmes for stroke rehabilitation

The characteristics of existing self-management programmes for stroke rehabilitation are summarised in this section. In particular, the common contents of the existing programmes are presented in table 2.3.4 below.

Table 2.3.4: Common contents of the existing self-management programmes for stroke rehabilitation

Reference code	Author & Year & Country	Intervention contents & structure	Generic / Personalized	Education with professional stroke specific health information
B1	(Harwood et al., 2012) New Zealand	<p>DVD:</p> <p>“inspirational” DVD was an 80-min professionally produced DVD about stroke & stroke recovery using inspirational stories of 4 Maori & Pacific people & their families. Messages include potential for good outcomes, overcoming adversity, personal & family roles & their contribution to recovery, encouraging meaningful activity & participation for stroke survivors, & where to access resources for them</p> <p>TCS:</p> <p>All participants had been assessed using Barthel Index & Frenchay Activities Index, measured blood pressure, weight, height, asked about smoking, heart disease & diabetes.</p> <p>A booklet includes heading of physical, communication, emotional/mood, information needs, financial, extended family issues (stress, information, involvement & safety), secondary prevention (reduce risk, improve quality of life)</p> <p>Control:</p> <p>Written material about stroke for people & their families, covering diagnosis, consequences, risk factors, secondary prevention & recovery after stroke</p>	Both	Included
B2	(Cadilhac et al., 2011) Australia	<p>Revisits information to ensure retention of learning & skills with stroke survivors</p> <p>Topics:</p> <p>Introduction, sharing the stroke journey, how does stroke make you feel? attitudes to stroke recovery, healthy lifestyle: leisure activities, social support and financial matters, working with health professionals, learning to be stroke safe for life & where to from here?</p>	Generic	Included
B3	(Huijbregts et al., 2010) Canada	<p>Information exchange on specific topic; followed by exercises</p> <p>Topics: same as “MOST”</p>	Generic	Included

(continue table 2.3.4)

Reference code	Author & Year & Country	Intervention contents & structure	Generic / Personalized	Education with professional stroke specific health information
B4	(Marsden et al., 2010) Australia	Physical activity & education	Generic	Included
		1 hour physical activity from the second week; then 1 hour education via presentation, group discussions & group activities		
B5	(Huijbregts et al., 2009) Canada	Topics:	Generic	Included
		Introduction to exercise, what is stroke? health-related goal setting, education topics of goal setting, taking control of health, review risk factors & warning signs, secondary prevention, nutrition information, talking to health professionals, depression information, fatigue management, memory, safety & fall prevention, stress & relaxation, community participation/accessing resources, & making long-term changes & maintenance strategies		
B6	(Lutz et al., 2009b) USA	1 hour discussion, 1 hour exercise	Personalized	Included
		Topics: same as "MOST"		
B7	(Taylor et al., 2009) Canada	Topics:	Generic	Included
		Stroke survivor & caregiver issues & concerns, assessment of physical impairment, depressive symptoms, fall prevalence, near falls and fear of falling, burden level among informal caregivers, service needs (therapy, supportive services & contact with the care coordinator), stroke prevention & management, falls, medication administration, stroke-specific outcomes information		
B8	(Jones et al., 2009) UK	2-hours per session (1 hour discussion, 1 hour exercise)	Generic	Included
		Topics: same as "MOST"		
B9	(Damush et al., 2008) USA	4 sections in the workbook to address self-efficacy:	Personalized	Nil
		Vignettes describing 10 individuals with a different impairments post stroke, described how they preserve & change in behaviour & performance via their own efforts		
		Stories describing individual experience & solutions to common problems post-stroke		
		Examples of different strategies to maintain & enhance functional activity & participation		
B9	(Damush et al., 2008) USA	Diary to record setting & judgements about small weekly personal targets	Generic	Not provided
		Self-management skills, goal setting to for behaviour change, negotiation of behaviour planning & problem-solving		

(continue table 2.3.4)

Reference code	Author & Year & Country	Intervention contents & structure	Generic / Personalized	Education with professional stroke specific health information
B10	(Huijbregts et al., 2008b) Canada	Moving On after Stroke (MOST) program: Topics: Goal-setting, why self-management? Why exercise? How stroke affects you/prevention, relaxation, daily activities & responsibilities, recreation & having fun, how stroke affects you think & feel, help from friends & family, community resources, communication, interaction with health professionals, alternative treatments, loving & caring, your doctor & your medications, nutrition, sleep & pain, wrap up/community-environment	Generic	Included
B11	(Johnston et al., 2007) UK	A workbook implementer to promote patients & their carers being in control, to increase perceived control by providing information, teaching coping skills & guiding self-management tasks Included monitored goals achievements & continued to provide encouragement Content: stroke & recovery information, coping skills, self-management instruction, cognitive behavioural therapy techniques to attain coping skills to encourage self-management with task materials & for goal setting, dairy sheets & audio relaxation cassette tape described simple body relaxation & breathing exercises	Generic	Included
B12	(Kendall et al., 2007a) Australia	Continued standard post-discharge rehabilitation	Generic	Included
B13	(Allen et al., 2004) USA	Elements of chronic illness care models with organizational leadership, incentives, resources for providers, delivery system redesign in an advanced practice nurse functions, clinical information systems, community linkages, self-management support & decision support for primary care physicians	Generic	Not provided
B14	(Kang et al., 2004) Korea	Community-based self-help group Health education of stroke, exercise, oriental nursing interventions & therapeutic recreation	Generic	Included
B15	(Lai et al., 2004) Hong Kong	Include 30-minutes exercise; & education, exercise, social support. Topics: Pathophysiology of stroke, signs & symptoms, medical management, rehabilitation pathways, identification & modification of risk factors, psychosocial impact, community support, home & environmental safety Exercise: Improve strength & balance Exercise logbook	Generic	Included
B16	(Frank et al., 2000) UK	Intervention designed to increase perceptions of control by giving information, enhancing coping resources and rehearsing planning and problem-solving skills. A workbook introduced to patients & their carers in the first session. It contains information about stroke, causes, management, & recovery. Patients will be asked to work through the sections, answering quizzes & deciding additional sections. Second visit after 1 week. Answer patients' questions. Introduce methods of coping & patients were each given a relaxation tape & instructions for use. A recovery plan, usually consisting of a small daily task with records, was made as a joint exercise between the researcher & patient & carer. Next 3 weeks, patients & their carers worked independently of the researcher on the workbook. Telephoned the patients to provide chance to ask questions and ask about their progress.	Generic	Not provided

Intervention contents

The common components of the existing programmes are shown in table 2.3.4 and 2.3.5 which shows that multiple contents were often included. A wide range of contents are included in the existing programmes. Over 90% of the interventions include general and diverted contents about stroke recovery rather than providing specific materials for stroke survivors to manage their own physical rehabilitation. In contrast, two of the identified programmes contain contents to personalise the interventions to address individual stroke survivors' needs for rehabilitation. In particular, the interventions reported by Jones et al (2009) (code B8 in table 2.3.4) and Lutz et al (2009) (code B6 in table 2.3.4) have included specific materials to personalise each programme for the individual stroke survivor. For instance, there are stories describing individual experience and solutions to common problems after stroke included in the workbook reported by Jones et al (2009). The information from similar case examples may motivate both the service provider and the user to reflect on what may be needed in each programme during the prescription process. This may help to decide what contents will be required to personalise the programme to cater for the individual.

It appears that the existing stroke self-management programmes are more intended to contain multiple kinds of contents. This is likely to be related to the concern of managing multiple consequences resulted from stroke. Although several components were shown to be more often included in most of existing programmes, such as general knowledge and information of stroke and recovery (9.8%) (code B1-5, 7, 8, 10-16 in table 2.3.4 and 2.3.5) and psychosocial support (9.1%) (code B1-8, 10-12, 15,16); the components required in a self-managed exercise manual especially for physical rehabilitation have not been determined in the literature.

However, educational information related to general knowledge about stroke recovery, different skills for stroke rehabilitation, physical exercise, goal-setting and progress monitoring and recording and psychosocial support were included in the most of the programmes (see table 2.3.4 and 2.3.5) .

Table 2.3.5: Summary of the common components of the existing stroke self-management programmes

Components	Total frequency	Reference code
Health education with general knowledge & information of stroke & recovery	14	B1-5, 7-8, 10-16
Psychosocial support	13	B1-8, 10-12, 15-16
Knowledge & skills for management of physical signs & symptoms/impairments	12	B1, 3, 5-8, 10, 12-16
Mood/emotion/behaviour management information & skills	12	B1, 3-12, 16
Goal setting & recording	10	B3-6, 8-12, 16
Physical activity / exercise	10	B2-5, 7, 8, 10, 12, 14-15
Knowledge of self-management principles/concepts	10	B1, 3-5, 8-11, 13, 16
Communicate /partnerships with healthcare professionals	10	B1-5, 8, 10, 12-13, 16
Secondary prevention for the risks and safety issues	9	B1, 2-5,7-8,10-11, 15
Problem-solving/coping skills	9	B3, 5-6, 8-12, 16
Use of supporting community resources/services	8	B1, 3, 5, 7-8, 10, 13, 15
Community participation/community- environment issues	7	B3-6, 8,10, 12
Functions for activities in daily livings	7	B1, 3-6, 8, 10
Nutrition	7	B1, 3-5, 8, 10, 12
Leisure /recreational activity	6	B2-3, 5, 8, 10, 14

Education & stroke-specific self-management

81.3% programmes contain educational elements (see figure 2.3.6). Health education of stroke recovery (code B1-5, 7, 8, 10-16 in table 2.3.5) and knowledge and skills for managing signs and symptoms (code B1, 3, 5-8,10,12-16 in table 2.3.5) are also the common components included in the existing stroke self-management programmes. This indicates that education is perceived as an important element for self-management in stroke-specific self-management programmes. However, no known educational theory has been reported to underpin the educational concepts and elements within the existing programmes. Thus, I considered it would be useful to involve educational theory for the development of the programme in this research to explore an approach to inform the survivors in the best way to facilitate them to self-manage their physical rehabilitation.

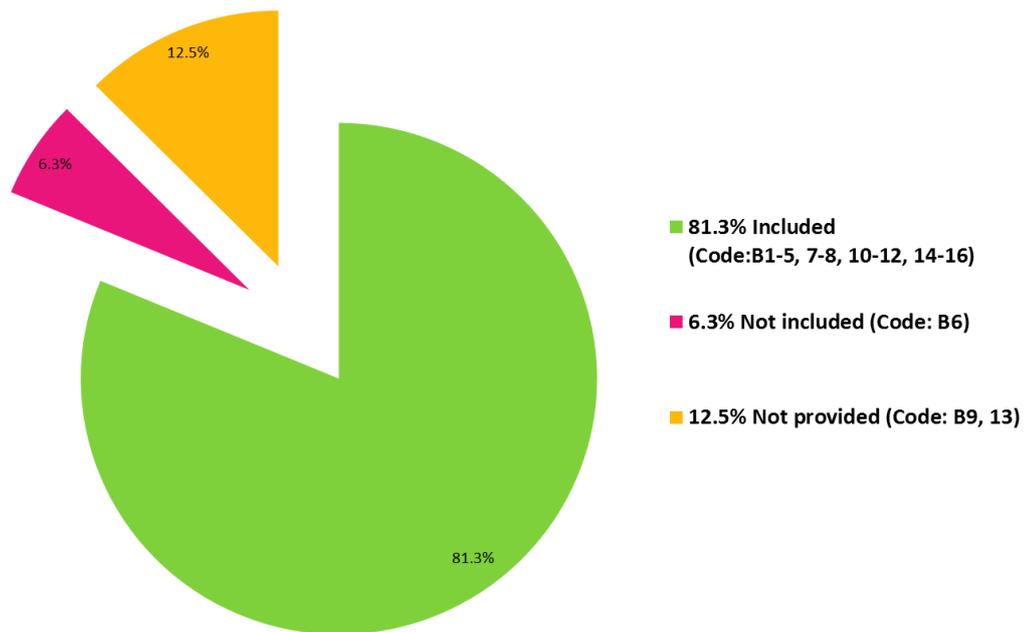


Figure 2.3.6 Educational sections in stroke-specific self-management programmes

Intervention duration

37.5% of the interventions lasted for 8 weeks or longer as shown in figure 2.3.7. This is followed by the duration of 6-8 weeks (18.8%). However, it is unclear how the duration of existing interventions was determined and the optimal length of intervention duration for the delivery of a stroke self-management intervention has yet to be determined from the existing studies. With regards to those interventions developed in the UK, none of them has mentioned how they can be used to meet the 6-months review national policy proposed by the government for the provision of stroke rehabilitation services (NICE, 2013, DH, 2007b). However, it will be helpful to design an intervention with the consideration of how to match it with the health policy related to stroke rehabilitation to better fit it into local health system for practice.

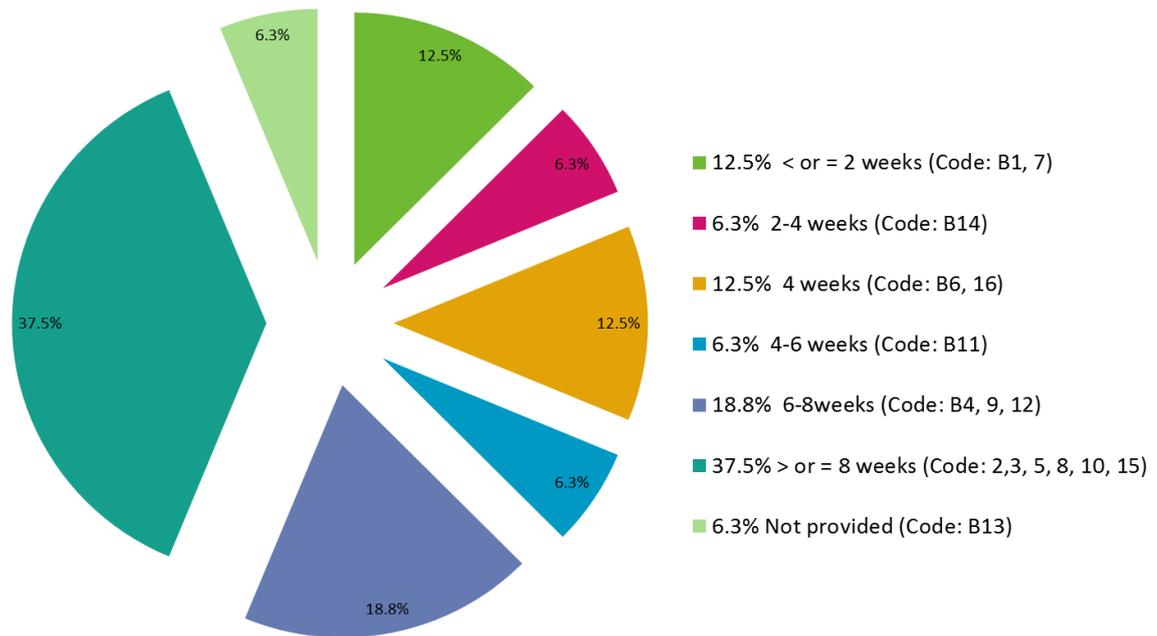


Figure 2.3.7 Summary of intervention duration

Intervention delivery methods

Delivery methods used in the current programmes are summarized in figure 2.3.8 below. 29.4% (Code B2, 4, 10, 12 and 14 in figure 2.3.8) of the programmes were delivered by face-to-face mode either in groups or individual formats. Therefore, it implies either mode is considered to be feasible and acceptable. Available technologies were used for intervention delivery or follow up purposes in some studies. 23.5% (Code B3, 5, 8, 15 in figure 2.3.8) of the programmes applied videoconferences to deliver the programmes in face-to-face mode in groups. However, the costs and cost-effectiveness of the different models to deliver self-management of stroke is underdetermined.

After all, face-to-face mode is the common method used in the existing programmes. However, the optimal delivery format of self-management interventions for stroke survivors according to the literature remains unclear (Jones and Riazi, 2011).

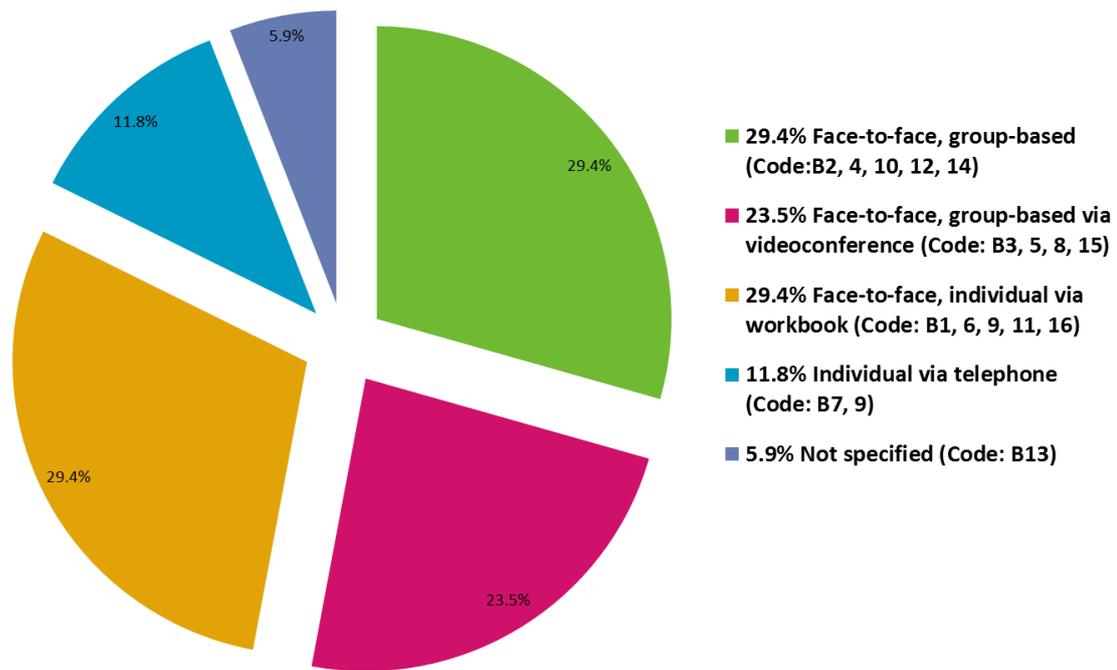


Figure 2.3.8 Summary of intervention delivery methods

Intervention delivery persons

Different types of service providers were used to deliver the existing stroke self-management interventions. This is summarised in table 2.3.6. Some were healthcare professionals, trained persons or peer-leaders, whereas some have not provided the background of the conductors (see table 2.3.6). The quality, consistency and accuracy of the delivered self-management concepts, skills and physical exercises may be different in different programmes since different kinds of providers were involved in providing the programmes.

Health conditions and needs of stroke survivors are unique due to multiple pathologies, different consequences of stroke, different personal health conditions, and co-morbidities. Since specific knowledge and skills are needed for the individual to deliver the self-managed programme for stroke rehabilitation, their knowledge and skills need to be considered. However, which kind of person is the most suitable to provide self-management interventions for stroke remains to be determined.

Table 2.3.6: Intervention delivery persons

Type of provider	Total frequency	Reference code
Trained facilitator	5	B1, 3, 5,6, 8
Trained unknown health professional	3	B2, 10, 12
Case manager /implementer/researcher with unknown profession	3	B9, 11,16
Physiotherapist	2	B4, 15
Not provided	2	B13, 14
Nurse	2	B4, 7
Dietician	1	B4
Speech pathologist	1	B4
Occupational therapist	1	B4
Social worker	1	B4
Trained peer-leader	1	B2

Application of technology in the existing interventions

In view of the delivery issues about the identified stroke self-management interventions, some technology have been adopted in the delivery process of some of the programmes (see code B1, 3, 5, 6, 7, 9, 11, 12, 15,16 in table 2.3.7). Different kinds of technologies have been adopted in some of the programmes. This indicates that the concept of using technology for stroke self-management appears to be possible and acceptable in the literature. Telephone and videoconference are commonly used in the programmes supported with technology.

However, little is known about how the technology was chosen in these programmes. The underpinning concept about using those technologies for the delivery of the interventions remains unclear. Little was known about how the stroke survivors and practitioners of those interventions think in relation to using those technologies for stroke self-management. The issues about using technology for stroke self-management are further explored and discussion in the literature review 3 reported in the next part in this chapter.

Table 2.3.7: Summary of the delivery method, person and the use of technology for the delivery of the existing stroke self-management programmes

Reference code	Author & Year & Country	Intervention delivery person & method	Application of technology
B1	(Harwood et al., 2012) New Zealand	Trained researcher assistants Face-to-face; in person & DVD-based	Yes (DVD)
B2	(Cadilhac et al., 2011) Australia	Trained health professionals & peer leaders Face-to-face; in person, group-based	Nil
B3	(Huijbregts et al., 2010) Canada	2 trained facilitators Face-to-face via videoconference; Group-based	Yes (videoconference)
B4	(Marsden et al., 2010) Australia	Stroke-specific multidisciplinary team; physiotherapist, social worker, dietitian, clinical nurse consultant, speech pathologist & occupational therapist Face-to-face, in person; Group- based	Nil
B5	(Huijbregts et al., 2009) Canada	2 trained facilitators Face-to-face; Group- based; via videoconference	Yes (videoconference)
B6	(Lutz et al., 2009b) USA	Registered nurses Individual via telephone	Yes (telephone)
B7	(Taylor et al., 2009) Canada	2 trained facilitators Face-to-face, Group- based; via videoconference	Yes (videoconference)
B8	(Jones et al., 2009) UK	Not provided Face-to face in person; Individual	Nil
B9	(Damush et al., 2008) USA	2 case managers half in person (3 sessions) & half by telephone (3 sessions) Face-to-face; in person, Group-based Half by in person, half by telephone	Yes (telephone to deliver half sessions)

(continue table 2.3.7)

Reference code	Author & Year & Country	Intervention delivery person & method	Application of technology
B10	(Huijbregts et al., 2008b) Canada	two trained health professions, a physiotherapy assistant & three volunteers Face-to-face; in person; Group-based	Nil
B11	(Johnston et al., 2007) UK	Implementer Face-to-face, in person; Individual follow up	Yes (telephone follow up)
B12	(Kendall et al., 2007a) Australia	2 trained health professionals Face-to-face; in person; Group-based	Yes (telephone to collect data)
B13	(Allen et al., 2004) USA	Not provided	Nil
B14	(Kang et al., 2004) Korea	Not provided Face-to-face; Group- based	Nil
B15	(Lai et al., 2004) Hong Kong	physiotherapist With non-professional assistant Face-to-face; Group-based, via videoconference	Yes (videoconference)
B16	(Frank et al., 2000) UK	Facilitator: researcher Face-to-face; in person; Individual follow up	Yes (telephone)

Supporting theory/model

Self-efficacy is the most commonly identified theory in the existing stroke self-management interventions which are followed by behavioural theory (13%) (Code B1, 11, 12 in figure 2.3.9). 25% (Code B6, 9, 10, 12, 16 in figure 2.3.9) of the interventions adopted self-efficacy as a concept support.

34% (Code B2-8, 14, 15 in figure 2.3.9) of the studies did not report any underpinning model/theory of the interventions. The concepts and beliefs supporting the components and practice of those interventions remain unspecified. Therefore, it raises a question about how to transfer the specific knowledge and skills of those interventions into practice. It will be challenging for the providers to deliver the programmes without clear guiding concepts and this may affect the possibility and accuracy of using the interventions. Moreover, insufficient information about the concepts of those programmes may affect the investigations in the future relating to

the influence and their impact. This may subsequently affect the usability of the interventions due to the lack of related knowledge and evidence to inform practice.

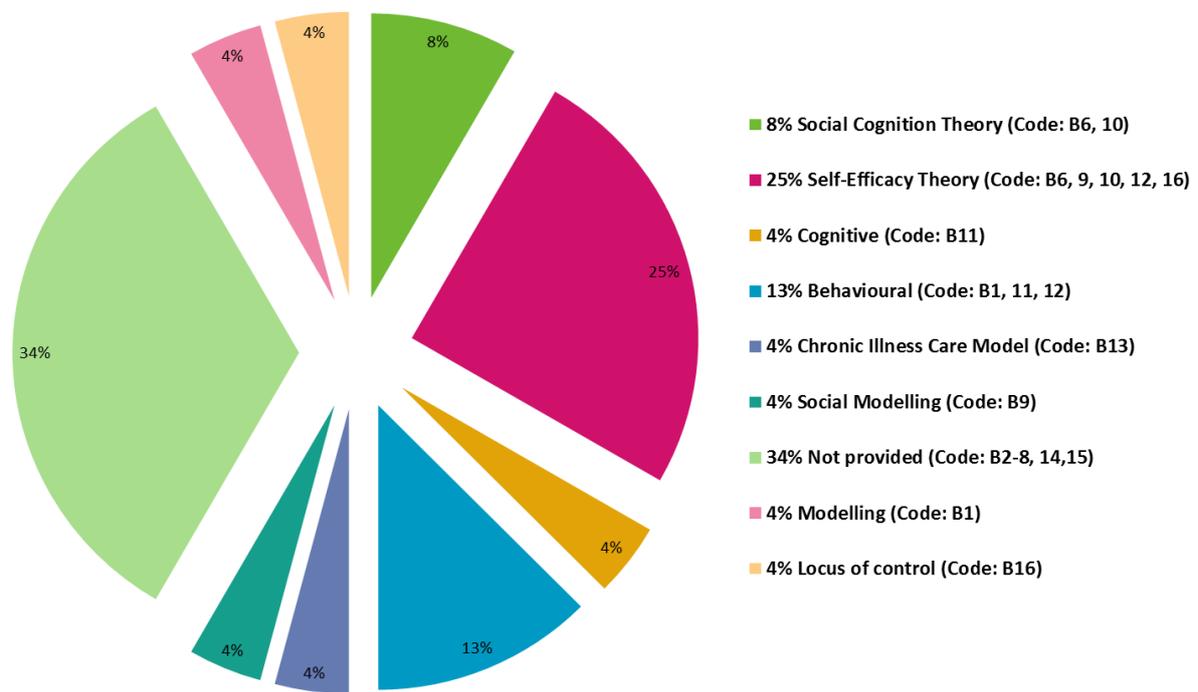


Figure 2.3.9 Underpinning theory of existing stroke-specific self-management programmes

Intervention development

The development process of most of the reported programmes has not been described. Interviews of stroke survivors and their caregivers were used to develop self-management in some studies. The contents and designs of some programmes were neither developed with stroke survivors nor professionals, but decided by the researcher of the intervention (Allen et al., 2009). Some studies directly adopted the existing generic self-management programme (see table 2.3.2). It remains unknown whether the components and designs of those programmes can satisfy stroke survivors' and clinicians' requirements in practice.

Hence, it is unclear whether those adopted elements, including physical exercises in current self-management programmes are determined based on stroke survivors' perceived needs of functional physical recovery. Two critical questions emerge from the development process of reported self-management programmes. Do stroke

survivors accept the contents in the programmes for their functional physical rehabilitation needs? Do healthcare professionals agree the relevance and safety of using the contents to provide functional physical rehabilitation services?

Implications

Self-management interventions are reported to be acceptable, beneficial, feasible, and safe for the management of stroke rehabilitation in the studies (see table 2.3.1). Positive health impact on self-confidence, self-care, quality of family roles, work productivity, ADLs and outcomes related to physical recovery, and health status have been reported (Lennon et al., 2013, McKenna et al., 2013, Jones and Riazi, 2011, Kendall et al., 2007). A range of methods, study designs, components, and outcomes have been used to investigate stroke self-management programmes.

Different contents and programme designs have been adopted. However, there is still insufficient content and theory specific to deliver self-management support for stroke survivors to manage their exercise for physical functional stroke recovery in the community. It appears that the majority of the programmes were designed to deal with multiple stroke consequences and needs for rehabilitation. However, little was known about supporting stroke survivors to self-manage their own exercise with the use of available technologies in the community. Hence, research is required to develop an alternative approach for promoting stroke survivors to manage their own exercise for their ongoing physical rehabilitation.

From the identified studies, the components of the existing programmes were often pre-determined by the researchers. However, it is essential to involve stroke survivors', carers' and professionals' perspectives to determine the components in a self-managed programme since they are the key stakeholders of such intervention.

Although self-efficacy is often the core of self-management interventions and has been shown to be important, relevant and useful in these programmes (Jones and Riazi, 2011), further work is needed to understand how it can be used to develop an approach to help stroke survivors to manage their exercise manual. In addition to self-efficacy, other theories have been adopted for different programmes. Further

studies are needed to understand how to incorporate different theoretical concepts to support stroke self-management programmes which often consists of multiple components and ideas in order to support community-dwelling stroke survivors to manage their own exercises for their continued physical functional rehabilitation.

Furthermore, educational components are commonly included in the identified stroke-specific self-management programmes (see figure 2.3.6). Although stroke survivors have expressed their needs to learn how to self-manage themselves in a study (Satink et al., 2014), no known educational theory has been embedded into the existing programmes for teaching them to learn how to self-manage their exercise for physical stroke rehabilitation. Therefore, in view of incorporating other theories in addition to self-efficacy for stroke self-management, educational theory may be helpful to enhance stroke survivors' learning ability to acquire knowledge and skills required to learn to take control over managing their own exercise manuals.

It is also unclear how to effectively deliver self-management support to help stroke survivors to continue to use their own rehabilitation programmes. It is essential to investigate the optimal format to provide stroke self-management intervention. Identifying new methods to deliver self-management of stroke is needed whilst it remains uncertain which is the most suitable and acceptable way to deliver stroke self-management programmes (Jones et al., 2013b, Jones and Riazi, 2011). There is an operational gap between knowing self-management principles and actually learning how to regularly self-manage.

In view of the development process of the interventions, it is unclear about how some of the programmes were developed. Transparency of the development procedures may help to improve the transferability, sustainability and usability of knowledge and skills in the field. To develop a user-centred, acceptable, usable and sustainable intervention for stroke-specific conditions, it is important to consider stakeholders' perspectives including stroke survivors, caregivers and people experienced in providing stroke care. It is likely that if people don't accept and agree the contents of the intervention, it may not be used in the future.

Mixed methods design has been shown to be feasible and the method of choice to investigate self-management intervention for stroke survivors with the aim of better understanding their specific experience and the health related effects from the intervention.

2.4 Review topic 3: Stroke, self-management and ICTs

This section describes a review of articles on the application of information and communication technologies (ICTs) to deliver self-management services for functional physical stroke rehabilitation.

2.4.1 Search terms

1. stroke.mp./stroke
2. (self management or self-management).mp
3. (Information and communication technolog\$).mp
4. telehealth.mp
5. telerehabilitation.mp
6. telestroke.mp
7. telemedicine.mp
8. telecare.mp

2.4.2 Search results

A total of 423 potentially relevant papers were identified and screened. A total of 29 articles were included and reviewed for this section.

Search topics	Identified & screened	Included
Stroke, rehabilitation, self-management & technology	132	9
Stroke, self-management & ICTs	35	12
Stroke, self-management & telehealth	93	17
Stroke, self-management & telerehabilitation	10	8
Stroke, self-management & telestroke	11	2
Stroke, self-management & telemedicine	126	10
Stroke, self-management & telecare	19	1
Total	426	23 (included and reviewed after removing duplicates)

2.4.3 Summary of findings

Application of technologies for stroke rehabilitation

The use of information and communication technologies (ICTs); including telephones and videoconferences, has been shown to be feasible, acceptable, safe and effective for the management of acute stroke care (Rubin et al., 2013, Schwamm et al., 2009, Johansson and Wild, 2010). A wide range of technologies have been used and investigated to deliver stroke care and rehabilitation, including telephone, videophone, DVD, virtual environment-based sensor motion (virtual reality), videoconferencing, audio-videoconsulting, internet-based systems, electrical devices, touch-screen computers, web-based and robotic devices and software (Parker et al., 2013, Harwood et al., 2012, Cikajlo et al., 2011, Johansson and Wild, 2011, Mountain et al., 2010, Durfee et al., 2009, Piron et al., 2009, Taylor et al., 2009, Lai et al., 2004, Piron et al., 2004, Reinkensmeyer et al., 2002).

However, the effectiveness and benefits of robot-assisted therapy for functional physical recovery for ADL post-stroke is uncertain (Prange et al., 2006, Kwakkel et al., 2008, Lo et al., 2010, Johansson and Wild, 2011); and this approach is not readily available or accessible. The availability and sustainability of using robotic systems and special technology devices for chronic stroke conditions requires further investigations. The focus of the research described in this thesis is on the use of the ICTs that are available and convenient to the general public including community-dwelling stroke survivors for the self-management of their physical rehabilitation using what they have and can use in daily practice.

In view of using ICTs for stroke rehabilitation, they are also found to be acceptable and beneficial for health and physical health post-stroke in the literature (Audebert and Schwamm, 2009, Johansson and Wild, 2011). It has shown to be possible to apply ICTs to stroke rehabilitation (Zheng et al., 2006). The application of ICTs has been shown to be effective to improve motor functions, functional health outcomes and overall health status post-stroke with the use of ICTs in the literature (Liebermann et al., 2006, Johansson and Wild, 2010, Johansson and Wild, 2011). Although no adverse effect has been reported in existing studies, more evidence is

still needed to understand the effects of using ICTs to deliver stroke rehabilitation services for improving mobility and health related quality of life (Laver et al., 2013).

Joubert et al discussed (2009) that the attention of using technology for stroke care, should ideally provide service support, education for stroke survivors and caregivers and integration of specialist and primary care services.

ICTs, self-management and stroke rehabilitation

It has been shown to be possible and beneficial to use available technologies to help stroke survivors to manage their own exercises (Mawson et al., 2013, Parker et al., 2013). The application of a specific devices and computer software has been reported to be useful for the self-management of stroke rehabilitation; including the delivery of feedback and information for functional improvements of upper limb (Mawson and Mountain, 2011). As previously discussed in the literature review 2, some ICTs have been adopted in stroke self-management interventions.

However, the ICTs selected in those interventions were not determined with users and professionals but pre-determined by the researchers of the studies. Hence, the acceptability, suitability and feasibility of using those ICTs to support stroke survivors to self-manage their own stroke-specific exercises for functional physical rehabilitation needs further investigation. The elements of stroke rehabilitation services should be decided with and by the stakeholders to ensure the intervention can be used for their needs in practice. Thus, users' and professionals' perspectives should be explored to determine acceptable and usable available ICTs for the development of a workable intervention.

Although the improvement of stroke survivors' self-efficacy and health status has been reported from using ICTs in a generic self-management programme (Jaglal et al., 2013), the way to incorporate available ICTs into a self-managed exercise manual containing self-efficacy concept for physical functional stroke rehabilitation is to be determined.

Conceptual support for the application of ICTs for stroke self-management

Although ICTs have been used to provide stroke care, including self-management programmes; most of them have adopted the technologies without using a

model/theory to support the application of it in the interventions. Whilst the concept of using ICTs for stroke rehabilitation has been introduced (Mountain et al., 2010, Zheng et al., 2006) (also see table 2.3.7), there is insufficient theoretical support to the idea of determining and using suitable technology for the delivery of self-management intervention for physical stroke rehabilitation in the literature.

Many studies reported the feasibility of applying ICTs in stroke self-management interventions, however, stroke survivors and clinicians have limited involvement in determining the ICTs to be used (Taylor et al., 2012, Mountain et al., 2010, Egglestone et al., 2009, Zheng et al., 2007, Harwood et al., 2012, Huijbregts et al., 2010, Parker et al., 2013). The studies have not described the concept for the stroke survivors and clinicians to choose and use technologies for supporting the management of the interventions. Stroke survivors and clinicians appear to have no involvement in determining the ICTs to be used in the literature. The underlying belief of choosing and using technologies in a self-managed programme for stroke rehabilitation is yet to be determined.

How do stroke survivors and professionals think about using available ICTs to support community-dwelling stroke survivors to self-manage their own exercises for functional physical rehabilitation? To develop an acceptable and usable intervention supported with the use of technologies, it is important to understand users' and providers' underlying psychology in choosing and using ICTs, and their acceptance towards using ICTs.

Implications

The application of technologies for acute stroke care has been described in the literature whilst it remains uncertain about the use of technologies for the other phases of stroke care (Rubin et al., 2013). It is important to understand stroke survivors' concerns in relation to using ICTs to support them to self-manage exercises as they are the key stakeholders of stroke rehabilitation services. Hence, studies are needed to identify the choices of ICTs which are available and preferred by stroke survivors for the self-management of exercises, as well as their considerations in view of using ICTs to do so.

Furthermore, it is important to establish how do clinicians, especially physiotherapists and occupational therapists, think about using available ICTs for stroke survivors to self-manage their own exercises in the community?

Studies are needed to understand the conceptual guidance for assisting stroke survivors and clinicians to determine suitable ICTs to be used for supporting the stroke survivors to tackle the management of their personalised exercises according to their preferences, abilities and available resources. Some general models about using technology for stroke rehabilitation have been proposed; such as home-based telehealth care model (Kuo et al., 2011) and the conceptual matrix for stroke personalised self-management system (PSPM) (Mawson et al., 2013, Nasr et al., 2009). The most appropriate intervention approach to utilise ICTs to deliver telerehabilitation services for stroke remains unclear (Laver et al., 2013). Thus, technology acceptance model (see chapter 1) is proposed to provide a conceptual support to the process of integrating available ICTs into a self-managed exercise manual ground on the users' preferences, abilities and resources for their ongoing physical rehabilitation in this study.

User-centred design approach has been used and been suggested for the development of self-managed rehabilitation system supported with the use of technologies for stroke survivors (Mawson et al., 2013, Nasr et al., 2010, Nasr et al., 2009). This implies that this patient-driven approach is possible and appropriate for the investigation of the development of a rehabilitation intervention supported with the use of technology for stroke self-management.

2.5 Overall implications to this research

The above three reviews provide information about the practice of physical exercises for physical functional stroke rehabilitation, stroke self-management interventions, and the use of available ICTs for the delivery of stroke rehabilitation services. The importance of physical exercise for stroke survivors' physical functional rehabilitation has been emphasised in the literature. Studies support the potential of using self-management interventions for stroke rehabilitation (Lo et al., 2014, Lennon et al., 2013, Jones and Riazi, 2011, Jones, 2006). In addition, studies imply that it is feasible and acceptable to incorporate the use of ICTs for stroke rehabilitation.

The stroke self-management interventions published in the literature were originated from several countries including the UK, USA, Canada, Australia, New Zealand, Korea and Hong Kong (see table 2.3.7). Different policy, services and other local contexts may exist between different countries for stroke rehabilitation. Hence, only the interventions originated and available in the UK were chosen to be compared with the programme developed in this research. This was to focus on developing an intervention to address the needs and conditions in the local system. In the UK, three stroke self-management interventions have been reported in which two of them are workbook based programmes and one is technology based system (Mawson et al., 2013, Jones, 2008, Frank et al., 2000).

Different components and a theoretical basis were involved in those interventions for different foci. However, further research is required to determine the concepts and components required in a self-managed programme for helping stroke survivors to manage their own physical exercises and activities with the use of available ICTs for their continued functional rehabilitation in the community.

In view of the three existing interventions in the UK, the feasibility and acceptability of using two of them; including Bridges (McKenna et al., 2013, Jones et al., 2009) and Personalised Self-Managed Rehabilitation System (PSMrS) (Parker et al., 2013, Mawson et al., 2013) have been reported. However, questions are raised about the acceptability and feasibility of the rest of the workbook based programme since no difference was found between the intervention group and the control group in any measures of function and perceived control. Moreover, there were a high number of stroke survivors who decided not to participate in that programme (Frank et al., 2000). This raises the importance of understanding the acceptability and feasibility of a self-managed intervention for stroke during the development process.

The features and theoretical concepts of these programmes are compared to the programme developed in this research for further analysis. The details are reported in the chapter 8b of this thesis.

Whilst there is evidence supporting the use of self-management programmes for stroke recovery, I feel this this can be further developed. How can we help stroke

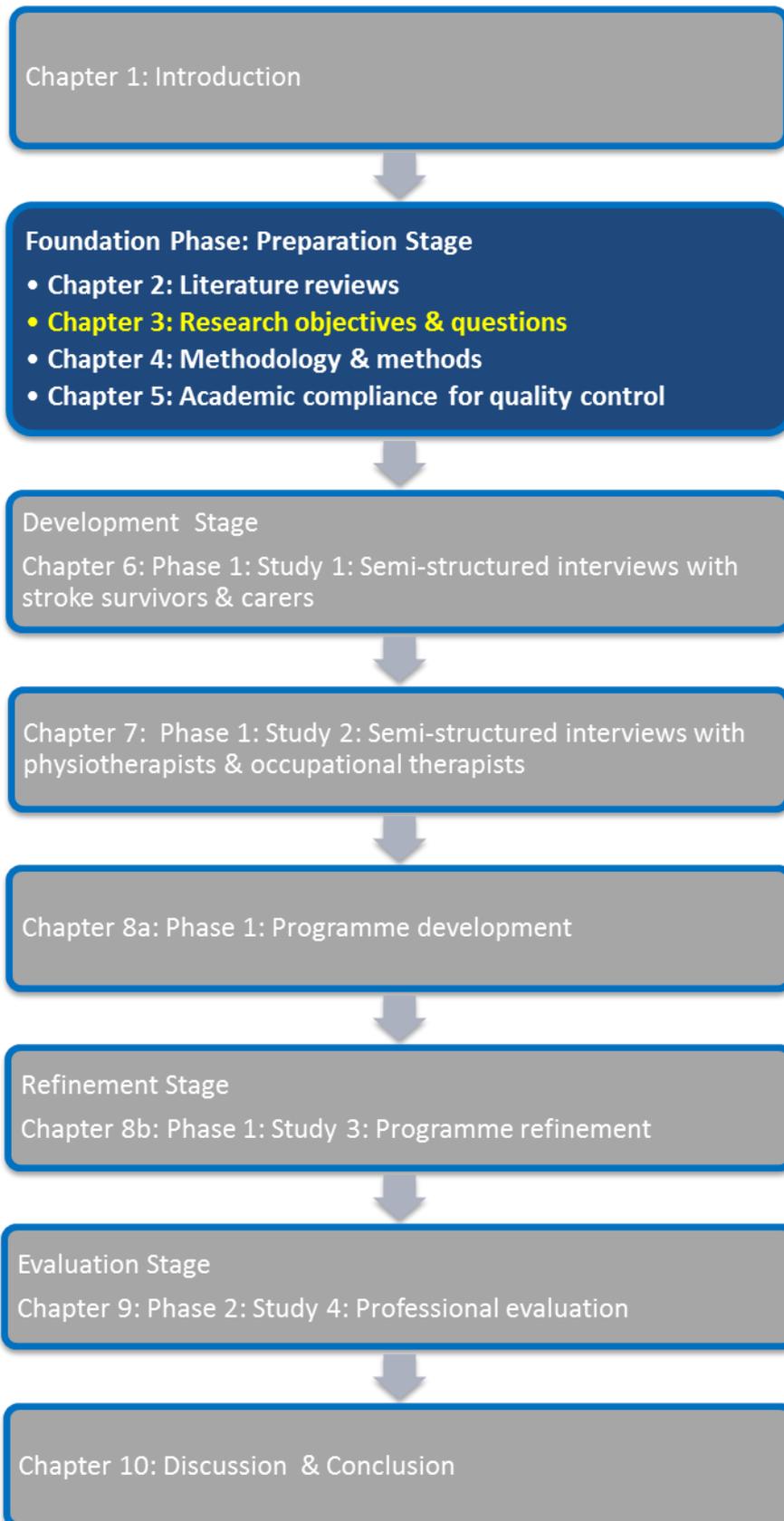
survivors to manage their own exercises with the use of available ICTs for physical stroke rehabilitation? The details of combining the concepts of using available ICTs, personalised exercises and provision of self-management support for functional physical stroke rehabilitation are yet to be specified in the literature. Thus, the followings are the implications to the area of this research:

- It is necessary to determine key components required to be embedded in a self-managed exercise manual with the use of available ICTs from stroke survivors' and professional perspectives to support stroke survivors to continue to manage their own exercise for their physical rehabilitation.
- Studies are required to identify what available ICTs that stroke survivors have and would like to use to support themselves to manage their personalised exercises for physical functional rehabilitation in the way they prefer.
- It is helpful to understand what stroke survivors and clinicians would consider when using available ICTs for stroke survivors to self-manage their own exercise manual when incorporating the idea of using technology.
- Theoretical support is required to support a self-managed exercise manual delivered with the support of using available ICTs.
- It is necessary to understand how to incorporate both practical components and theoretical concepts to inform an alternative approach to support stroke survivors to self-manage their own exercises using available ICTs for their physical functional rehabilitation in the community.

Therefore, this research focused on determining practical components, theoretical concepts and delivery process required for a self-managed and remotely supported exercise manual for community stroke physical rehabilitation services.

Summary

This chapter has provided an overview about the issues related to physical exercise for functional stroke rehabilitation, stroke self-management interventions, and the concept of using available information and communication technologies for the self-management of stroke rehabilitation. It has informed the study detailed in this thesis.



Chapter 3: Research objectives and questions

3.1 Introduction

The focus of phase 1 is on the development and refinement a prototype intervention to enable stroke survivors to self-manage their own physical exercises for their physical functional rehabilitation with the use of available information and communication technologies (ICTs) in the community informed by the findings of the literature reviews of the needs of stroke survivors and professionals.

The focus of phase 2 is on the evaluation of the acceptability, suitability, feasibility and safety of using the new intervention using professional judgement. The objectives and questions of this research are presented below.

Phase 1

3.2 Research objectives and questions: Phase 1

Objectives

The primary objective of phase 1 is to identify the determinants required by stroke survivors and professionals for the self-management of physical exercises with the supported of available ICTs for functional stroke rehabilitation in the community. The second objective is to design an usable programme using the information from literature and the findings of the primary objective.

Questions

The following questions were proposed for the above objectives. The term “clinicians” in the following statements represents physiotherapists and occupational therapists.

1. What are the major physical functional difficulties faced by stroke survivors after their discharge from the NHS community stroke rehabilitation services?
2. What do clinicians think are the common physical functional difficulties in community stroke rehabilitation?

3. What are the common goals of physical functional recovery in the community from the stroke survivors' perspective?
4. What are the common goals of physical functional recovery in the community from the clinicians' perspective?
5. What do stroke survivors consider important in relation to the management of their own exercise in the community?
6. What do clinicians consider important in relation to the self-management of exercise by stroke survivors in the community?
7. What do stroke survivors think can help them to manage their own exercise in the community?
8. What do clinicians think can help stroke survivors to manage their own exercise in the community?
9. What physical exercise would stroke survivors like to practise for their own functional recovery within the community?
10. What physical exercise would clinicians consider clinically useful and safe for stroke survivors to independently achieve their own functional goals of recovery?
11. What available ICTs that stroke survivors would prefer to use to support them to manage their own exercise in the community?
12. What do stroke survivors think about using available ICTs to support them to manage their own exercise in the community?
13. What do clinicians consider about using available ICTs to support stroke survivors to manage their own exercise in the community?
14. What are the components required to develop a self-managed exercise programme supported with available ICTs for physical functional stroke rehabilitation in the community?

15. Do stroke survivors understand the programme?
16. Do stroke survivors think the programme is usable?
17. Do clinicians think the programme is understandable?
18. Do clinicians think the programme is usable in practice?

Phase 2

3.3 Research objective and questions: Phase 2

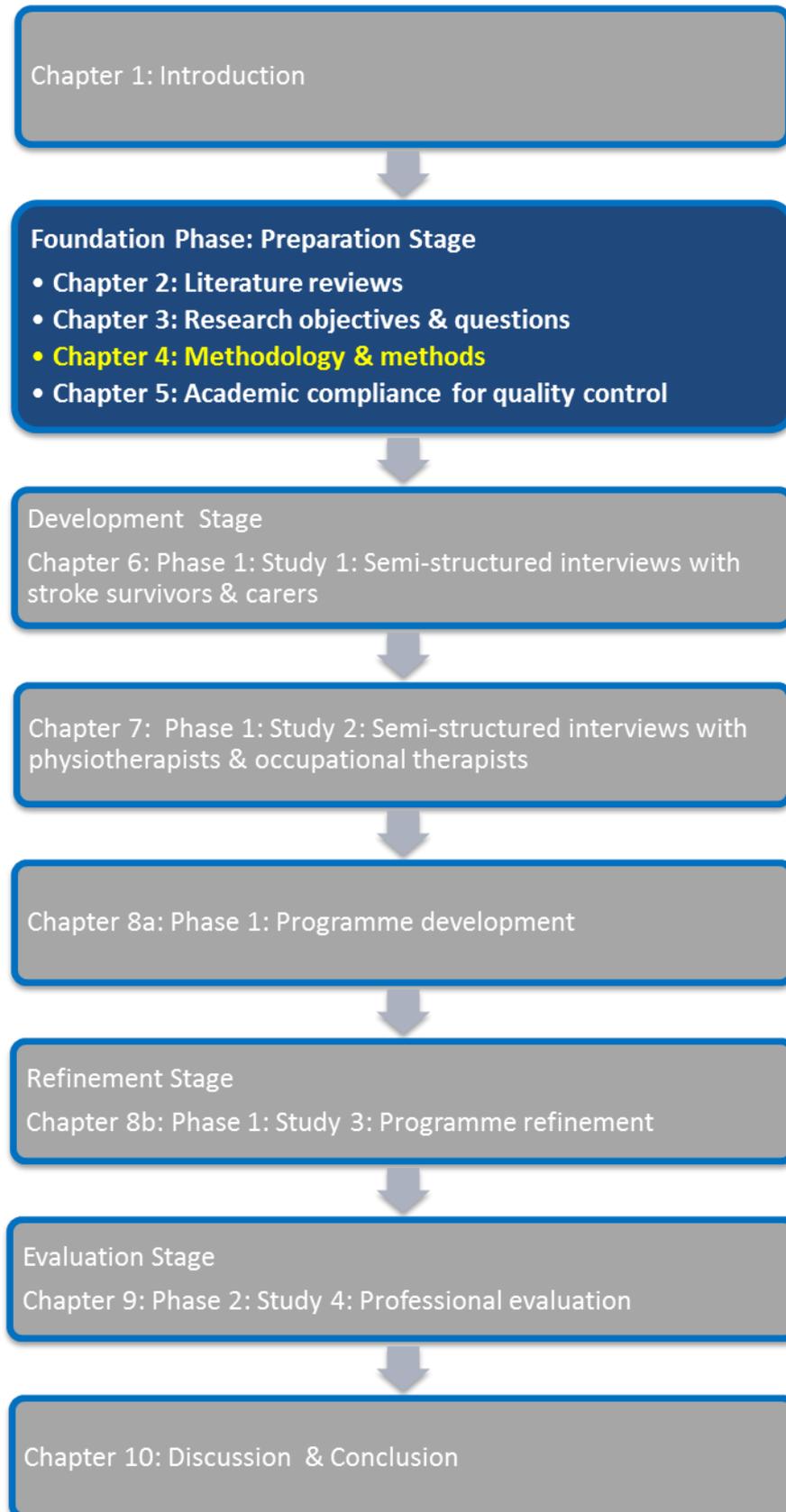
Objective

The objective of phase 2 is to determine the appropriateness and possibility of using the programme in clinical practice.

Questions

1. What do clinicians think about the acceptability of the programme for physical functional stroke rehabilitation in the community?
2. What do clinicians think about the suitability of using the programme according to the current health service system and policy for stroke rehabilitation?
3. What do clinicians think about the feasibility of using the programme in practice?
4. Do clinicians consider the programme is safe to be used in clinical setting?

The above questions were used to guide the process of this research and are addressed in the following chapters of this thesis.



Chapter 4: Methodology and methods

Chapter summary

The design, methodology and methods of this research are provided in this chapter. Mixed methods approach was adopted. It was designed with the principles of user-centred design and the model for evidence-based clinical decision making to develop a patient-centred programme.

4.1 Study design

Research design is the overall structure or plan of the research (Trialists'Collaboration, 1997). This research was structured with 3 main phases: foundation phase, phase 1 and 2 as illustrated in figure 4.1.1. This was to provide a stepwise approach to systematically investigate the objectives based on existing information, evidence and the types of research.

The purpose of the foundation phase was to identify and understand the information and evidence related to the topic of this research. This allowed me to gain an overall understanding for the issues about stroke self-management, physical stroke exercise and the application of available information and community technologies for the delivery of health services for stroke rehabilitation. This helped me to design the other 2 phases of this research.

The purpose of phase 1 was to generate a personalised, remotely supported and self-managed physical exercise manual. It consisted of development and refinement stages.

Phase 2 was designed to evaluate the acceptability, suitability, feasibility and safety of using the programme according to professional judgement.

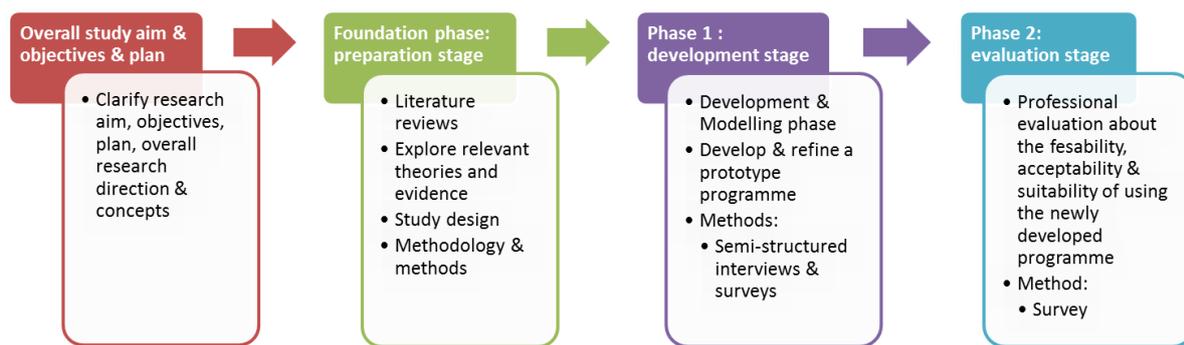


Figure 4.1.1 Overall study design

Involving stroke survivors and professionals for patient-centred rehabilitation

A 'patient-centred' approach is increasingly regarded to be important for the delivery of high quality healthcare (DH, 2004b, Mead and Bower, 2002, Mead and Bower, 2000). It is essential to recognise patients' expertise, values, and preferences to provide patient-centred services. Patients should be involved in decisions affecting them. It is important to listen to their views and elicit their feedback (Coulter and Dunn, 2002). The concept of Patient-Centred Care (PCC)¹³ is crucial for the improvement of healthcare services and outcomes, and to support patients to self-manage their own conditions (Silva, 2014). Hence, this research was designed with regards to the value of providing patient-centred service to develop a programme to cater the needs of individual stroke survivors for their physical rehabilitation.

¹³ Patient-centred care (PCC) is regarded as a philosophy which sees patients as equal partners in planning, developing and assessing care to make sure it is most appropriate for their needs. This involves patients and their families being the heart of all decisions (Silva, 2014).

There is a lack of a universally agreed definition of the term "patient-centred care" (PCC) for the delivery of healthcare services (Silva, 2014, DH, 2004b, Mead and Bower, 2002, and Mead and Bower, 2000). Thus, in this research, PCC is defined as the practice of putting the patients as the centre and end-user of a healthcare intervention in which their views are involved in making informed and evidenced-based decisions with clinicians during the prescription and delivery processes of the intervention to provide appropriate services to manage individual patients' conditions according to the individuals' needs and wishes using usable resources in a given clinical situation.

With regards to the value of PCC, stroke survivors should be at the centre of the development of any stroke self-management intervention. The involvement of stroke survivors and their carers has been highlighted as being of key importance in decision-making for rehabilitation services (NICE, 2013, ISWP, 2012, DH, 2007b). Therefore, it is essential to involve service users' (stroke survivors in this research) and providers' (physiotherapists and occupational therapists in this research) perspectives and involvement to develop an intervention to tailor to their needs, conditions and preferences. The provision of patient-centred services has been emphasised in recent clinical guidelines for stroke rehabilitation (NICE, 2013, ISWP, 2012, DH, 2007).

Stroke survivors' experience in stroke and recovery should be understood to develop effective and proper rehabilitation services (Burton, 2000). User-Centred Design (UCD) approach has been shown to be feasible and been suggested for the design of a rehabilitation intervention with the use of technology for supporting stroke survivors to self-manage their conditions (Mawson et al., 2013, Nasr et al., 2010, Nasr et al., 2009). Therefore, based on the vision of developing a self-managed programme for stroke survivors, the value of providing patient-centred care, the UCD was adopted to design this research.

It is important to consider information from both patients and clinicians as the aim of this research was to develop a practical intervention intended to be used by both. Thus, professionals should work in partnership with stroke survivors to deliver self-managed services using the information from related evidence in practice. Hence, in addition to the UCD principle, the Model for Evidence-Based Clinical Decisions (MEBCD) was adopted to support the design of this research. From MEBCD, the importance of research evidence, patient preferences and the viewpoints from clinical expertise are integrated.

Therefore, based on the value of developing a programme for PCC, I used the concepts of both UCD and the MEBCD (Haynes et al., 1996, Haynes et al., 2002) as the core support of the study design. This concept is illustrated in figure 4.1.2 below.

According to UCD and MEBCD, it is necessary to involve both users' preference and clinical experts' perspectives together with research evidence. Thus, stroke survivors' and professionals' needs and views were taken to develop the programme in addition to the information of related evidence.



Figure 4.1.2 Combining UCD and MEBCD for the design of this research

4.2 Methodology: Mixed methods approach

A mixed methods study¹⁴ approach was adopted as the methodology¹⁵ (Creswell, 2012, Creswell, 2009) to obtain detailed and comprehensive knowledge from users' and professional perspectives. Mixed methods research helps to answer questions that cannot be answered by a quantitative or qualitative approach alone. Combining quantitative and qualitative data may yield a more complete analysis and complement each other in a single research. This can help to produce more complete knowledge needed to inform theory and practice than using a single method (Creswell and Plano Clark, 2011, Tashakkori and Teddlie, 2010, Johnson and Onwuegbuzie, 2004). Thus, this approach was adopted to obtain relatively boarder knowledge to develop and evaluate the programme of this research.

¹⁴ Mixed methods studies provide comprehensive understanding of underlying experience by integrating quantitative and qualitative methods and information (Creswell et al., 2004, Clarke, 2009)

¹⁵ Methodology is about the process for discovering the answer to the research question that is formed from the groundwork of research design and procedure to fit with the research context (Creswell, 2012, Creswell, 2009)

Multiphase design can be used to address a set of incremental research questions for research to develop and evaluate a programme (Creswell and Plano Clark, 2011, Teddlie and Tashakkori, 2009). I considered the nature of this investigation to inform the design. Thus, multiphase mixed methods approach was selected as the underlying logic in order to systematically answer a series of research questions, since there were multiple stages involved in the development of the programme.

Both qualitative and quantitative methods were used in both phases of this research using the strengths of different types of data. With regards to the inductive nature of developing a new programme as the ultimate goal in this research, the overall design of this project can be classified as a qualitative dominant mixed methods study supplemented with quantitative data for analysis. The overall methodological approach is illustrated in figure 4.2 below.

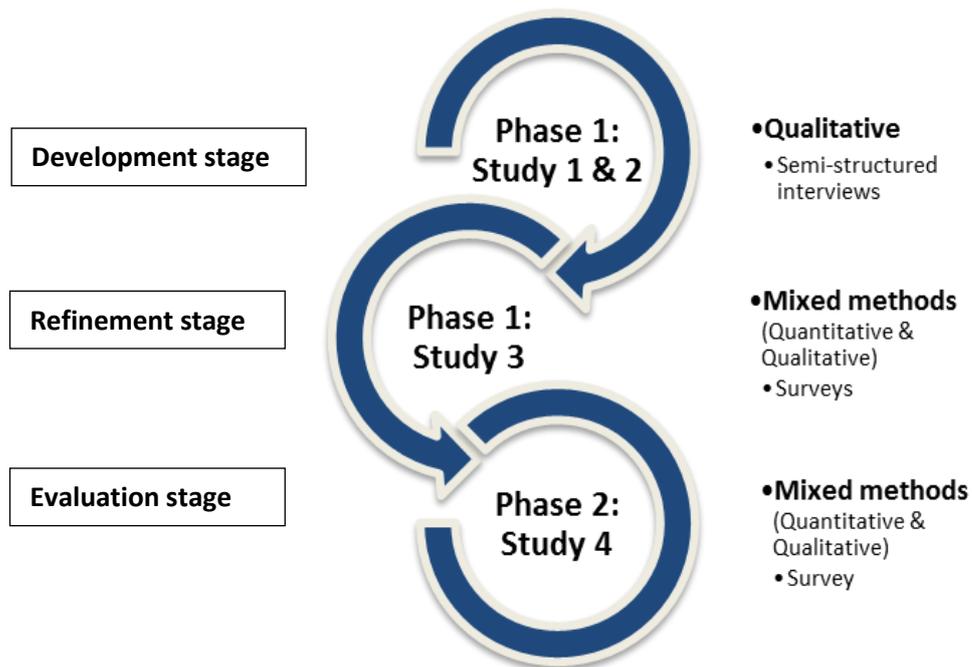


Figure 4.2 Overall methodological approach of this research

Phase 1

4.2.1 Phase 1 Methodology

The qualitative approach was adopted in phase 1 aimed to explore the components required to form a prototype programme with an underlying theoretical foundation. Phase 1 was an exploratory stage to describe and explore the needs and conditions of stroke survivors, and determine essential components required to develop a prototype programme. Literature reviews of relevant topics from the foundation phase informed this phase. The underlying concept of phase 1 is shown in figure 4.2.1 below.

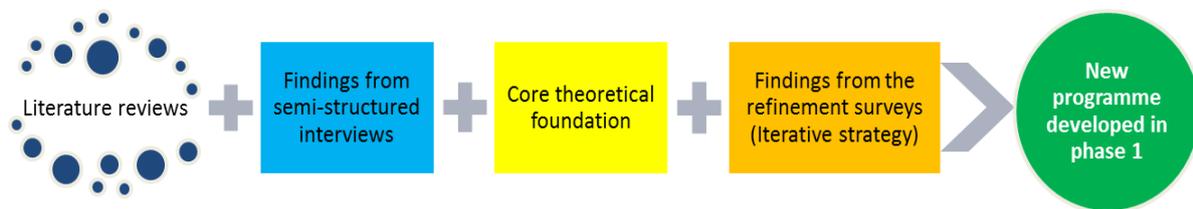


Figure 4.2.1 Underlying concept of phase 1

An iterative strategy was adopted to refine the programme to verify the contents with those who had provided the information. This was to ensure the programme contained the elements required by the participants. The development and evaluation processes are detailed below.

Participants

Stroke survivors discharged from the specialist stroke rehabilitation with difficulties in physical functioning in ADLs and their caregivers were invited to express their specific needs and experience in functional physical rehabilitation.

To develop a clinically relevant and safe intervention for specific physical conditions post-stroke, relevant professional perspectives were needed. Thus, physiotherapists (PTs) and occupational therapists (OTs) experienced in providing healthcare services for functional physical stroke recovery were invited to provide their views based on their experience.

Recruitment

This is community-based research. It was conducted within Sheffield and Rotherham in South Yorkshire. Community-dwelling stroke survivors living with long-term physical disabilities and discharged from community rehabilitation units, and their carers were recruited via local charities in Sheffield and Rotherham. PTs and OTs working in Sheffield and experienced in providing community physical functional stroke rehabilitation services were invited to participate. They were recruited via their managers in the Sheffield Teaching Hospitals trust.

Part 1: Semi-structured interviews

Semi-structured interviews were conducted to identify specific needs, goals and suitable exercises to achieve the goals from stroke survivors and therapists in part 1. The use of semi-structured interviews allowed the respondents to develop their own narratives while the investigator can still control and facilitate the process of the interview by using structured topic guides that covered the important aspects of the research questions (Bowling and Ebrahim, 2005). Topic guides for these interviews were based on the aim of this research, literature reviews and my clinical experience.

Each stroke survivor and their caregiver were invited to participate in 1 semi-structured interview. Each interview lasted for 1-1.5 hours. They were being asked to express their continued physical needs and experience of functional recovery after being discharged. They were invited to share their ideas to shape the self-managed intervention. A topic guide with questions designed to explore the information from their perspective was used to guide the interviews with the stroke survivors and carers.

Each PT and OT was invited to take part in a semi-structured interview. Each interview lasted for about 1 hour and aimed to collect their professional experience and ideas about providing community physical functional stroke rehabilitation. A topic guide containing questions designed to explore the information from professional perspective was used to guide the interviews with the professionals.

The interviews were analysed with qualitative content analysis since this is a method for systematically describing the meaning of qualitative material via classifying parts of the material (Schreier, 2012). The use of qualitative content analysis is mainly an inductive process to identify themes to explore the underlying meanings within content (Elo and Kyngäs, 2008, Hsieh and Shannon, 2005).

Part 2: Surveys

The objective of part 2 was to refine the programme by collecting feedback and advice from the interviewed participants. Surveys were used for this objective. All previously interviewed stroke survivors, therapists were invited for this part.

Questionnaires using standardized forms aimed to quantify specific comments from the respondents. Furthermore, the respondents could take more time to think of their own particular answers to the questions in questionnaires. This helped to elicit specific information after appraising the contents and concepts of the programme by the individual respondents.

Open-ended and closed questions were used to balance the strengths and limitations of each type of question. This allowed the collection of different data to explore the attitudes and opinions of the respondents (Schmeler et al., 2009, Bandura, 1997b, Bandura, 1997a, Barlow et al., 2002a, Wales, 2009).

Descriptive analysis was adopted to analyse the quantitative data in the surveys. This organized and summarised data to increase understanding of the information (McCormack et al.). In addition, descriptive statistics allowed describing and summarising the data to further understand the underlying information and the relationships (Party, 2012, Rycroft-Malone et al., 2004, Buckingham and Saunders, 2004). Thus, it was used to describe and display the quantitative data of this survey to illustrate the pattern of the results.

Qualitative content analysis was used to analyse the textual materials collected from the open-ended questions in the surveys. Thematic analysis is an analysis under the qualitative content analysis approach, according to Manfred Bergman (Tashakkori and Teddlie, 2010). It was used to analyse the collected qualitative material and classify the identified data into themes and subthemes.

Survey with stroke survivors

The interviewed stroke survivors were invited to respond to an interviewer-administrated questionnaire to refine the prototype programme. It helped by exploring their unique personal opinions towards the prototype programme.

Survey with physiotherapists and occupational therapists

The interviewed professionals were invited to respond to a self-administrated questionnaire to share their professional attitudes and opinions towards the prototype manual for refinement.

Administration methods of surveys

For stroke survivors, who are lay persons, an interviewer-administered questionnaire was adopted to collect information. Stroke survivors were asked to answer questions on a questionnaire in a 1-hour face-to-face session. The completed questionnaire was collected immediately at the end of each session.

For physiotherapists and occupational therapists, self-administered questionnaires were distributed by emails. This was to allow the therapists to complete the questionnaire at their own time, considering their busy and irregular work schedules. Each was given 2 weeks to read, complete and return the questionnaire.

Data integration for programme refinement

The quantitative and qualitative findings of the surveys were integrated for further analysis and interpretation. Data integration enhances the knowledge yield from the findings by learning more from the collected information which is important process in a mixed methods research (Jones, 2013, Creswell and Plano Clark, 2011, Hardy et al., 2006, O’Cathain et al., 2010). The integration of data helped to draw the strengths of each component to maximise the understanding of the information. Pragmatism has been suggested to be the philosophical support for mixed methods research (Johnson and Onwuegbuzie, 2004). The use of the pragmatic approach helped to further analyse, elaborate and clarify both quantitative and qualitative results to determine how to comprehensively refine the manual based on users’ and providers’ views. The identified qualitative data were categorised and quantified for

further interpretation and integration. Quantifying qualitative data can provide numerical information for further analysis and integration with quantitative data during mixed methods analysis, which is a process to transform qualitative data into quantitative form via coding (Creswell and Plano Clark, 2011, O’Cathain et al., 2010, Sandelowski et al., 2009, Onwuegbuzie et al., 2009).

The integration process was conducted by the merging data approach (Creswell and Plano Clark, 2011, Creswell et al., 2011, Sandelowski et al., 2009), in which, the quantified qualitative dataset was compared and combined with the quantitative dataset. The integration of two different natures of components happened via tables that combine quantitative and qualitative data called a mixed methods matrix (Creswell et al., 2011, O’Cathain et al., 2010).

Mixed methods matrix was adopted to integrate and joint display both key quantitative and qualitative results of the same topic within a combined table and allows analysing and interpreting major quantitative and qualitative findings about the same issue simultaneously. Using a joint display can help to merge two forms of data and to decide on the dimensions to be considered and the particular information to be compared across dimensions (Creswell and Plano Clark, 2011). Hence, mixed methods matrix was used to draw practical conclusion from both forms of data.

Phase 2

Phase 2 evaluated the acceptability, suitability, feasibility and safety of using the newly developed intervention in a clinical setting. It is important to understand the perceived appropriateness, safety and applicability of a new intervention using professional knowledge before further using it in practice. This is to help better utilization of limited resources before further trials or practice. The reasons of professional evaluation are detailed in the chapter 9 of thesis.

4.2.2 Phase 2 Methodology

4.2.2.1 Quantitative & Qualitative methods

Again mixed methods research was used for phase 2 for the same reason in phase 1. Quantitative and qualitative data were collected via a survey. This may provide relative comprehensive information to evaluate the programme. Both quantitative and qualitative data were integrated in the same way as the refinement study.

Administration methods of surveys

A different group of PTs and OTs experienced in providing community rehabilitation services for physical functional stroke rehabilitation were invited to evaluate the acceptability, safety, feasibility and suitability of using the programme from a professional angle. The respondents of phase 2 had not participated in the previous development process of the programme of this research. This iterative evaluation process was to avoid potential bias or carryover effect from collecting the information from the same people who had informed the manual.

4.3 Sampling

Purposive sampling was employed to recruit the participants in both phases of this research. This was to recruit the people who can fit the particular criteria in order to obtain specific information for the aim of this research. The participants were purposively selected in Sheffield and Rotherham in the South Yorkshire for both phase 1 and 2. The details are described in chapter 6, 7, 8 and 9 of this thesis.

4.4 Ethical issues

Research ethics approvals from the University of Sheffield and the NHS governance permission from Sheffield Teaching Hospitals trust were granted before recruiting the participants. The letters are attached in appendix 1 and 2.

4.5 Data analysis

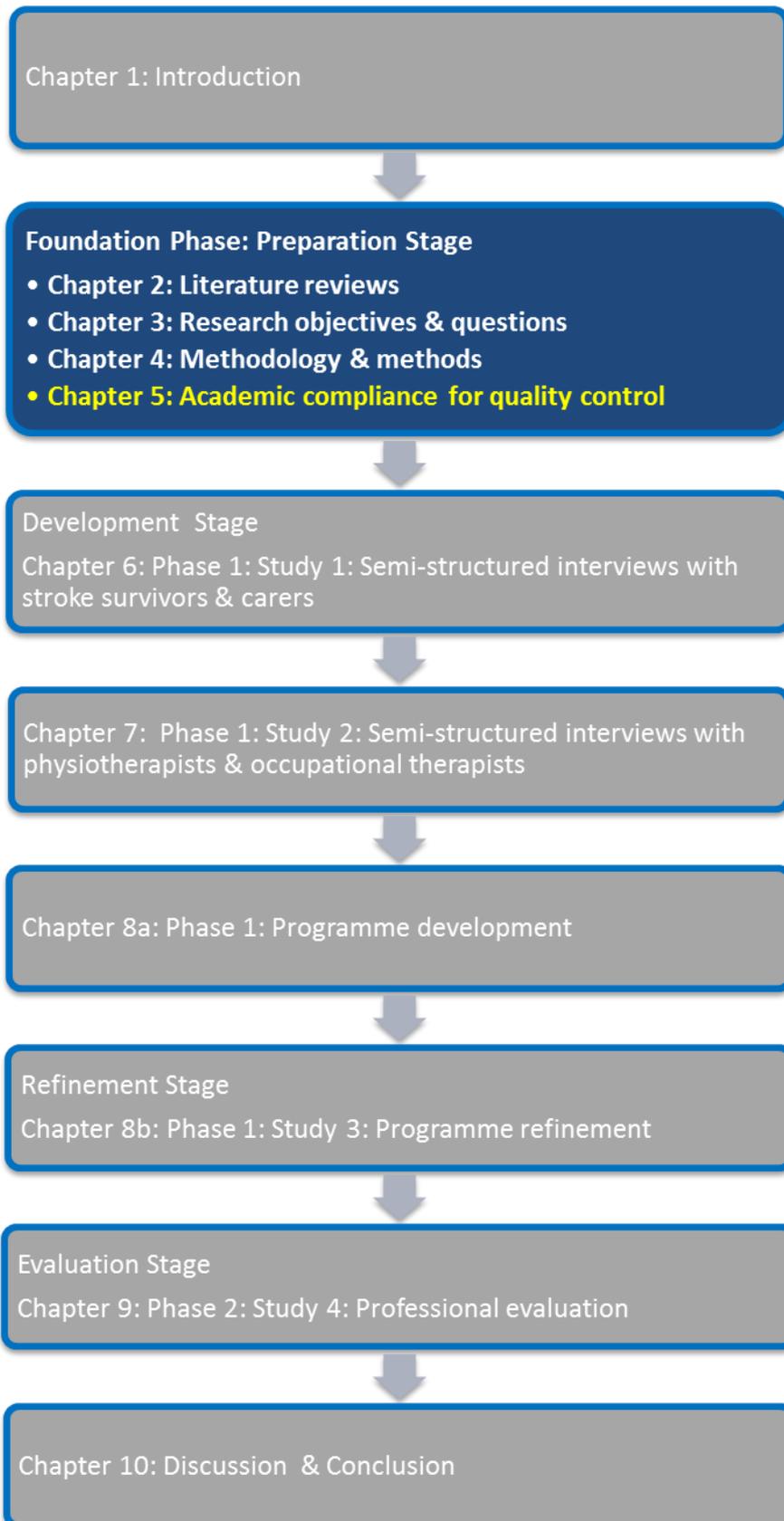
For data analyses, qualitative content analysis was adopted to analyse the data and descriptive statistics was used to analyse the quantitative data. Both quantitative and qualitative data obtained in the surveys were integrated for further analysis.

Computer software programs were used to manage the quantitative and qualitative data of this research. Computer-Aided Qualitative Data Analysis Software (CAQDAS) was used to manage qualitative data for analysis, of which Nvivo (Bazeley and Jackson, 2013) (in particular, Nvivo version 9) was the software used. The IBM SPSS statistics version 21 was used to generate descriptive statistical information to analyse the quantitative data. The Microsoft Excel 2007 software was used to manage both qualitative and quantitative findings. It was used to present the themes and subthemes emerging from the qualitative data. It was used to establish mixed methods matrix to display the integrated findings for further analysis.

4.6 Summary

This is a qualitative dominant and multiphase mixed methods research, which was supplemented with quantitative data. The principles of the user-centred design and model of evidence-based clinical decisions were adopted for the study design. Three phases were involved in this research to develop and evaluate the programme: foundation, phase 1 and 2.

Semi-structured interviews were used in phase 1 to collect representative information from community-dwelling stroke survivors and their carers, and physiotherapists and occupational therapists. An iterative approach was used to refine the programme with the interviewees via two surveys. Then, a different group of therapists was invited to evaluate the programme using their professional judgement in phase 2 via a different survey.



Chapter 5: Academic compliance to quality control

Chapter summary

The methods and procedures used to manage the quality of the quantitative and qualitative sections in this research are reported and explained in this chapter.

5.1 Quality control for qualitative studies: Trustworthiness

The consistency (or reliability) and accuracy (or validity) of the data were considered to ensure the quality of this research. The reliability and validity can be appraised in view of trustworthiness for qualitative inquiry (Morse et al., 2008, Duncan et al., 2005). Trustworthiness¹⁶ was managed to ensure the rigour of the processes of qualitative studies. The following criteria can be used to determine and control the trustworthiness of the qualitative sections of this research: credibility, transferability, dependability, confirmability and reflexivity, which are described below (Guba, 1981, Lincoln and Guba, 1985, Golafshani, 2003, Shenton, 2004, Rolfe, 2006).

5.1.1 Credibility

Credibility can be regarded as the internal validity for a qualitative study. It concerns the extent to which the findings are believable, well presented and meaningful to others (Elo et al., 2014, Lincoln and Guba, 1985, Shenton, 2004, Rolfe, 2006, Kitto et al., 2008, Kuper et al., 2008). Checking interpretations against raw data, member checking, frequent debriefing sessions, tactics to ensure honesty in informants when contributing data, reflexivity and triangulation can enhance the credibility of a study (Shenton, 2004, Krefting, 1991).

The internal validity is concerned with credibility. I validated the topic guides with people from similar backgrounds of the targeted participants before using them for interviews with stroke survivors and therapists which are detailed in the chapter 6 and 7 of this thesis.

The use of member checking helps to ensure the researcher has analysed the data correctly to establish credibility (Long and Johnson, 2000, Rolfe, 2006, Shenton,

¹⁶ The aim of ensuring trustworthiness in a qualitative inquiry is to support the argument that the findings of the inquiry are worth paying attention to (Elo et al., 2014, Lincoln and Guba, 1985)

2004). Hence, I invited the participants to check the transcripts of their own interviews for accuracy. I showed the lists of findings from the analysis of the interviews to the participants in the second interviews explaining the identified items to the stroke survivors and enquiring if it reflected their meanings from the findings of the initial interviews. This helped me to further check my interpretation. I conducted the same procedure via emails and telephone calls after the initial interviews of the therapists. I checked the transcripts against the information in my fieldnotes to check my interpretation to the interviews contents.

I encouraged the participants to be frank, and to freely share their ideas and opinions from their own knowledge, experience and needs at the beginning of each interview to ensure honesty in informants. I adopted active listening technique to establish a rapport with each participant for credibility. Moreover, I reassured the participants that all data collected from them would be kept secure and anonymous and they would not be identified from this study. I reassured them their participation and data would not affect their health service provision for “stroke survivors” or their jobs for “professionals”. These were to encourage honesty in informants as they shared their own experience and opinions.

I had frequent debriefing meetings with my supervisors during data collection and analysis to critically discuss my findings. This helped to widen my understanding and interpretation of my data and helped to minimise the limitation from my own perception or preferences when I analysed my findings.

5.1.2 Transferability

Transferability¹⁷ can be regarded as the external validity or generalisability of the study. It is about the ability of the findings of research to be transferred to situations with similar parameters, populations and characteristics (Elo et al., 2014, Kitto et al., 2008, Rolfe, 2006, Shenton, 2004). Information about the number of local organisations taking part in the study, the type of informants, the data collection methods and the numbers and length of the data collection sessions, enhance the transferability of the study (Kitto et al., 2008, Shenton, 2004). Representativeness of

¹⁷ Transferability looks at how useful findings to reflect the context and concerns the applicability of the findings of a study.

the subjects for that particular group is also important in transferability (Krefting, 1991).

Hence, I describe the details of the design, methods, the processes of data collection and analysis, and the findings of each study in the following chapters. This provides the information to enable other researchers to judge the transferability of the findings to other settings or contexts. I also used specific selection criteria to recruit representative participants to ensure the representativeness of the informants for data collection.

However, the transferability of the data may be limited to South Yorkshire region due to the geographical constraint for data collection. This is further discussed in the limitation section in the chapter 10 of this thesis.

5.1.3 Dependability

Dependability can be referred to as reliability for qualitative research. It concerns the consistency of the data and describes the extent to which the findings are dependable for the social context (Kuper et al., 2008, Rolfe, 2006, Shenton, 2004, Golafshani, 2003). It involves the level of consistency of data collection instruments (Long and Johnson, 2000). Conducting code-recode procedure can increase the dependability of data analysis. It is important to describe the methodological details to enable future researchers to repeat the work addressing the dependability (Shenton, 2004, Krefting, 1991).

Hence, I tested out the topic guide using a trialling interview with a stroke survivor and his carer. I also conducted a trial interview with an occupational therapist who is experienced in providing physical stroke rehabilitation in the community to test the topic guide for interviews with professionals.

For transcribing the interviews with stroke survivors and therapists, I conducted a consistency check procedure with the consideration of dependability. I listened and transcribed two audio records of two different interviews, one with a stroke survivor and the other one with a therapist. Then, I transcribed both interviews again after two weeks and compared the contents of the second transcript to the first of the same

interview. The contents of the transcripts were consistent before and after two weeks, except I had to correct a few spelling mistakes in the initial transcripts.

In addition, for coding of the data from the transcripts, I performed a code-recode procedure to check the consistency of the coding process to promote the dependability of data analysis. I coded two transcripts obtained from two different interviews, one from the interview with a stroke survivors and the other one from interview with a therapist. Then I waited for two weeks before I returned to recode the same transcripts and compared each of the data sets obtained in the second trial to the first of the same interview. The types of the identified themes and subthemes were consistent before and after two weeks.

I also describe the details of the research design, method and procedure for data collection and analysis that I used for each stage of my research in order that it is replieable.

5.1.4 Confirmability

Confirmability refers to the extent to which the characteristics of the data can be confirmed by others who read or review the results of qualitative studies in particular. It is concerned with the objectivity of the study in relation to the predispositions of the researcher. It considers whether the findings are the result of informants' experiences and opinions or researchers' preferences or bias. Detailed methodological description, the use of audit trail supported with diagrams and the application of triangulation may enhance confirmability. Additionally, recognising the researcher's beliefs and assumptions may help to test the confirmability (Rolfe, 2006, Shenton, 2004, Krefting, 1991). These strategies used in this research.

In addition to methodological description for each study, I adopted audit trail approach to promote the confirmability of the qualitative studies. This may help to present the decisions made and procedures described for the steps when carrying out the study. Hence, the research process was documented and described in detail which is required for audit trail (Ohman, 2005). Moreover, I present the data with the support of quotations from the participants. I also use diagrams to demonstrate the relationships between the identified themes and the study aim, and the steps of the studies for keeping audit trail.

A data-oriented approach was used to show how the findings of the interviews eventually led to the formulation of the intervention. Different diagrams are presented to show the connections between the findings. This is to illustrate my predisposition when I determined the components required to form the programme from stroke survivors' and professionals' perspectives. Analytical frameworks were used to analyse the interviews and expose my predisposition during data analysis.

I used triangulations to promote confirmability described in chapter 8, and fieldnotes were used to confirm the interpretation and findings of the interviews.

I present the information and rationale about using the UCD and the MEBCD to design this research. I reflect on and provide the philosophy which influence the overall organisation and process of this research; realist philosophy (Pawson, 2013, Pawson and Tilley, 1997), which may have influenced my thoughts in this research. Realism is defined as a positive and down to the earth attitude to life and concerns a practical outlook to manage things and presupposes the need for some control by human beings (Malpas, 1997). My philosophical predisposition based on realist philosophy informs the logic leading to the decision I made when I conducted and analysed this research. This is further discussed in the chapter 10 of this thesis.

5.1.5 Reflexivity

Reflexivity is often referred to as recognition of the researcher's own influence on the qualitative research process, such as their backgrounds, social status and perceptions. This may influence data collection and analysis for inductive inquiries. This requires the researcher to be aware and address the influence between the researcher, topic and subjects on the results from the researcher's knowledge and experience (Kitto et al., 2008, Kuper et al., 2008, Mays and Pope, 2000).

Thus, I kept my reflective journal during data collection and analysis to reflect on my beliefs, understandings, perceptions and influence during the process. This helped me to be aware of my influence and thoughts on this research. I aware that due to my professional background as a physiotherapist and my clinical experience in providing physical functional rehabilitation services in the community, some stroke survivors assumed I understood the kinds of physical difficulties that they had encountered, and the most suitable physical exercises for their conditions, and how

to support them to self-manage their exercises. Some therapists also assumed I have already understood the appropriate exercises for stroke rehabilitation and how to support stroke survivors to undertake their practice. Hence, my professional background may have influenced my data collection process, although my professional background was advantageous to develop a professional rapport to communicate with the clinicians to facilitate the interview process.

To address the influence of my professional background, I repeated the questions after repeating what they had responded to ensure I have not misinterpreted their meanings and implicate during the interviews. I clarified their answers by asking them to tell me more to encourage them to express and explain their replies. I also encouraged them to feel free to tell me their answers according to their own views, experiences and opinions during the interviews. Furthermore, I invited the participants to check the transcripts and prototype programme to ensure they reflect their views and contain their suggestions based on their situations.

To encourage my participants to share detailed information from their experience of receiving or providing community stroke rehabilitation for physical rehabilitation; I used active listening¹⁸ that can help to recognise their real concerns (Shaughnessy and Resnick, 2009, WHO, 2012) to enhance my communication with the interviewees. I established rapport to communicate with each of my participants at the beginning of each interview using active listening skills. For interviews with stroke survivors, I started by asking their activities for daily livings and social lives in the community. This enabled me to understand their needs and experience in rehabilitation.

For the interviews with therapists, I started by sharing clinical experiences and knowledge of providing community rehabilitation services for stroke survivors. This helped to “warm up” the therapist to encourage them to share their specific

¹⁸ Active listening is a specific communication skill involving both verbal and non-verbal communication. It required the listener try to understand the speaker’s own understanding of an experience without introducing the listener’s own views or solutions. Attentive body language (including posture and gestures showing involvement and engagement, proper eye contact, nondistracting environment), following skills (give the speaker space to tell his/her own story in his/her own way) and reflecting skills (include paraphrasing, reflecting back feelings and content, and summarising the key issues) are included in active listening skills (Robertson, 2005, Lang et al., 2000)

knowledge, experience and opinions. The skills of active listening provided in the footnote 18 were adopted in both interviews with stroke survivors and therapists.

Having been born and raised in Hong Kong, I am aware of the potential influence from my sociocultural and language backgrounds which might affect my understanding and interpretation of local daily functional activities and the use of available technologies in daily living in this country. Hence, I asked the stroke survivors and carers to describe and clarify their meanings to me when I encountered unfamiliar terms about local society, activity, culture and habit during the interviews. For instance, I could not immediately figure out the meaning of “allotment” for gardening activity during an interview when the stroke survivor and his carer told me about their restricted activity and participation post-stroke, since that kind of activity was not common in Hong Kong.

I also used the information from local therapists to support my data interpretation. Additionally, I used member checking to verify the transcripts and to check the data with each participant to ensure the findings reflected their meanings in the interviews.

My knowledge and concepts about self-management for chronic conditions and health from the training that I received in Hong Kong and the UK may have influenced my belief in developing a self-managed exercise manual in this research. To minimise the limitation from potential bias due to my understanding towards self-management, I cross checked my concepts and the contents of other self-management programmes and literature about stroke self-management, including systematic reviews and recent guidelines for stroke rehabilitation. This was to avoid the programme being distorted from the generally acceptable concepts about self-management in the field.

5.1.6 Triangulation

Triangulation was another strategy that I adopted to ensure the trustworthiness of the qualitative sections in this research. Triangulation refers to the combination of data sources, investigators, methodological and theoretical aspects in the same research (Denzin, 2009, Thurmond, 2001). This aimed to promote the credibility, dependability and confirmability of qualitative research. Triangulation can be conducted by combining methodologies, using multiple data sources, investigators,

theoretical perspectives, or analytical methods (Hussein, 2009, Shenton, 2004, Thurmond, 2001, Guba and Lincoln, 1994). It may increase confidence in research data and allow relatively comprehensive understanding of the findings. This may help to compensate for the deficiency or limitation of using a single research strategy, thereby improving the ability to interpret the findings (Kuper et al., 2008, Thurmond, 2001, Kretting, 1991). The use of triangulation was used to extend my knowledge from the findings of this research.

Methodologic triangulation

Triangulating multiple methods of data collection and analysis is used to enhance the trustworthiness of qualitative research (Shenton, 2004). Using mixed methods can compensate for any deficiencies, weaknesses and bias from a single data collection method (Creswell and Plano Clark, 2011, Teddlie and Tashakkori, 2009, Johnson et al., 2007). I triangulated semi-structured interviews and surveys for data collection in this research. I used semi-structured interviews to collect qualitative data in the development stage of phase 1. Surveys were used to collect both qualitative and quantitative data in both refinement and evaluation stages of this research.

Data source triangulation

Using different types of data sources and collecting data from different persons are deemed as data source triangulation. Data source triangulation is suggested to minimize the distortion from a single data source by cross-checking data and interpretation (Hussein, 2009, Shenton, 2004, Thurmond, 2001, Guba and Lincoln, 1994). Thus, I used data collected from different kinds of participants. I used both numeric and qualitative data sources in this research. The details are provided in chapter 8b and 9 of this thesis.

Theoretical triangulation

Theoretical triangulation involves using more than one theoretical perspectives, which could provide a broader and deeper analysis of findings. I triangulated different theoretical underpinning related to the study aim and objectives, including Learning Theories, self-efficacy and Technology Acceptance Model to analyse the findings of the interviews. This helped to form the theoretical foundation to support

the design of the programme. Triangulation of theories aimed to analyse the programme with multiple lenses. The relevant details are described in the chapter 8a of this thesis.

5.2 Quality control for quantitative section

The validity of using questionnaires as the instrument to collect specific data were considered for refinement and professional evaluation purposes of the surveys. Thus, I validated the questionnaires before the main surveys.

The validation of the questionnaires were established by expert opinion and pilot tests. The wordings and contents of the questionnaires were checked before the main studies. Face and content validities were established to validate the questionnaires to ensure the questionnaires could be used to collect the data required for the particular objective of each study. The procedures are detailed in chapter 8 and 9 of this thesis.

Potential threats that may influence the external validity of the quantitative part of this research included: sample characteristics, setting characteristics and survey research attrition effect. These factors may limit the generalisability of the findings of this research to other similar populations in the future (Bryman, 2012, Lavrakas, 2008). Thus, the above factors were controlled as far as possible to ensure the external validity for the quantitative section.

Non probability sampling was used to ensure the selected participants were representative samples of the target population. I invited stroke survivors from different age groups and with different complexities of physical disabilities for the refinement survey. Furthermore, the therapists recruited for this research were experienced in providing physical stroke rehabilitation in the community of the UK to ensure the therapists were similar to the target providers of the programme.

To ensure the findings could be generalised across the community; I recruited the community-dwelling stroke survivors who had gone through the entire stroke rehabilitation service. I only recruited the therapists who were experienced in providing physical stroke rehabilitation services in the community.

For the accuracy and consistency of coding the answers in the questionnaires collected in the surveys, I checked the data set obtained from each survey two weeks after the initial coding to check for any difference in the two data sets. I also checked for any missing data.

Since the survey findings may be affected by the drop-out (attrition) of the individuals and the completion of the instruments; I tried to keep the drop-out rates for the refinement study as low as possible. This was the reason I used face-to-face interviews for the refinement with stroke survivors to minimise attrition after interviewing them for a period of time. I also reminded the respondents to complete the questionnaires for the surveys.

5.3 Quality criteria for mixed methods research

The quality of mixed methods studies can be improved by giving more consideration to describing and justifying the design, being transparent about the qualitative component, and integrating data from individual components (Wu et al., 2011, O'Cathain et al., 2008). These were considered during the course of this research.

Transparency is important to ensure the quality of a mixed methods study in health research. Hence the criteria of Good Reporting of A Mixed Methods Study (GRAMMS) (Creswell et al., 2011, O'Cathain et al., 2008) was adopted as guidance for reporting the integrated findings from both quantitative and qualitative components to promote the transparency of the mixed methods sections for the quality control of this research, in addition to ensuring the quality control of the individual components.

The criteria of GRAMMS are listed in table 5.3 below, which was used as a checklist to ensure the quality of the report of the mixed methods sections of this research. The items of GRAMMS are provided in the chapter 8b and 9 of this thesis.

Table 5.3: Good Reporting of A Mixed Methods Study (GRAMMS)

<p>GRAMMS</p> <ol style="list-style-type: none">1. Describe the justification for using a mixed methods approach to the research question2. Describe the design in terms of the purpose, priority and sequence of methods3. Describe each method in terms of sampling, data collection and analysis4. Describe where integration has occurred, how it has occurred and who has participated in it5. Describe any limitation of one method associated with the present of the other method6. Describe any insights gained from mixing or integrating methods

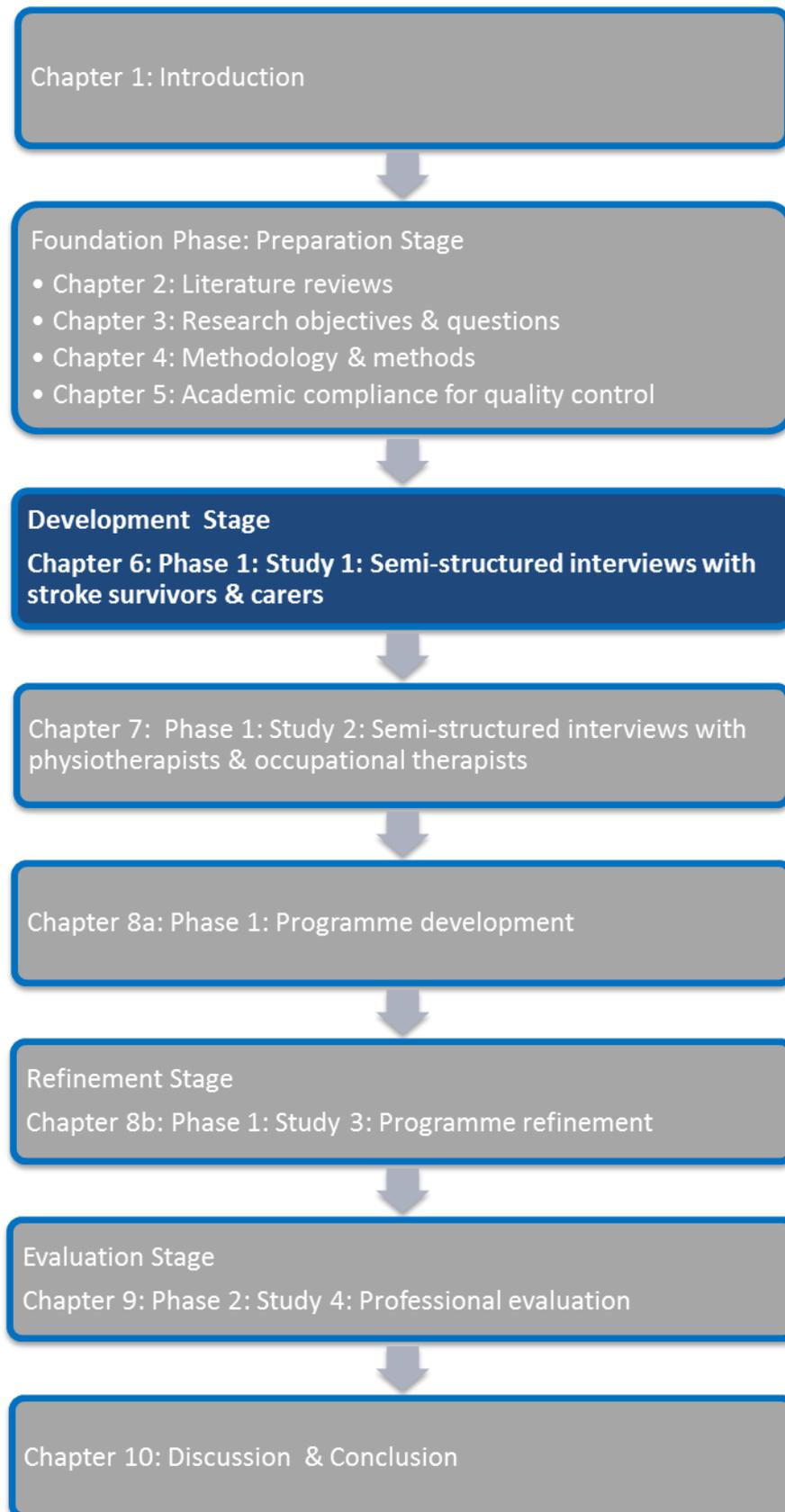
(O'Cathain et al., 2008)

5.4 Summary

This chapter describes the strategies adopted for the quality control of this research. This was to ensure the quality of the processes of data collection and analyses, and the interpretation of findings to promote the trustworthiness of this research and the programme developed based on the findings in each study.

Since it is a mixed methods research, quality control for the individual components of the quantitative and qualitative sections were managed and reported in this chapter. With regards to the specific nature of mixed methods research, the criteria of GRAMMS was added to ensure the research quality when mixing quantitative and qualitative data collected in the surveys of this research.

Section 3: Phase 1: development stage



Phase 1 ----Study 1

Chapter 6: Semi-structured interviews with stroke survivors and carers

Chapter summary

This chapter details the study design, method, procedures, analysis and findings from the semi-structured interviews with stroke survivors and their carers.

6.1 Introduction

Self-management is recommended in the guidelines for stroke rehabilitation (NICE, 2013, ISWP, 2012). In addition, stroke survivors' beliefs and strategies for recovery have been explored, in which personal control over progress, optimism, fears of dependency on other people, markers of independence and therapeutic interactions have been reported to be the factors influencing stroke recovery (Jones et al., 2008a). However, little is known about stroke survivors' opinions in what should be included in a self-managed exercise manual supported with the use of available information and communication technologies (ICTs) for their physical functional rehabilitation in the community.

Goal-setting is an important practice in rehabilitation (Wade, 2009). Goal-setting has been widely investigated and emphasised for stroke rehabilitation (Parry, 2004, Monaghan et al., 2005, Langhorne et al., 2011, Rosewilliam et al., 2011, ISWP, 2012, NICE, 2013). Despite realistic goal-setting having widely investigated and included in a range of clinical guidelines for stroke rehabilitation, the goals for daily functional stroke rehabilitation in a self-managed and remotely supported exercise manual remains less clear (NICE, 2013, ISWP, 2012, SIGN, 2010). It is necessary to identify goals specific to physical functioning to trim the contents of the programme to fit stroke survivors' needs in physical rehabilitation.

Despite exercises for the improvement of aerobic fitness and muscle strength have been clearly recommended in current literature and guidelines for stroke, the exercises that stroke survivors would prefer to be included in a self-managed

exercise manual to address their needs for functional rehabilitation remain to be determined.

Although the potential of using ICTs for stroke rehabilitation has emerged from literature, the types of ICTs that stroke survivors would like to use to self-manage exercises and their considerations about using ICTs to do so have yet been specified.

Aim

To explore the experience and needs of stroke survivors to identify essential components required to formulate a self-managed exercise manual.

Objectives

The objectives of this study are to:

- Explore limiting factors for stroke survivors to perform daily physical activities
- Identify daily physical functional goals that stroke survivors would like to achieve through self-managing their exercises
- Identify the physical exercises that stroke survivors would prefer to do to self-manage their recovery
- Explore what stroke survivors' needs to enable them to self-manage their exercises
- Identify what support stroke survivors prefer to assist them to self-manage their exercises
- Identify what ICTs are available to stroke survivors and which devices they prefer to use to facilitate them to self-manage their exercises
- Understand the key factors required to form a remotely supported and self-managed exercise manual with the support of ICTs from a stroke survivors' perspective

- Understand the potential influence of stroke survivors' age on the key factors identified to develop the programme

6.2 Methods

Semi-structured interviews were conducted with stroke survivors and their carers for data collection in this study. The interviews were transcribed and managed with Nvivo9 software, then analysed with a qualitative content analysis approach.

Both the stroke survivor and his/her carer were interviewed together within the interview session, when the carer was available to enrich the data. Interviewing both stroke survivor and carer together provided supplementary information and clarification of underlying meanings whilst they discussed the answers and reflected on others' views via dynamic interaction within the session (Gillham, 2005, Silverman, 2010). This aimed to minimise the chance of missing important information.

6.2.1 Study design

6.2.1.1 Design of topic guide for interviews with stroke survivors and carers

A topic guide was developed and used in the interviews. I developed the topic guide based on the objectives of this research. I also referred to the knowledge and service gaps identified from the literature review and background sections in the previous chapters in conjunction with the research objectives.

The interview questions were aimed at identifying necessary components and considerations for the development of the programme from the stroke survivor's perspective. The interview questions were grouped together and reviewed to ensure the sequence and content of the questions facilitated the natural flow of the interview.

Prompts and probes were prepared as supplementary questions for the interviews. This helped to facilitate the participants to answer the questions so as to generate more in-depth information for a better understanding of their viewpoints (Gillham, 2005, Bryman, 2012, Silverman, 2010).

Interview questions & rationale

To yield rich and detailed data through listening to the participants', I used open-ended questions for interviews (Merriam, 2009, Silverman, 2010, Bryman, 2012). The rationale of the interview questions is detailed in table 6.2.1.1 below.

Table 6.2.1.1: Question and rationale for interviews with stroke survivors

	Main interview question	Rationale
1	“What day-to-day physical activity do you find difficult since your discharge from stroke services?”	To identify the kinds of daily functional physical difficulties of stroke survivors
2	“Why is it physically difficult to do these tasks?”	To identify the types of physical impairments and/ disabilities that limited stroke survivors' day-to-day activities
3	“Which are the most important day-to-day activities that you need to learn again?”	To find out the goals of physical functional recovery for daily activities that stroke survivors usually have
4	“How would you feel about taking responsibility for managing your own exercises to help you make progress?”	To explore stroke survivors' attitude and main considerations about managing their own exercises and the reason why they would have those considerations
5	“What do you think would help you (or stroke survivor) to conduct your physical exercises?”	To identify the potential assistance required to help stroke survivors to self-manage stroke-specific functional physical exercises in long-term
6	“What technology do you have?”	To understand what were the available ICTs that the stroke survivors has and can use so far, before identifying which ICTs he / she would prefer to use
7	“Which one/ones would you prefer to use?”	To identify which was (or were) the ICTs that he /she would prefer to use for remote support to manage their exercises in long-term
8	“Why would you prefer that ICTs?”	To understand his / her considerations in using the ICTs to receive remote support

6.2.1.2 Validation of topic guide

To ensure the rigour of qualitative data collection, the topic guide was validated before semi-structured interviews being undertaken. This was to establish the trustworthiness, in which 2 stages were involved.

Stage 1: Validation

The wordings of interview questions were checked by a panel consisting of 11 members, including 3 stroke survivors, 2 carers, 2 stroke researchers experienced in conducting stroke research in the community who are also experienced healthcare professionals in providing physical stroke rehabilitation (1 physiotherapist and 1 occupational therapist). Two supervisors experienced in providing stroke rehabilitation and conducting stroke research in the community, and 2 lay native English speakers (1 below and 1 above 65 years old) were consulted to ensure the contents and questions were appropriate and clear for native English speakers in different age groups. Each member was given 2 to 4 weeks to read and make comments before they sent their feedback to the researcher. The wording was amended after collecting all comments and advice from the panel members.

Stage 2: Verification: pilot interview

A pilot interview was conducted to ensure the topic guide questions could be understood by stroke survivors. The structure and content of the topic guide was further refined after this pilot. The amended version was then reassessed by the supervisors of this research to ensure the questions contain specific and necessary information to collect essential data before the main interviews. This also allowed me to practise the procedure for conducting the interview.

6.2.1.3 Participants

Sampling strategy

The study population were recruited purposively as stroke survivors with a specific range of profiles were needed to collect information in the interviews (Ritchie and Lewis, 2003, Gillham, 2005, Catherine Pope, 2006, Silverman, 2009). This was

because I was interested in stroke survivors who have the best knowledge concerning the topic of this research.

Potential participants with particular representative characteristics based on the selection criteria below and their caregivers were identified via voluntary stroke groups in South Yorkshire. From recent national statistics of stroke events from the NHS Information Centre, there were 2865 strokes recorded in South Yorkshire during 2005-2006 (HES, 2011).

Sampling frame and matrix

Stroke survivors were screened and classified into 2 categories based on complexity of their physical difficulties to enable the collection of information that reflects the needs and conditions of stroke survivors with different levels of disabilities. The stroke survivors were classified into complex (C) or non-complex (NC) type stroke survivors based on the complexity of their post-stroke mobility in daily activities determined by Rivermead Mobility Index (RMI)¹⁹ (Collen et al., 1991). RMI is valid, reliable, sensitive and specific to determine the mobility status of stroke survivors (Forlander and Bohannon, 1999, Hsieh et al., 2000, Green and Young, 2001, Rossier and Wade, 2001, Antonucci et al., 2002, Hsueh et al., 2003, Chen et al., 2007). It was used to determine stroke survivors' mobility to identify and select stroke survivors with problems with physical functions and ADL after discharge. Stroke survivors identified with physical difficulties in both upper and lower limbs were referred as complex; those with only difficulties in upper or lower limb were classified as non-complex.

Stroke survivors were also classified by their age for data collection and analyses, since people at different ages may have different understanding, access, acceptance and usage of technology (Morris and Venkatesh, 2000, Burton-Jones and Hubona, 2005, Porter and Donthu, 2006, Schaper and Pervan, 2007, Wang et al., 2009). This was also to prepare for age subgroups analysis in this study.

¹⁹ The RMI was used to determine the ability of a person to mobilize independently in a nonclinical environment. It is short and covers a wide range of physical functions for ADLs (Collen et al., 1991)

The range in the age of stroke survivors across the UK is predominantly between 45 and 85 years old for both genders (Hippisley-Cox et al., 2004, Truelsen et al., 2006, Peter S, 2010). According to the Office for National Statistics (ONS) and DH of the UK, people aged 19 or over can be defined as adults (ONS, 2009, DH, 2011). People aged 65 years or above are generally classified as older adults (or elderly) for both genders (UN, 2009, ONS, 2011, DH, 2011, WHO, 2012). Therefore, stroke survivors aged 19 or above were recruited for this study, and 65 years old was used as the point to categorise the participants with stroke into adult or older adult groups in this study based on the generally accepted definition of adults and older adults nationwide and worldwide. A sampling matrix in table 6.2.1.3 was used to guide the recruitment process based on the above criteria.

Table 6.2.1.3 Sampling matrix for semi-structured interviews with stroke survivors

Age groups	Target number of stroke survivors	
	Complex	Non-complex
Adult (age 19-64)	3-5	3-5
Older adult (age 65 or above)	3-5	3-5

Eligibility

Inclusion criteria

Adults stroke survivors (aged 19-65+) discharged from specialist stroke rehabilitation services within 5 years were included. This was to ensure the individuals were likely to remember their earlier experience of recovery after discharge. Interviewees needed to have at least one disability in mobility relevant to their daily activities identified by RMI and able to understand and communicate in English.

Exclusion criteria:

Stroke survivors who scored less than 26 in the Montreal Cognitive Assessment (MoCA)²⁰ (Nasreddine et al., 2005) were excluded for this study. The MoCA is a

²⁰ Montreal Cognitive Assessment (MoCA) was used to assess whether the stroke survivors had difficulties in cognition, memory and attention or not before recruiting them. This was to ensure the recruited stroke

short, valid, reliable, sensitive and specific screening tool to identify the cognitive, memory and attention difficulties of stroke survivors (Nasreddine et al., 2005, Smith et al., 2007, Koski et al., 2009, Dong et al., 2010, Wittich et al., 2010).

The Frenchay Aphasia Screening Test (FAST) (Enderby et al., 1986a, Enderby et al., 1986b) was used to detect any language difficulty of the participant identified in MoCA screening. This was to ensure he/she could participate in the interviews. FAST has shown to be short, valid, reliable, sensitive and specific to identify language disorder of stroke survivors (Enderby et al., 1986a, Enderby et al., 1986b, Sweeney et al., 1993, Al-Khawaja et al., 1996, Enderby and Crow, 1996, Philp et al., 2002, Salter et al., 2006).

Recruitment procedure

The Different Strokes group in Sheffield and the Stroke Association in Rotherham helped to identify and contact suitable stroke survivors living in the community. I explained my study to the group coordinators and voluntary leaders before presenting the study to their members in their group meetings in July 2012.

After the presentations, I sent out the information sheets, leaflets and cover letters to invite participants to take part. I contacted them again after 24 hours to arrange home visits to the stroke survivors living in Sheffield and Rotherham for screenings their eligibility to participate and obtaining written informed consent.

6.2.1.4 Procedures of data collection

Interview procedure

The procedures used in each interview with recruited case are described below. I first introduced the interview and explained the process to the potential participants at the beginning of each interview. Then, I answered any of their questions about the study and the interview process. I ensured they understood the information about this study and the interview process, before confirming they were willing to participate. I ensured each potential participant agreed to participate in the eligibility

survivors were able to participate in interviews and understand the information of the study including the questionnaires.

screening to assess their cognitive and physical mobility levels using MoCA and RMI assessments.

After using the demographic sheets to collect basic information from the participant, I used the topic guide to carry out the interview. Probe questions were used to facilitate the participants to elaborate on their own experience and opinions. The preferred types of physical exercises by stroke survivors were also collected using the demographic sheets at the beginning of each interview for easy record and data extraction. The carers of the stroke survivors were invited to participate to provide supplementary information.

Audio tape recording was used to record each session after obtaining permission from the participant. I transcribed all audio records for data analysis.

Ethics approval

Research ethics approval was granted by the School of Health and Related Research of the University of Sheffield (Reference number: 0524/CAO) before the start of this study. The approval letter is attached in appendix 1.

6.3 Data analysis

6.3.1 Qualitative content analysis

After transcribing the interviews, I analysed the data from the transcripts using a qualitative content analysis²¹ approach. Nvivo9 software was used to manage transcripts, codes, themes and sub-themes, and data sets. Microsoft Excel 2007 was used to generate and report the data. This helped me to systematically identify and organise the themes and subthemes to elicit key components required to develop a self-managed exercise manual.

²¹ Qualitative content analysis is an analysis approach to interpret the content of the text or document via systematic classification process of coding and identifying patterns using raw data. It helps to analyse written, verbal or visual communication messages to explore the meanings underlying physical messages. It aims at providing explicit knowledge and understanding of the phenomenon under study (Graneheim and Lundman, 2004, Hsieh and Shannon, 2005, Elo and Kyngäs, 2008, Bryman, 2012, Schreier, 2012)

Thematic analysis

Under the principle of qualitative content analysis, thematic analysis was the technique that I used to analyse the data emerging from the interview contents. Themes and subthemes related to the focus of this study were generated from the analysis. Inductive thematic analysis was used to identify the themes associated with the study aim. A data-driven strategy²² was adopted during the analysis. I coded and analysed the identified themes and subthemes using a guide proposed by Virginia Braun and Victoria Clarke (Braun and Clarke, 2006).

The ICF framework (WHO, 2002) and ICF core set for stroke (Geyh et al., 2004, Aljurén, 2010, Aljurén et al., 2010) were used as the underlying guidance to classify and group the data relevant to physical functioning post-stroke. This provided a structure to interpret the data related to medical and social aspects for physical functional stroke rehabilitation.

Six phases of thematic analysis were used to systematically analyse and extract the data from the main interviews. The procedure of the analysis is illustrated in figure 6.3.1.1 below. Additionally, MindGenius software was used to create and present models to demonstrate the structures and connections of the themes and subthemes.

²²Data-driven strategy allowed creating categories and sub-categories inductively from the data during the analysis (Braun and Clarke, 2006, Schreier, 2012)

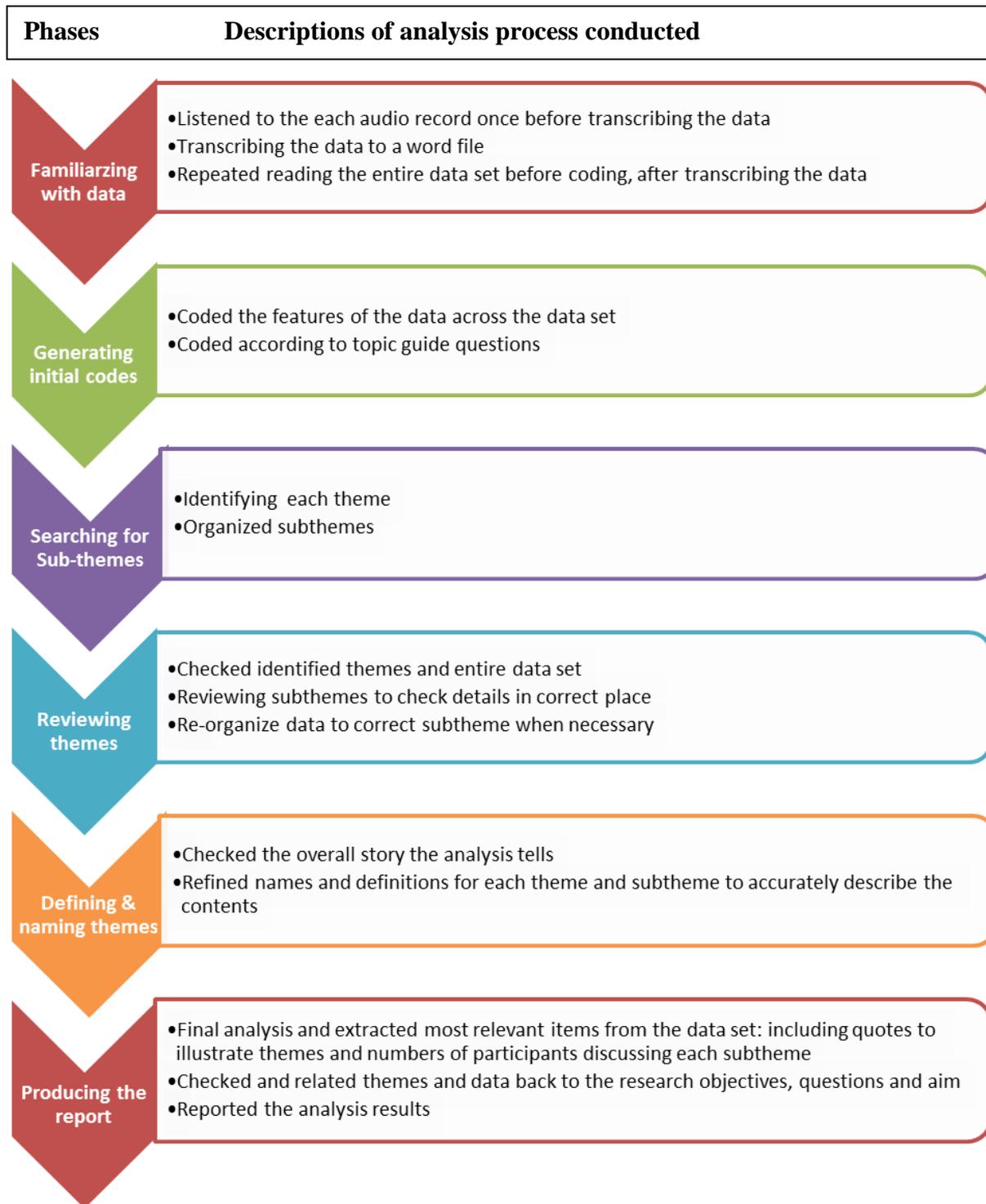


Figure 6.3.1.1 Six phases of thematic analysis of interview contents

Coding framework

Using a coding framework helps to avoid creating bias whilst selecting relevant material (Bryman, 2012, Schreier, 2012). A hierarchical coding framework was established and used to organise the identified categories of the findings obtained in qualitative content analysis to assist the overall analysis process. This was applied to differentiate relevant and irrelevant data for this research. This helped to systematically code, organise and describe the data to determine the components required to develop a self-managed exercise manual.

Figure 6.3.1.2 illustrates a coding framework showing the categories and subcategories obtained after analysis of the interviews. The framework shows the relationships among identified categories and the aim of this research to structure the interpretation process. The findings were transferred onto the framework to provide a base to analyse and integrate the entire data set under the study aim.

Frequencies of themes and subthemes

Absolute frequencies²³ (i.e. N) were used to describe how often an identified issue was being discussed by the participants in this study. This assisted me to systematically organise, analyse, compare and interpret the issues frequently considered and raised by the participants in order to develop a programme to address needs frequently presented by stroke survivors.

²³ Absolute frequencies of category and subcategory indicate the frequency of that issue being coded across the material in qualitative content analysis (Schreier, 2012)

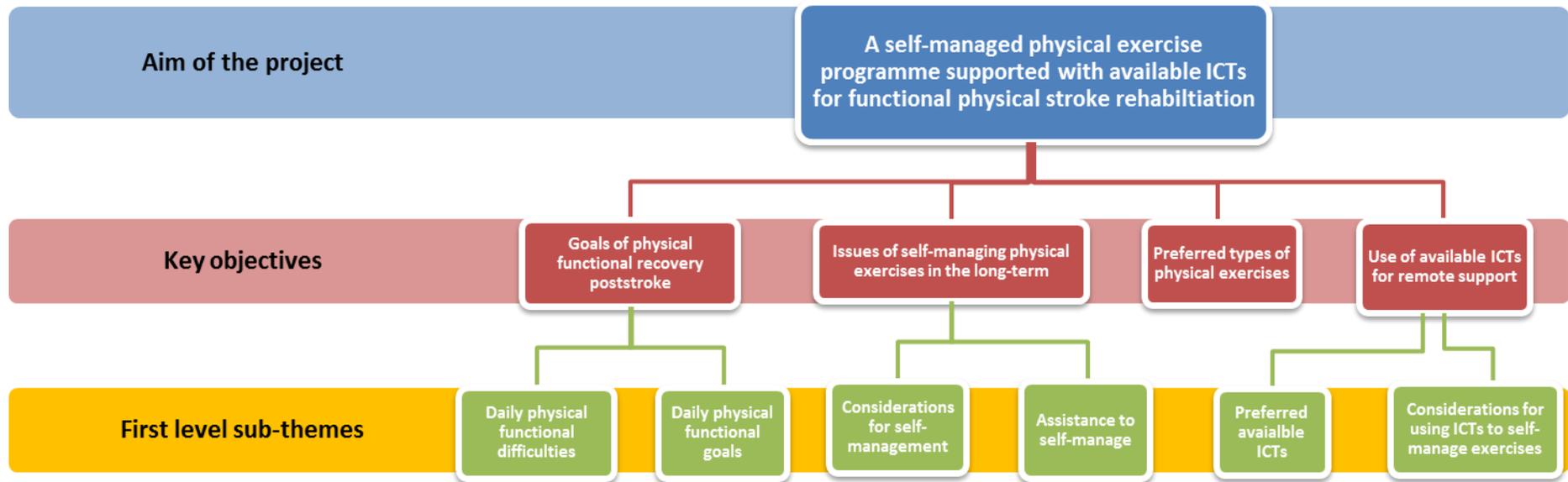


Figure 6.3.1.2 Hierarchical coding framework showing the categories of the interviews data collected from stroke survivors

Age sub-groups analyses

Although age may not be a limiting factor for stroke rehabilitation (Kugler et al., 2003, Luk et al., 2006), older stroke survivors have been shown to have greater disability at discharge (Kelly-Hayes et al., 2003, Saposnik et al., 2009). Age may affect physical stroke recovery (Kugler et al., 2003, Pinter and Brainin, 2012). It may influence people's attitude and behaviour toward accepting and using technology (Burton-Jones and Hubona, 2005, Porter and Donthu, 2006). Older adults may have the views about appropriate exercises and activities different from adults (McMurdo, 2000). According to the technology acceptance model (TAM), the users' acceptance toward using a technology is important to develop the programme of this study. Their attitude and behaviour can influence their intention and the use of technology. Therefore, it was necessary to understand the potential influence of age on stroke survivors' perception and acceptance of using available ICTs to support them to manage their own exercises in the programme. This assisted the determination of acceptable choices of technology to provide remote support stroke survivors.

To understand how adult and older adult stroke survivors think about self-managing exercises and using available ICTs to do so, the selection criteria was designed to recruit stroke survivors from different age groups. The data from the two age groups were compared for further analysis. I have, therefore, compared the findings of the themes between stroke survivors aged below and above 65 years old to understand the views, needs and suggestions between them.

6.4 Results

Twenty stroke survivors participated in interviews, two of which were excluded after screening tests. One was found to have mild cognitive deficit based on the MoCA score, whilst the other one had no physical mobility problem according to RMI. Eighteen stroke survivors were finally interviewed and 8 carers participated. The medians of their MoCA and RMI scores were 29 and 8.5 respectively. This reflected all recruited stroke survivors were cognitively within normal range and had physical mobility problems in their daily activities. Each interview lasted between 1 to 2 hours.

The following table 6.4 and 6.4.1 and 6.4.2 show the results of sampling for stroke survivors and participants' characteristics respectively.

There were total of 18 stroke survivors recruited in which 9 were categorised as complex and the other 9 were non-complex cases. Ten of the total participants were adult aged between 19 to 64 and the rest of 8 were classified as older adults aged 65 or above. The average age of all participants was 61.6 years old (range 35-80). Thirteen of them were male and five were female. The average time following stroke onset of them was 1.9 years, therefore, they all were discharged from stroke rehabilitation services but not too long time ago. All of them had at least one stroke onset.

Seven participants with stroke have at least 1 physical limitation before the onset of their stroke. Ten of them have other health restrictions other than stroke; such diabetes and asthma. Seventeen of them had been given physical exercises before their discharge from stroke rehabilitation services. Seventeen of them have regularly practised their exercises since their discharge. One of them had experience of using ICTs to receive physical rehabilitation services from healthcare professional after stroke. They practised exercises daily after discharge.

Table 6.4: The sampling matrix for stroke survivors

Age groups	Number of recruited stroke survivors	
	Complex	Non-complex
Adult (age 19-64)	5	5
Older adult (age 65 or above)	4	4
Total	9	9

The characteristics of the participants are reported in table 6.4.1 below.

Table 6.4.1: Participant characteristics

Participant characteristics	Summary
Gender	Male: 13, Female: 5
Average age (years)	Mean: 61.6 (Youngest: 35, oldest: 80)
Average time following stroke onset (years)	1.9
Number of stroke per participant	Frequency: 1 (Range: 1 to 4 times)
Number of participants with at least 1 physical limitation before stroke onset	7
Number of participants with other health restrictions other than stroke (e.g diabetes & asthma)	10
Number of participants had been given physical exercises before their discharge from specialist stroke services	17
Number of participants regularly practised exercises since their discharge daily	17
Number of participants had experience of using ICTs to receive physical rehabilitation services after stroke	1
Minimum day of physical exercises practice per week (except walking)	7 (Range: 1-7 per week)

The stroke survivor who had experience of using ICTs to receive physical rehabilitation service after stroke reported that she used video recording function on her mobile phone to keep the records of her progress. She consulted her occupational therapist for advice on her physical performance using the video records.

Table 6.4.2: Participant characteristics (Demographics)

The demographic characteristics of individual participant are presented in table 6.4.2.

Participant code	Age	Gender	Numbers of times of stroke	MoCA (Normal range 26-30)	RMI (Lower score indicates lower mobility in daily functions; full score is 15 which indicates full functions)	Category of physical function classified in this study (C= Complex, NC= Non-complex)	Continued physical exercise practice since their discharge (Yes / No)	Experience of using ICTs to receive healthcare service for physical stroke rehabilitation (Yes / No)
S001	47	M	4	26	10	C	Yes	No
S002	49	M	1	29	11	NC	Yes	No
S003	59	F	1	27	8	NC	Yes	No
S004	62	M	1	26	12	C	Yes	No
S005	51	F	1	26	1	C	Yes	Yes
S006	67	F	2	29	8	NC	Yes	No
S007	78	M	1	30	11	C	Yes	No
S008	57	M	1	27	9	C	Yes	No
S010	63	M	1	28	10	NC	Yes	No
S011	35	M	1	30	7	NC	Yes	No
S012	69	M	3	29	9	C	Yes	No
S013	53	M	1	27	10	NC	Yes	No
S014	57	M	1	30	5	C	Yes	No
S015	80	M	1	30	10	NC	No	No
S016	65	M	1	28	7	C	Yes	No
S017	65	F	1	30	8	NC	Yes	No
S018	72	M	1	27	6	C	Yes	No
S019	79	F	1	30	8	NC	Yes	No
Total	Mean 61.6	M: 13, F: 5	Average Frequency: 1 (Range: 1-4 times)	Median: 29	Median: 8.5	C: 9, NC: 9	Yes: 17, No: 1	Yes: 1, No: 17

Preferred types of physical exercises identified by stroke survivors

The preferred types of physical exercises by stroke survivors were identified using a demographic sheet. Fifteen stroke survivors reported walking exercise (N=15) which is followed by strengthening (N=12) and mobilizing (N=11) exercises.

The results are shown in the table 6.4.3 below. This informed a list of exercises that should be included in the programme according to stroke survivors' preferences.

Table 6.4.3 Identified preferred types of physical exercises from stroke survivors

Types of preferred physical exercises	Numbers of participants
Mobilizing	11
Stretching	4
Coordination	5
Balance	5
Strengthening	12
Walking	15
Aerobic	4
Combined task-oriented functional movements/physical activities	7

Themes

Based on figure 6.1.4.2, 6 main themes emerged from interviews with the 18 stroke survivors and 8 carers.

- A. Daily physical functional difficulties
- B. Daily physical functional goals
- C. Considerations of self-managing physical exercises
- D. Assistance to self-manage physical exercises
- E. Preferred types of available ICTs for remote support
- F. Considerations of using available ICTs to deliver the remote support

Defining themes is important to ensure the understanding of their meanings and use of terms consistently. It provided the rules for coding data into categories (Schreier,

2012, Bryman, 2012). Themes and their definitions are described in table 6.4.4 below for analysis and interpretation.

Table 6.4.4: Themes and definition of each theme for interviews with stroke survivors

Theme	Name	Definition
A	Daily physical functional difficulties	The difficulty of the individual due to his/her physical discomfort and/or affected physical health condition, which limits his/her ability to perform a normal purposeful day-to-day physical activity in a particular environment
B	Daily physical functional goals	The explicit targets to achieve as a result of a change / action for a particular individual to perform a normal purposeful day-to-day physical activity in a particular environment
C	Considerations of self-managing physical exercises	The thoughts of the individual in response to determining the management of a physical exercise by himself/herself
D	Assistance to self-manage physical exercises	The action taken to help someone in order to enable him/her to manage his/her physical exercise by himself/herself
E	Preferred types of available ICTs for remote support	The kind of existing and accessible information and communication technologies (ICTs) that the individual would tend to choose to remotely support him/her
F	Considerations of using available ICTs to deliver the remote support	The thoughts of the individual in response to use existing and accessible information and communication technologies (ICTs) to provide remote support to him/her

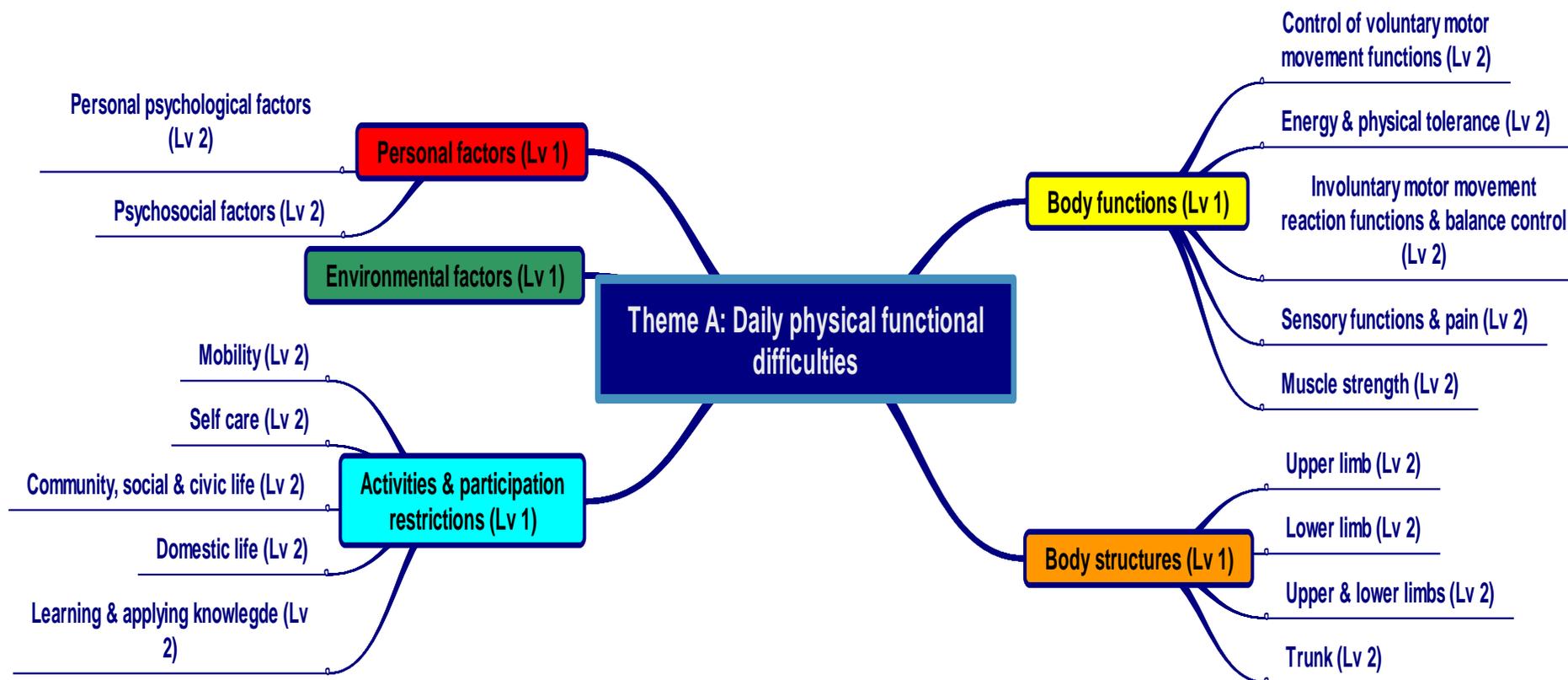
Sub-themes

The sub-themes were further analysed from the contents in stage 2 and organized under the main themes. They were organized into 3 levels according to the nature of the information, the depth of the information and meanings revealed from the data, the hierarchy of the meanings of the contents and the relationships between the contexts under each main theme.

Each subtheme was labelled according to its content under the definition of the corresponding main theme. Level 1 is the most basic level, and reflects a relatively general scope of a certain main theme. Specific components were identified in lower levels of the hierarchy.

Total of 18 stroke survivors were interviewed, the categories supported by the results from less than 2 stroke survivors were not used in programme development. This was to preserve a wide range of collected data from this specific population to enable generalizability. It aimed to minimize the chance of individual bias by using the data from a single case alone.

Theme A: Daily physical functional difficulties



Abbreviation: Lv= Subtheme Level

Figure 6.4.6a1: Overall connective conceptual model of theme A and related subthemes

Body functions & structures

Daily physical functional difficulties due to physical impairments in body functions and structures from stroke were identified in Table 6.4.6a. The control of voluntary motor movement functions were reported as the major influence to the impairment by all stroke survivors in view of body function.

For body structures, most of the stroke survivors were affected by both upper and lower limbs impairment (N=9) affecting their daily physical functions.

Table 6.4.6a Theme A: Daily physical functional difficulties----body functions and body structures

Subtheme (level 1)	Subtheme (level 2)	Quotation
Body functions	Control of voluntary motor movement functions (N=18)	"I just don't have the control. Don't have the function I used to have" (S004)
	Energy and physical tolerance (N=14)	"Fatigue limits my ability to complete daily activities" (S003)
	Involuntary motor movement reaction functions & balance control (N=17)	"Because I am all over places, I am wobbling. It is my balance problem" (S006)
	Sensory functions and pain (N=7)	"I have pain in the left upper arm that affects my physical tasks. The pain prevents me doing physical tasks, it is too severe" (S017)
	Muscle strength (N=15)	"Is the weakness of left side of body, arm and leg" (S005)
	Mobility of joint (N=11)	"Mobility, you have dropped foot, haven't you? You can't pick up your foot to walk properly" (S008, carer)
Body structures	Upper limb (UL) (N=5)	
	Lower limb (LL) (N=4)	
	Upper & Lower limbs (UL & LL) (N=9)	
	Trunk (T) (N=6)	

Activity and participation restrictions

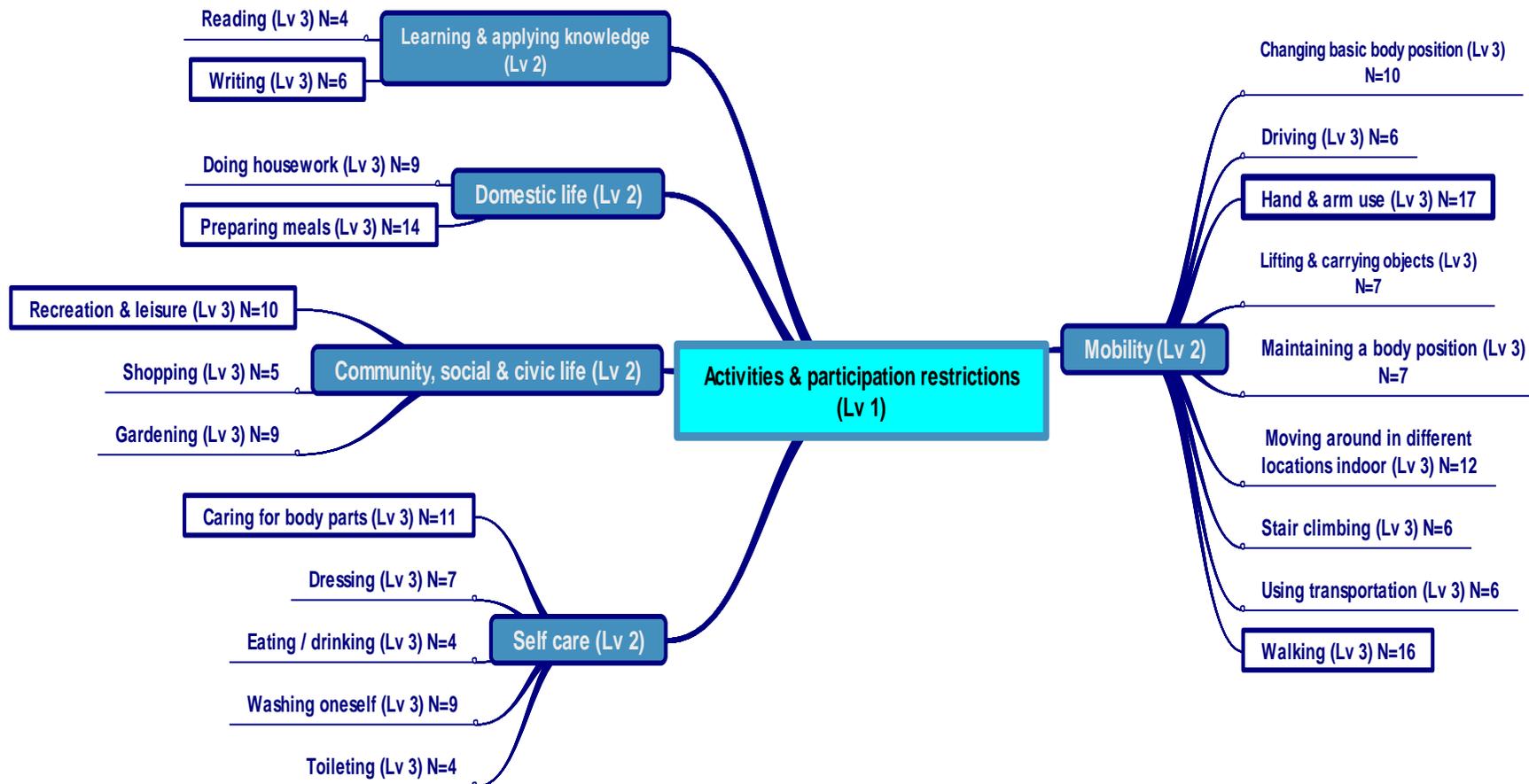


Figure 6.4.6a2: Connective model of theme A findings ---activities & participation restrictions

Stroke survivors reported that their activities and participation were restricted which was categorized as a level 1 subtheme. Five level 2 subthemes were identified under the scope of activities and participation restrictions, in which mobility, self-care, community, social and civic life, domestic life, and learning and applying knowledge were further identified as the major difficulties limiting their daily functional activities and participation.

Twenty-one level 3 subthemes were further identified from the level 2 subthemes. The following table 6.4.6a demonstrates the items of the restricted activities and participation which are supplemented with sample quotations.

Table 6.4.6a: Identified activity and participation restrictions and quotations

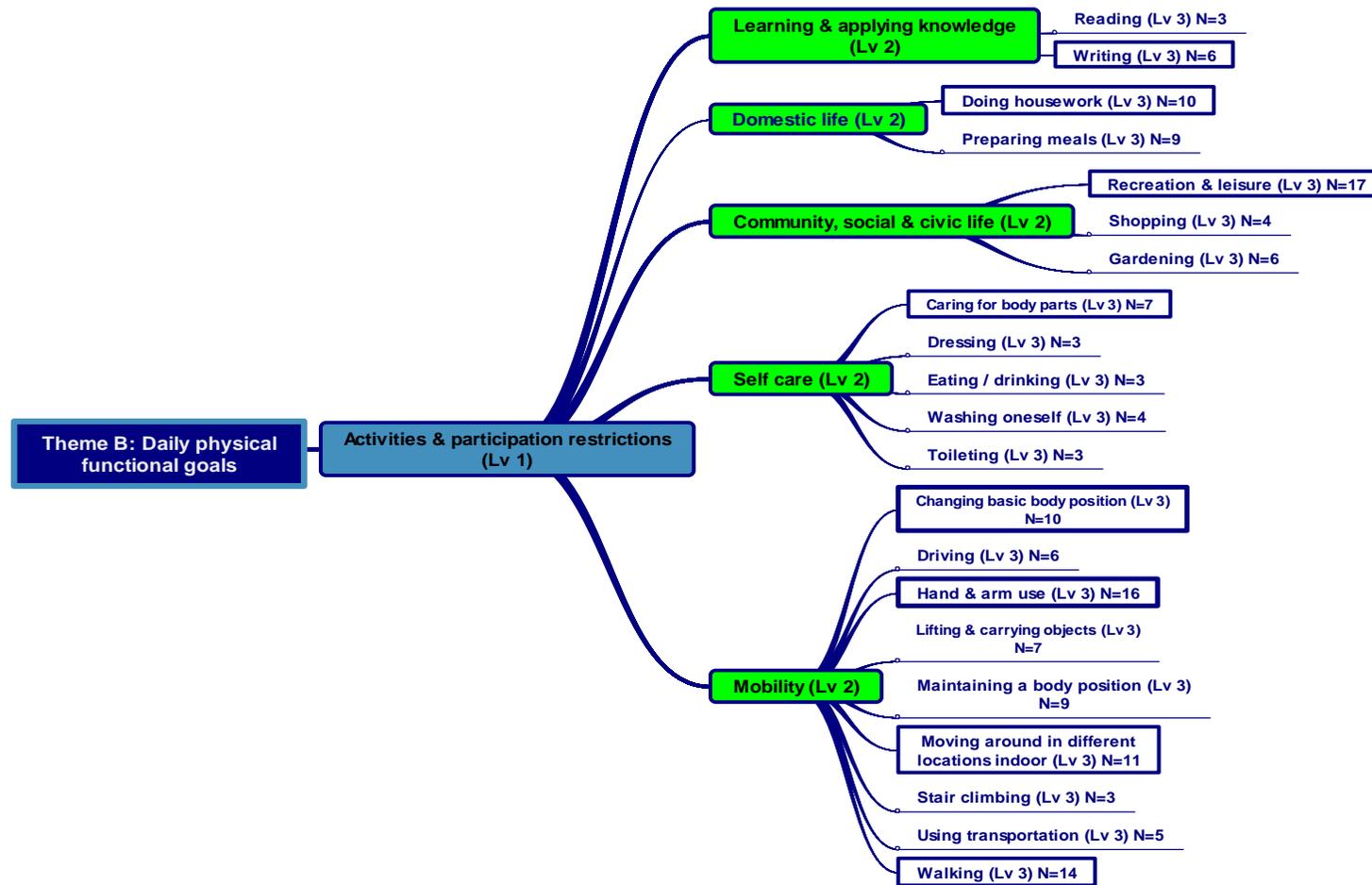
Subtheme (level 1)	Subtheme (level 2)	Subtheme (level 3)	Quotation
Activity and participation restrictions	Mobility	Changing basic body position (N=10)	"Standing up and sitting down" (S003)
		Driving (N=6)	"I cannot ride on my motorbike" (S002)
		Hand and arm use (N=17)	"Holding and grabbing things with my hands" (S018)
		Lifting and carrying objects (N=7)	"Anything involves leaving heavy things" (S013)
		Maintaining a body position (N=7)	"Because of his balance, he can't sit on the floor to pray. And if he has got on the floor, he doesn't know how to get up from the floor. It is because of his balance and his right leg" (S018, carer)
		Moving around in different locations indoor (N=12)	"Move around in the house is difficult for me. Because it is so easy to fall over, you know" (S016)
		Stair climbing (N=6)	"I can't do stair-climbing. I can't use my arm to pull myself to go up stairs" (S016)
	Self-care	Using transportation (N=6)	"Getting in and out of a car is difficult" (S005)
		Walking (N=16)	"Most difficult thing is walking I found" (S007)
		Caring for body parts (N=11)	"Well, from my example, I can't reach my back to scratch my back" (S012)
		Dressing (N=7)	"I can't dress, I can't put clothes on myself" (S018)
		Eating / drinking (N=4)	"I can't use this arm to operate the knife" (S012)
		Washing oneself (N=9)	"Washing face, arm and body before he prays, this is very difficult for him, and he needs assistance" (S018, carer)
		Toileting (N=4)	"going to the toilet alone" (S005)
Community, social & civic life	Recreation and Leisure (N=10)	"I also found it difficult to play my guitar. I can't play it now" (S015)	
	Shopping (N=5)	"I cannot go shopping and pick up the bags and walk home" (S002)	
	Gardening (N=9)	"I love gardening, but I can't" (S006)	
Domestic life	Doing housework (N=9)	"laundry, to be able to do laundry and vacuuming" (S006)	
	Preparing meals (N=14)	"Cooking, and cutting vegetables and preparing the foods for eating" (S016)	
Learning and applying knowledge	Reading (N=4)	"I read a lot of magazines. But I found it difficult to turn the pages of magazines, newspapers and books. So, I can do it, but, it is very difficult for me to read" (S016)	
	Writing (N=6)	"I cannot fill the forms in, because of my stroke, as I am left-handed" (S007)	

Environment (N=13) and personal factors were identified as influencing factors to daily physical functions of stroke survivors. Personal psychological (N=15) and psychosocial factors (N=7) were further identified from personal factors which were reported to be the limiting factors to their activities and participations by stroke survivors. The numbers were reported in Table 6.4.1a below.

Table 6.4.6a Theme A: Daily physical functional difficulties: environmental and personal factors

Subtheme (level 1)	Subtheme (level 2)	Quotation
Environmental factors (N=13)		“It depends on their space, their living environment, your partners and children. If you are living with your partner who is not being very helpful. I think you have got to have the cooperation of the persons you are living with. There are people they don’t have a good relationship at home, and so that might make it difficult. Is the relationship with the partner, family members and carer, because they need to be involved” (S016)
Personal factors	Personal psychological factors (N=15)	“I think I’ve got to be brave enough to do this, so I’ll need someone to come with me who comforts me and helps me to clear that fear” (S003)
	Psychosocial factors (N=7)	“Hospital staff should be more supportive and encouraging” (S012)

Theme B: Daily physical functional goals



Abbreviations: Lv= Subtheme Level, N= Numbers of participants with stroke

Figure 6.4.6b: Connective model of theme B findings --- Daily physical functional goals (activities & participation restrictions)

Return to daily activities and participation was the overall common goal for physical functional stroke rehabilitation by the interviewed stroke survivors. There were five level 2 subthemes identified based on the goal of dealing with activity and participation restrictions.

Twenty-one level 3 subthemes were identified from the 5 level 2 subthemes. The identified items in the activity and participation goals are the same as that in the activity and participation restrictions. The details and relationships between the theme and subthemes are shown in figure 6.4.6b above. Table 6.4.6b shows the items of the restricted activities and participation reported by stroke survivors which are supplemented with sample quotations.

Table 6.4.6b: Identified activity and participation goals and quotations

Subtheme (level 1)	Subtheme (level 2)	Subtheme (level 3)	Quotation	
Activity and participation goals	Mobility	Changing basic body position (N=10)	"...bending down to put things out, but because of my balance problem" (S012)	
		Driving (N=6)	"I have not been on my bike since then, I love to be on a bike. But, I am not confident. I am not even dare to go and try at the moment" (S002)	
		Hand and arm use (N=16)	"I want to be able to draw pictures with my grand kid" (S016)	
		Lifting and carrying objects (N=7)	"Carrying things in your (his) right hand" (S008, carer)	
		Maintaining a body position (N=9)	"Anything involves standing. Because she has the weakness on her left side, and because her balance is seriously being affected" (S005, carer)	
		Moving around in different locations indoor (N=11)	"I have no intention of sitting down and being a "cabbage" just because of a stroke" (S007)	
		Stair climbing (N=3)	"...just to be able to walk upstairs without falling down" (S001)	
		Using transportation (N=5)	"When walking stick I can hold onto a steady support like a bus rail with my free hand. Where as a stick in some cases can be disabling, for example holding a bag and a stick" (S003)	
		Walking (N=14)	"I would like to learn to walk properly on my own" (S005)	
		Self-care	Caring for body parts (N=7)	"Learn to do my hair properly" (S005)
			Dressing (N=3)	"...to dress myself" (S005)
			Eating / drinking (N=3)	"I would like to be able to eat properly, using the knight and fork" (S012)
			Washing oneself (N=4)	
			Toileting (N=3)	"...it will be nice to just get up and go to toilet on my own. And clean myself afterward" (S005)
Community, social & civic life	Recreation and Leisure (N=17)	"I want to go out to have social life, to watch football and cricket in the stadium again" (S013)		
	Shopping (N=4)	"I (hope) I can go shopping" (S018)		
	Gardening (N=6)	"I would like to do gardening. we had an allotment that we used to manage together" (S003)		
Domestic life	Doing housework (N=10)	"I can't put the washing to there on the washing line, I nearly fall" (S014)		
	Preparing meals (N=9)	"Make a cup of tea, and make a sandwich for myself when nobody look after in the house" (S018)		
Learning and applying knowledge	Reading (N=3)	"...to be able to sit and read" (S001)		
	Writing (N=6)	"To be able to write properly" (S007)		

Theme C: Considerations of self-managing physical exercises

Table 6.4.6c: Table of theme C findings---considerations of self-managing physical exercises

Theme	Subtheme (level 1)	Quotation
Considerations of self-managing physical exercises	Motivation (N=14)	"I don't have the motivation to do it on my own" (S004)
	Self-confidence (N=9)	"You have to give me the confidence to go ahead and do it" (S012)
	External support & reassurance (N=18)	"I need to be assured that I am doing in a way that is going to benefit me" (S012)
	Relevance to rehabilitation goals & needs & health conditions (N=6)	"...specific goals related to social activities it would not only encourage the participation in doing exercise and participate in their social life but also to build up their self esteem so they can have the motivation to continue to practice their exercises" (S003)
	Personalisation of the exercise programme (N=10)	"I think that should be specific to their conditions and personalized to their needs" (S015)
	Simple & specific instruction (N=14)	"I can't see any problem with it; providing you know what exactly you have got to do and clearly know what they expect of you" (S007)
	Application of self-monitoring & self-regulation (N=12)	"I think you have to monitor it from the beginning, to make sure they know what they are doing. You can't just drop them the thing and say that's it. I think you would need to manage it" (S013)
	Teaching & Learning how to self-manage exercise (N=8)	"...learn to complete exercises in a motion that is not too rapid. If people learn how to breathe after a stroke they will have a quicker improvement. If you don't breathe properly, you will find it hard to follow the exercise and will feel fatigue more quickly as you don't have adequate oxygen. A lot of people don't understand this concept and are not taught it" (S003)
	Knowledge of safety & risk (N=9)	"When I push myself to do the exercises, I may overdo it, over-exercise. Because I want to push myself, and I would push myself too hard, too soon. That could be a problem" (S002)
	Technical skills (N=5)	"That will be good to have health professionals, telling what to do, demonstrating the exercises, getting the people together, and assessing the progress for the people, that will help to manage the exercises" (S019)
	Access to relevant health & social care resources & network (N=5)	"Making contact with the right people, and a supporting network is important" (S003)
	Enjoyable exercises (N=6)	"...the exercises that whether the person like to do or not would also be considered" (S006)
	Suitable environment (N=7)	"...about space and a safe environment for them to do the exercises" (S012)
	Sustainability concept (N=8)	"Help you (me) to keep managing it" (S013)

Stroke survivors expressed their particular considerations for self-managed exercises in the future. Fourteen subthemes were identified as the main factors. The items are reported in the table 6.4.6c and supplemented with quotations.

Theme D: Assistance to self-manage physical exercises

Table 6.4.6d: Table of theme D findings --- assistance to self-manage physical exercises

Theme	Subthemes		Quotation	
	Subtheme (level 1)	Subtheme (level 2)		
Assistance to self-manage physical exercises	Professional contact & support & feedback	Occupational Therapist (OT) (N=7)	"a professional support, like a physio and occupational therapist helping you to do your exercises" (S001)	
		Physiotherapist (PT) (N=13)		
		Personal Trainer (N=3)		
		Social care professional (N=3)		
		Any healthcare professional (N=11)		
	Peer support & feedback (N=18)		"Peer support is very important, or I would just be sitting there. Well, just to have people to pick you up to do your exercises" (S001)	
	Carer support & feedback (N=5)		"The carer needs to be included. But if you just tell the stroke survivors, they would forget it, then they would withdraw from it. So, carers need to be involved" (S001)	
	Financial issues & support (N=6)		"I think it might not be possible, because it will cost money" (S014)	
	Self-management strategies & methods	Access to relevant resources (N=14)		"the access to the health resources will also be helpful to manage the exercises. So is not only the contact number, but actually to provide the access. Like access to physical aids, and if there is any group, maybe something about social care resources that should be included in the programme" (S017)
			Facilitation for self-motivation (N=15)	"Is about the motivation of it. To get them (other stroke survivors) motivated" (S006)
		External support & feedback to enhance self-confidence (N=18)		"You need to support people to manage their own exercise programmes and do the exercises" (S017)
			Goal setting (N=11)	"The aim to achieve something is very important, even something simple as being able to walk outside without a wheel chair or mobility scooter" (S003)
		Information provision (N=16)		"Proper information about what you have got to do, and what not to do" (S007)
			Monitoring, regulation & progress evaluation (N=16)	"What you have got in that record that you keep. Is a diary of whether you have done it or not. I know that it can get to it, like it can get to me, if you haven't done it. So, that's a visual kind of prompt, and a motivator" (S004, carer)
		Education & Learning skills for self-management	Professional instruction & advice (N=18)	"a contact with healthcare professionals can give you some specific advice, skills and knowledge for you to manage your exercises" (S004)
Systematic action planning (N=12)	"...having a good planning and preparation would be helpful for people to manage their physical exercises" (S012)			
Education of knowledge & learning skills to self-manage (N=16)	"Teaching self-management and giving right information are what health professionals should do when they finish supporting you during the initial stage" (S003)			
	Safety education (N=14)	"You need to be able to identify where they are likely to be dangerous" (S012)		

There were different types of assistance identified by stroke survivors to help them to self-manage their own exercises. Six level 1 subthemes were identified that contained 15 level 2 subthemes. The items are reported in the table 6.4.6d and supplemented with quotations.

Theme E: Preferred types of available ICTs for remote support

Table 6.4.6e: Preferred types of available ICTs for remote support

Subthemes		
Subtheme (level 1)	Subtheme (level 2)	Quotation
Audio-visual technology (N=14)	TV (N=7)	"Because purely and simply that is a TV, I have got a big screen" (S015)
	CD (N=4)	"You can also do exercises with music with CD" (S007)
	DVD (N=11)	"a DVD, so they can see the exercises and do" (S007, carer)
	Video recording (N=4)	"I prefer video-recording. Because I have something to physically show people and the healthcare professionals" (S005)
Computer (N=8)	Desktop / laptop computer machine (N=8)	"I prefer the computer" (S010)
	Touch screen computer machine (N=2)	"I prefer that ipad" (S001)
Internet technology (N=13)	Internet access to information online (N=6)	"...using information technology can help you get information about products for you to do exercises" (S004)
	Online social media and discussion forum (N=8)	"Using e-forum for bouncing ideas on each other, that's place where peer support comes in, I think. It is the place I can talk to somebody professionally. Or I can talk to somebody about my level, perhaps, some users about what I am doing" (S002)
	Online video link (N=5)	"...if somebody shows her the exercise video on her laptop, then she will be able to copy actions" (S005)
	Electronic record system (N=4)	"...on the web-site, perhaps, you can have a log-in system on it. Only if you are under the care of NHS system you can log-in to it. I can log-in to the exercises I have to do. I can log-in to it and watch it. A clever system would allow you and your physio to be able to know how to log-in and see it" (S001)
	Email (N=7)	"...use email as a reminder" (S011)
	Interactive videoconference (N=8)	"...kind of support over interactive, you have that like Skype, things like get video-links to somebody could reach the outside of the world" (S002)
	Apps on touch screen computer (N=2)	"I think you could have an App on your mobile phone related to your exercise programme" (S017)
Telephone communication technology (N=15)	Electronic computer games (N=4)	"I think the interaction is what you need, so it should be interactive. People can interact with the computer and the video. Like the wii, with the computer game. That's interesting and interactive" (S013)
	Landline telephone (N=11)	"Landline telephone. We have telephone technology for a very long time now" (S004, carer)
	Mobile phone call (N=12)	"Mobile people can still talk to support survivors with their exercise" (S003)
	Mobile phone text message (N=6)	"I would prefer text message" (S014)
Mixed multimedia technology (N=13)	Mixed multimedia technology (N=13)	"I prefer to have a mixture of everything, not just one thing" (S002)

There were different types of available information and communication technologies (ICTs) reported by stroke survivors as their preferred choices. Five level 1 subthemes were identified, in which 4 different kinds of ICTs were included as shown in table 6.4.6e above.

Theme F: Considerations of using available ICTs to deliver remote support

Table 6.4.6f: Table of theme F findings---considerations of using available ICTs to deliver remote support

Theme	Subtheme Subtheme (level 1)	Quotation
Considerations of using available ICTs to deliver remote support	Accessibility (N=14)	"...because that's accessible to me" (S004)
	Availability (N=14)	"It is important that technologies are available; otherwise there is nothing survivors can use" (S003)
	Perceived ease of use (N=15)	"It is important to find things that are easy to use and doesn't become a frustration" (S003)
	Perceived usefulness (N=15)	"I use facebook. I am using that already. I prefer to use it like that. It is useful to me" (S005)
	Flexibility (N=9)	"It is more convenient, when somebody send me a text message, I can check it later, I don't need to check it straight way; same with the email when I open my computer I will see. It is convenient to control and also to pass the information to others, at the same time without hindrance" (S014)
	Age of users (N=7)	"People are at 80s at the moment, they don't understand the technology. people at different ages would have different understandings of technology" (S002)
	Sustainability & maintenance issues (N=7)	"...in the future I hope that there is programme that will allow me to use similar simple technology, like sending a fax" (S003)
	Technical support (N=4)	"Some people are a bit kind of technical fall, they can't go beyond technology. Maybe it is just too much, particularly for stroke survivors" (S004)
	User centred design for personal needs & conditions (N=13)	"It should be personalized, it depends on the person. So, you ask the person, if this is the thing you have, if this is the difficulty that you have. You need to cater to the person according to their abilities to use the technologies" (S018, carer)
	Cost utility of using ICTs (N=4)	"I can't afford internet, it is too expensive" (S012)

There were 11 considerations identified about using available ICTs to deliver remote support to stroke survivors for the self-management of their own exercises. The identified considerations in using available ICTs to self-manage exercises are reported in the table 6.4.6f1 above and supplemented with quotations.

Additional themes

Additional information emerged from the interviews beyond the findings directly related to the questions in the interview topic guides. Two additional themes were obtained in which seven subthemes were identified. They are reported below.

Theme G: Attitudes toward managing own exercise

Three subthemes emerged that illustrated stroke survivors' attitudes toward managing their own exercise: *independent*, *determined*, and *positive*. The findings and quotes from stroke survivors are shown in table 6.4.6g below.

Table 6.4.6g Attitudes toward managing own exercise

Theme	Subtheme	Quotation
Attitudes toward managing own exercise	independent (n=15)	"I have been able to take more control over. I think you should manage yourself, if you can. I am taking control of it. I am quite happy to manage my own exercises" (S004)
	determined (n=13)	"I have got the real power to do these exercises. You will be determined to do the exercises...Is about self-determination to manage physical exercises. I can control and make sure to do the exercises, which is the real power." (S016)
	positive (n=14)	"...being positive would help you to manage their exercises. It would help, if they feel positive, whilst they doing the exercises, it would not only strengthen the body, strengthen the mind; it would probably help to live longer, that's what I think" (S006)

(n= number of participants involved)

Independent

Fifteen interviewees described their feeling of being independent to take control over the management of their own exercise manual. They expressed that they would like to be able to take control of their own exercise regularly. The following quotes illustrate this independent attitude from their perspective.

"If you don't do it, you stop leading it yourself. I feel happy about taking responsibility for managing own physical exercises. I feel being in control of my own well-being. I want to push myself, which what I have done. To do the exercises and to improve....I think people are going to manage their own fitness, their own recovery" (S002)

'I motivated and encouraged myself to do the exercises... if you just sit on the wheelchair or at home doing nothing. Your life isn't worth, is it? You really need to keep going with a stroke. Because you need to get yourself back to what you were previously before your stroke" (S007)

“For me to achieve what I want to achieve. Just to go out and do it with myself, whenever I like. Managing own exercise program then we will be in control. I will be in control for my exercises if I manage my own exercise program” (S013)

Stroke survivors may not always need external motivation but internal. They may encourage themselves to manage their exercise independently as they wish.

“Because I feel the pace in myself depends on how I feel. I can’t expect too much on myself. I can control what I do depends on how I feel for my health. I can set my own target. Control by yourself. Control your own life, is the self-control, not be in-charged by somebody for what you do. You can do it when you want to do it. You don’t have somebody to come at 2 o’clock to do it, you don’t have to wait anybody to do it. (S008)

Determined

Thirteen participants expressed that they are determined to take up the control of their own exercise. The following quotes demonstrate that they are determined to do so for their own recovery.

“I would try. I don’t worry about it (managing own exercise). I just do my best. I am sure this right leg will come back in months with exercises. It improves so much, since I have stroke. I am determined that it will come back” (S006)

“I have no intention of sitting down and being a “cabbage” just because of a stroke. I would intend to keep it going. I don’t see any problem. I should do it. I think I am not worry, I am used to when I had my stroke. I can’t see any problem with it; providing you know what exactly you have got to do and clearly know what they (healthcare professionals) expect of you” (S007)

“I can’t see any difficulty. As long as you know what you are doing and decided the time to do it. I would do it” (S011)

Clinicians should be aware of the individual’s attitude in taking up the responsibility to manage their own exercise in practice. It will be helpful to figure out the way to assist the individuals to be determined in controlling their exercise.

Positive

Fourteen participants showed positive attitudes toward managing his/her own exercise for their own recovery in the long-term. The following quotes report this view.

“You have got to try to do things. You have got to be positive. Thinking positive would help you to do the exercises. You have got something to aim for, and you have got to have something to look forward to. Is to make your life better, and everything makes your life better is good” (S010)

Some participants expressed that they feel good to have something to hope for as they manage their own exercise.

“I think I can do it with the physical exercise program. I feel good to do it. I have higher hopes to do it” (S019)

“Other stroke survivors need to think of tomorrow. It took me a long to learn it. Don’t think about what I did yesterday, think about what I can do tomorrow. It is about positive thought, I think” (S015)

Keeping the individuals feeling positive may be another factor helping to promote them to continue to manage their own exercise in addition to the provision of extrinsic support or encouragement by others.

“(I think) other than encouragement from others, you own positive thinking would be quite important to motivate yourself to do the exercises” (S007)

Although not all participants directly said that they are being positive toward taking the management of their own exercise, most of them have expressed positive thoughts toward doing it for themselves during the interviews. Future research may need to investigate how to keep their positive attitude to motivate and maintain their exercise behaviour for their ongoing physical recovery in the longer term.

Theme H: Rationale for the preferred technology

In addition to the types of available ICTs and the considerations of using available ICTs to deliver remote support, this theme illustrates the rationale for stroke survivors to select a technology to support them to self-manage their own exercise.

Stroke survivors identified 4 possible reasons for them to decide a technology for supporting them to manage their own exercise: *personal preference, ease of understanding, tailored to the user condition, and allow easy communication and interaction*. The findings are shown in table 6.4.6h below.

Table 6.4.6h Rationale of the preferred technology

Theme	Subtheme	Quotation
Rationale of the preferred technology	Personal preference (n=12)	“No, I don't prefer to use telephone...I prefer to use computer to manage exercise programme. I also prefer to use email...it is my choice to put it on when I want it” (S015)
	Ease of understanding (n=14)	“if you don't understand it, you won't use it. So you need to understand it” (S005)
	Tailored to the user condition (n=9)	“It should be tailored to the individuals. You could email them the exercises if they are wanted to” (S008)
	Allow easy communication and interaction (n=9)	“Well, in touch with people through facebook®, through email” (S010)

Personal preference

Twelve stroke survivors indicated that it is important to understand the individuals' preference for using the technology for managing their own exercise. The technology should be acceptable to the individual. The following quotes illustrate their view about respecting individual's acceptance during the selection process.

“...because I need those face-to-face contact, when I say face-to-face, I accept that via videolinks, I can accept that” (S002)

“Just like how people can accept using a normal house phone with a land line. Include technologies that survivors have learnt earlier and have become part of their lifestyle in the development and not abandon that.” (S003)

“Stroke survivor: I use facebook. I am using that already. I prefer to use it like that.

*Carer: She feels comfortable to do it herself, so, she doesn't need me to do it for her”
(S005)*

These indicate that clinicians may need to recognise whether the individual survivor's have a preference for the use of a certain technology during prescription. It may be helpful to know whether the patient has positive feeling towards using the preferred technology before discussing how to use the selected technology to support the individuals to manage the exercise. If the patient does not prefer it, they may not use it.

Ease of understanding

Fourteen participants mentioned that it is important to think whether that technology is considered to be easy to understand to the individual survivor before it can be used to support the individual. The following quotes show the needs of selecting the technology that is easy for the individual to understand.

“...if it is kept simple, like as simple as an ipad or any pad, something square, which is linked to a network of electronic systems that is easy to manage.” (S003)

“Well, they (Email and exercise DVD) are the most understood to people, is easy to understand....For the computer, I don't know how the older people could understand them. I am not sure if the older people they understand them or have them or use them. Probably very few, I suspect. I am not sure if the older people they would prefer...You can't pick something they don't understand, is useless” (S008)

“I just easy to pick the telephone and if they don't answer the phone you can just text them. I know how to use them, that's easy ...I know there is something to do with the smartphone, but I don't know enough about that. Simple is important. It needs to be simple, if it is too complicated, people would just stop” (S017)

Hence, it is important to ensure the functions of the technology are understandable to the individual survivor. No matter how special or sophisticated that could be, it is likely that the individual may not use it if it is too complicated for the user to understand how to use it.

Tailored to the user condition

Nine participants who indicate that it is necessary to select the technology based on the individual conditions and abilities after stroke. The following quotes illustrate their views about choosing technology which can be tailored to each survivor.

“Although generally people can use computers, survivors might have been able to use computers pre stroke but they can’t anymore yet they would like to” (S003)

“Well, you need to treat people as individuals” (S011)

“To me, personal DVD/CD would be good. Because it personalizes for household with my own aim on it. It is important to make it more personalized” (S016)

The individual's personal conditions and living environment after stroke may contribute to the decision in the selection process. Clinicians may need to base on the survivor's personal variations when deciding the technology with the individual.

Allow easy communication and interaction

Nine participants expressed that the technology to be selected should allow easy communication and interaction while practising their own exercise. The following quotes illustrate stroke survivors' thoughts about choosing the technology that allows easy communication and interaction for supporting them to manage exercise.

“Technology I use now is a mobile phone, and ordinary phone, a computer when I can get to do it, and hopefully now a phone which allows direct communication with someone, which is sophisticated for me to speak into and don’t need me to write the message down” (S003)

“I think those kind of “care-netvigators” service using telehealth that will be excellent. I can emphasise for stroke survivors a kind of “staff telephone line” provided by a call centre. Like asking “are you ok? Have you eaten anything?...So, you get somebody care-netvigating pathway to what their needs that might be. You know a practical way, you are on your own, you are feeling weak, you don’t know what to do. Or you simply want to ask a question. That’s a 24-hrs line there, there is care-netvigating. That’s a telehealth technology action. I can see that’s for stroke survivors” (S004)

Some participants mentioned the alternative way to use interactive technology. Some stroke survivors prefer technology allowing them to have interaction with others or a software system to support them when they need.

“I prefer to use e-forum. Using e-forum for bouncing ideas on each other, that’s place where peer support comes in, I think. It is the place I can talk to somebody professionally. Or I can talk to somebody about my level, perhaps, some users about what I am doing” (S002)

“You have got to have somebody human there. You can’t be all on technology, you have to have some human contact. I think the interaction is what you need, so it should be interactive. People can interact with the computer and the video. And, like the wii, with the computer game. That’s interesting and interactive” (S013)

Therefore, therapists may need to identify the type of communicate and interaction that the individual survivor would like to have before selecting the suitable kind of interactive technology with the patient accordingly.

6.5 Findings of age sub-groups analyses

The findings of age sub-groups analyses of the subthemes of goal-setting of activity and participation, considerations of self-managing physical exercises, assistance to self-manage physical exercises, types of preferred available ICTs, and considerations of using available ICTs are reported below.

In the following result tables, the greater differences between age groups are highlighted in yellow, whilst similarities between age groups are highlighted in blue.

6.5a Sub-group analysis of age factor versus goal-setting of activity and participation

The findings between age and goal-setting of activity and participation are compared in table 6.5a²⁴.

Table 6.5a: Findings of sub-groups analysis between age and goal-setting of activity and participation

Goals in activity & participation level 1 subtheme	level 2 subtheme	Age		Total number of participants
		below 65 (out of total 10)	65 or above (out of total 8)	
Mobility	Maintaining a body position	5	4	9
	Changing basic body position	5	5	10
	Moving around in different locations indoor	5	6	11
	Hand and arm use	10	6	16
	Lifting and carrying objects	4	3	7
	Walking	7	7	14
	Stair climbing	2	1	3
	Using transportation	3	2	5
	Driving	5	1	6
	Self-care	Caring for body parts	4	3
Dressing		1	3	4
Eating / drinking		2	1	3
Washing / drying oneself		2	2	4
Toileting		1	2	3
Community, social & civic life	Recreation and Leisure	9	8	17
	Shopping	1	3	4
	Gardening	4	2	6
Domestic life	Doing housework	5	5	10
	Preparing meals	5	4	9
Learning and applying	Reading	2	1	3
	Writing	3	3	6

For goal-setting of activity and participation of stroke survivors at different ages, hand and arm use and driving were relatively more often concerned by stroke survivors aged below 65(N=10) and gardening(N=4), whilst there were relatively more aged 65 or above would concern the issues of dressing (N=3) and shopping (N=3). Equal amount of stroke survivors in both age groups mentioning the goals of

²⁴ Colour codes for the table:

Blue indicates the subthemes suggested by the same amount of participants from both age groups.

Yellow shows the subthemes suggested relatively more participants in one age group than the other after

physical recovery in walking (N=7), changing basic body position (N=5), doing housework (N=5), writing (N=3) and washing/drying oneself (N=2).

6.5b. Sub-group analysis of age factor versus considerations of self-managing physical exercises from stroke survivors

The findings of comparison between age and the considerations of self-managing physical exercises from stroke survivors were reported below.

Table 6.5b: Findings of sub-groups analysis between age and the considerations of self-managing physical exercises from stroke survivors

Considerations of self-managing physical exercises	Age		Total number of participants
	below 65 (out of total 10)	65 or above (out of total 8)	
Motivation	8	6	14
Self-confidence	3	6	9
External support & reassurance	10	8	18
Relevance to rehabilitation goals & needs & health conditions	4	2	6
Personalisation of the exercise programme	6	4	10
Simple & specific instruction	6	8	14
Application of self-monitoring & self-regulation	6	6	12
Teaching & Learning how to self-manage exercise	3	5	8
Knowledge of safety & risk	5	4	9
Technical skills	2	3	5
Access to relevant health & social care resources &	4	1	5
Enjoyable exercises	4	2	6
Suitable environment	4	3	7
Sustainable concept	3	5	8

The findings indicate the concerns of simple and specific instruction (N=8) and self-confidence (N=6) were common for stroke survivors aged 65 or above, however, it may not be the main concern for those aged below 65.

More stroke survivors aged below 65 mentioned access to relevant health and social care resources and networks (N=4) as important.

The same amount of stroke survivors from both groups considered the application of self-monitoring and self-regulation (N=6) as important for managing their own exercises.

6.5c. Sub-group analysis of age factor versus assistance to self-manage physical exercises

Table 6.5c: Findings of sub-groups analysis between age and assistance to self-manage physical exercises

Assistance to self-manage physical exercises	Age		Total number of participants
	below 65 (out of total 10)	65 or above (out of total 8)	
Professional contact & support & feedback	9	8	17
Peer support & feedback	10	8	18
Carer support & feedback	2	3	5
Financial issues & support	4	2	6
Self-management strategies & methods	10	8	18
Education & Learning skills for self-management	8	8	16

Both peer support and self-management strategies and methods were deemed as important help for self-managing physical exercises by all participants. Equal numbers of stroke survivors in both groups deemed education and learning skills for self-management is the important (N=8).

6.5d. Sub-group analysis of age factor versus types of preferred available ICTs

Table 6.5d: Findings of sub-groups analysis between age and the types of preferred available ICTs

Types of preferred available ICTs	Age		Total number of participants
	below 65 (out of total 10)	65 or above (out of total 8)	
Audio-visual technology	6	8	14
Computer	7	1	8
Internet technology	9	4	13
Telephone communication technology	9	6	15
Mixed multimedia technology	8	5	13

Table 6.5d indicates that there were relatively more stroke survivors aged below 65 would prefer to use available ICTs to manage their own exercises. There were relatively more stroke survivors below 65 who preferred using computers (N=7), telephone communication technology and internet technology (N=9) to manage their own exercises.

6.5e. Sub-group analysis of age factor versus considerations of using available ICTs

Table 6.5e: Findings of sub-groups analysis between age and considerations of using available ICTs to self-manage exercises

Considerations of using available ICTs to self-manage exercises	Age		Total number of participants
	below 65 (out of total 10)	65 or above (out of total 8)	
Accessibility	7	7	14
Availability	6	8	14
Perceived usefulness	7	8	15
Perceived ease of use of ICTs	7	8	15
Flexibility	4	5	9
Age of users	4	3	7
Sustainability & maintenance issues	2	5	7
Technical support	3	1	4
User centred design of ICTs for personal needs & conditions	5	8	13
Cost utility of using ICTs	2	2	4

All the interviewed stroke survivors aged 65 or above highlighted availability, perceived usefulness, perceived ease of use of ICTs and user centred design of ICTs for personal needs as essential considerations for them to use available ICTs to manage their physical exercises, although that was not the case for those aged below 65.

Equal numbers of stroke survivors from both groups considered accessibility (N=7) and cost utility (N=2) as important factors for them to use available ICTs.

6.6 Discussion

This study identified factors to inform the development of a new stroke exercise manual from a patient's perspective. The importance of involving stroke survivors and their carers for the planning and development of stroke services has been emphasised in clinical guidelines for stroke rehabilitation (ISWP, 2012, NICE, 2013). It is important to incorporate users' views at an early stage of the design and development process to meet their needs (Zheng et al., 2007). To facilitate stroke survivors to engage with the management of their own exercise, this study sought to identify core components for the development of a self-managed physical exercise program for stroke survivors with the support of available ICTs from their perspectives. Six key themes were identified from the interviews with 18 community-dwelling stroke survivors and 8 of their carers using the topic guides. The themes are discussed below which served to answer the research questions proposed in the chapter 3 of this dissertation.

Two additional themes emerged from the interviews in addition to answer to the topic guide questions which raised the issues about their attitudes toward managing their own exercise and the rationale underpinning their choices of technology to support to keep managing their own exercise. This helps to further examine their viewpoints about the management of their own exercise using available technology.

Theme A: Daily physical functional difficulties

This theme provides the information to answer the following research question:

“What are the major physical functional difficulties faced by stroke survivors after their discharge from the NHS community stroke rehabilitation services?”

The recovery in impairment and disability have been commonly investigated to study the effect of intervention on stroke rehabilitation for which the ICF framework and core set for stroke have been widely investigated and recommended to classify impairments, disabilities and problems in social functioning (WHO, 2002, Geyh et al., 2004, Lemberg et al., 2010, Langhorne et al., 2011). The ICF has regarded important for stroke rehabilitation (Tempest and McIntyre, 2006, Geyh et al., 2007).

The use of ICF framework to structure a programme to educate stroke survivors about their functional recovery was shown to be possible and acceptable (Neubert et al., 2011, Best et al., 2010). However, there is no study has adopted the ICF model to develop a self-managed exercise manual for functional stroke rehabilitation. Thus, I have used it to identify and classify functional specific elements in this study.

The information in this theme reflects physical rehabilitation needs of community-dwelling stroke survivors. This helped to determine the way to form a functional oriented exercise manual based on stroke survivors' desire for physical rehabilitation. Stroke survivors described a range of difficulties that they have encountered for their physical functioning. This study indicates that the control of voluntary motor movement, the control of reaction and balance, muscle strength, energy and physical tolerance and joint mobility were the functional difficulties of highest concern. The identified subthemes are in line with the physical disabilities and functional limitations identified by stroke rehabilitation experts in the ICF core set for stroke (Lemberg et al., 2010, Geyh et al., 2004).

Further research will be needed to investigate the reason why certain items were more frequently recognised to understand how different functional difficulties may influence the planning and delivery of physical stroke rehabilitation services.

Theme B: Daily physical functional goals

This theme provides the answers for the following research question:

“What are the common goals of physical functional recovery in the community from the stroke survivors' perspective?”

Setting functional goals was highlighted in the guideline for stroke rehabilitation as a key priority in the UK (NICE, 2013). Understanding goals of daily activities will help to determine the components required in a stroke self-management rehabilitation programme. It is clear that stroke survivors should be involved in setting goals for community rehabilitation.

This study suggests a list of functional oriented goals in relation to activity and participation from a stroke survivors' perspective. This provides a list of user-centred options to design the programme based on their needs and abilities.

There were relatively more items identified in the area of mobility. This implies that the improvement of mobility was deemed as a key goal of functional rehabilitation for daily activities by stroke survivors. This may be because the programme is physical functional oriented, thus, the participants provided more rich information related to the rehabilitation to mobility in this study. This indicates that mobility is regarded as an important aspect in view of setting goals in a self-managed exercise manual from patients' perspective. Therefore, it is crucial to pay attention to the details of setting goals to facilitate mobility rehabilitation in a self-managed exercise manual for physical functioning after stroke to deliver patient-centred services.

The goals of recreation and leisure, hand and arm use, walking, moving around in different locations indoor, changing basic body position and doing housework were also important concerns of the interviewees. These should be considered in a self-managed exercise manual for functional stroke rehabilitation to enable stroke survivors to set functional goals for their needs in activity and participation in the community.

Theme C: Considerations of self-managing physical exercises

This theme helps to answer the following research question:

“What do stroke survivors consider important in relation to the management of their own exercises in the community?”

Generalised stroke self-management programmes have been shown to be safe, feasible, and acceptable and effective for physical stroke rehabilitation (Huijbregts et al., 2008, Jones et al., 2009, Cadilhac et al., 2011, Jones and Riazi, 2011). Stroke survivors should be actively involved in the planning process for stroke service development, according to current guidance (ISWP, 2012). This study identified specific factors required to facilitate stroke survivors' engagement with a

personalised and self-managed exercise manual targeted at their individual physical needs for functional rehabilitation.

This research elicited 14 different considerations of self-managing physical exercises identified from stroke survivors including self-confidence, motivation, external support and reassurance, personalisation of the exercise manual, simple and specific instruction, and application of self-monitoring and self-regulation, relevance to rehabilitation goals and needs and health conditions, teaching and learning how to self-manage exercise, knowledge of safety and risk, technical skills, access to relevant health and social care resources and network, enjoyable exercises, suitable environment, and sustainability. These findings indicate that practical information and skills are required in the programme to address their concerns in self-managing their own exercises in the community.

Theme D: Assistance to self-manage physical exercises

This theme provides the information to answer the following research question:

“What do stroke survivors think can help them to manage their own exercise in the community?”

Although barriers for stroke survivors to participate in exercises have been reported (Rimmer et al., 2008), little was known about what stroke survivors think can help them to manage their own exercises. This study elicited 6 kinds of help including professional contact and support and feedback, peer support and feedback, carer support, financial issues and support, self-management strategies and methods, and education and learning skills for self-management from stroke survivors' perspective. These are the helps that they felt useful to assist them to manage their own exercises in addition to understanding their considerations to self-manage exercises in the previous theme. This provides further information to deliver the personalised information to assist stroke survivors to continuously engage in their functional rehabilitation. It appears that it is inadequate to provide information alone as each stroke survivor often needs to manage multiple issues for physical rehabilitation.

Recent evidence, national guidelines and the finding of this study suggest that the improvement of self-confidence of stroke survivors is the key for the self-management of stroke rehabilitation (Jones and Riazi, 2011, ISWP, 2012, NICE, 2013). Therefore, theoretical concepts and skills should be included in the programme to enhance their self-confidence to motivate them to self-manage their own exercises.

The findings also indicate that educational concepts and skills may be useful to enable stroke survivors to take control over the self-management of their own exercises and rehabilitation from their perspective.

Theme E: Preferred types of available ICTs for remote support

This theme helps to answer the following research question:

“What available information and communication technologies that stroke survivors would prefer to use to support them to manage their own exercises in the community?”

A range of available technologies were identified from stroke survivors' perspective in this study including audio-visual devices, computers, internet technologies and telecommunication technologies. The findings provide a list of available options for stroke survivors and clinicians to select during visits. Based on the UCD and technology acceptance model (TAM), stroke survivors' preferences and perceptions are important to facilitate them to use the selected technology.

Although the use of telephone device to deliver stroke rehabilitation service was suggested to be feasible and effective for the improvement of disability and physical function of stroke survivors (Chumbler et al., 2012), this study indicates a broader range of technologies may be useful to different stroke survivors to support them to manage their own exercises in addition to telecommunication technologies.

Theme F: Considerations of using available ICTs to deliver the remote support

This theme provides answers for the following research question:

“What do stroke survivors think about using available information and communication technologies to support them to manage their own exercise in the community?”

It is necessary to ensure the application of ICTs in a self-managed programme is based on stroke survivors' preferences to provide patient-centred services. In view of the dearth of knowledge on how stroke survivors think about selecting and using available ICTs to support them to self-manage their own exercises, this theme aimed at identifying their key considerations to understand what they consider important about using ICTs to support them to self-manage their own exercises. There were 10 considerations identified by stroke survivors in this theme including perceived ease of use, perceived usefulness, availability, accessibility, flexibility, age of users, sustainability and maintenance issues, technical support, user centred design for personal needs and conditions, and cost utility of using ICTs. These findings help to guide therapists and patients to decide suitable ICTs for self-management support. To ensure the programme could address different needs from different stroke survivors; all identified concerns will be adopted to develop it.

Preferred physical exercises

This theme provides the information for the following research question:

“What physical exercise would stroke survivors like to practise for their own functional recovery within the community?”

Although a variety of physical exercises and activities have been recommended for stroke rehabilitation (Best et al., 2010a, Grimby et al., 2010, Gordon et al., 2004), it remains important to identify the types of exercises that stroke survivors would like to practise for their physical functional recovery in the community. They may not continue to practise the exercises and activities prescribed to them by their therapists, if they do not like to do so; no matter how good the exercises have been reported in research evidence. A range of physical exercises was suggested by

stroke survivors in this study, which formed a list of exercise options to design the programme. This study has provided some insights in relation to the types of exercises that stroke survivors prefer to self-manage.

Stroke survivors reported 8 different types of physical exercises that they would like to practise including walking, mobilising, strengthening, stretching, coordination, balance, aerobic and combined physical activities in which there are relatively more participants indicated that walking, mobilising and strengthening exercises are those they would prefer to do in the community. These findings provide possible options to be included in a self-managed exercise manual for physical stroke rehabilitation. However, as each individual will respond differently after stroke (Jones, 2004), the programme will need to be flexible enough to enable the therapist and patient to discuss and determine appropriate types of exercises and prescription for the individual patient.

Additional themes

Two additional themes emerged from the interviews with stroke survivors in addition to those obtained by the topic guides: (1) *attitudes toward managing own exercise* and (2) *rationale for the preferred technology*. Three subthemes are about attitudes and 4 are reasons the participants select their preferred technology to self-manage exercise respectively. These findings suggest additional insights to further understand stroke survivors' needs and how to think about managing their own exercise to design a tailor-made manual with the support of available technology.

With the growing of studies about the effects of stroke exercise and the application of technology for stroke rehabilitation, little is known about stroke survivors' attitudes toward managing their own exercise and their underpinning reasons for selecting the desirable technology to support them to manage their own exercise. Prior to this study, there was very limited understanding of the stroke survivor's perspective on using technology to help them to manage their own independent exercise; according to the evidence, manuals and guidelines related to stroke exercise discussed in chapter 2. Since this research sought to develop a new exercise manual to be

managed by stroke survivors, it is important to understand their thoughts and rationale to shape the manual to address their needs.

Theme G: Attitudes toward managing own exercise

The findings suggest that stroke survivors with physical disabilities may have different attitudes toward managing their own exercise: *independent, determined and positive*. Understanding stroke survivors' attitudes may provide insights to determine how to facilitate their positive behaviour in engaging with the management of their own exercise from the patient's perspective.

Patients' attitudes may influence their participation in exercise and physical activity (Ene et al., 2011 and Buttery and Martin, 2009). Studies suggest that stroke survivors' attitudes and beliefs are important for their recovery and response to rehabilitation (Young and Forster, 2007). Thus, the findings of this theme offer insights into how to encourage individual survivors via understanding their attitudes.

Theme H: Rationale of the preferred technology

Multiple types of preferred technologies were reported by stroke survivors in theme E. Reasons which may underpin their preference and decision on the selection of technology to manage their own exercise are explored in this theme. They expressed 4 possible reasons: *personal preference, ease of understanding, tailored to the user condition, and allow easy communication and interaction*. This may assist clinicians to determine the suitable technology together with the individual survivors with more understanding about how stroke survivors think.

The potential of using technology for supporting stroke survivors' exercise and activity has been suggested in the guideline for stroke exercise (Billinger et al., 2014). Whilst Chen and colleagues reported factors influencing therapists' decision in the acceptance of new technology for stroke rehabilitation (Chen and Bode, 2011), little is known about factors influencing stroke survivors' decision to choose and use technology to support them to continue to manage their own exercise for their own rehabilitation from their perspective in current studies. Although stroke survivors' view about using tablet technology during recovery have been recently discussed in

a study (White et al., 2015), there is a lack of robust research reporting the reasons of the decision on what technology to choose to manage exercise for functional stroke recovery from a stroke survivor's perspective. Understanding the possible considerations that underpin the patient's choice of technology may facilitate the decision-making process between the individual survivor and clinician in practice. This study suggests factors that may affect stroke survivors to determine suitable technology for supporting them to manage their own exercise from their perspective to address their physical rehabilitation needs.

After all, information from these additional themes may support clinicians to work out possible solutions with stroke survivors to optimise their adherence to their own exercise for self-managed rehabilitation and promote their engagement in service delivery process. Communication and the development of working partnership between patients and healthcare professionals have been suggested to be important for self-managed interventions (Jones, 2011, Bodenheimer et al., 2005, Lorig and Holman, 2003, Barlow et al., 2002b). Hence, exploring stroke survivors' attitudes and rationale may help clinicians to better communicate and collaborate with them and to understand how they think that may work for them and what might best encourage them to continue to manage their own exercise. Listening to patients and identifying their individual needs have been suggested to be the first step to provide appropriate and relevant information (Abela, 2009). This may help to develop a tailor-made and understandable material to enable them to take an active role in the intervention.

Age sub-groups analyses

The use of age sub-group analyses facilitated comparative analysis of data obtained from the stroke survivors in different age groups. This may help to better understand the perception about the self-management of exercises using available technologies from stroke survivors from different age groups to ensure the programme consists of components required and suitable for stroke survivors across different ages.

All stroke survivors aged below 65 (N=9) concerned the goal of functional recovery of hand and arm use, whilst all aged 65 or above (N=8) concerned the goal of recovery for recreation and leisure. Thus, age needs to be considered in the delivery

of the programme. For instance, people of different ages may have different acceptance, adoption and usage of technology (Burton-Jones and Hubona, 2005, Porter and Donthu, 2006). There are relatively more stroke survivors aged below 65 preferred to use available ICTs to manage their own exercises.

However, overinterpretation of subgroup differences should be avoided (Wang et al., 2007, Assmann et al., 2000). All stroke services should respond to the particular needs of an individual stroke survivor regardless of age factor according to current guideline (ISWP, 2012). The influence of age to the self-management of stroke exercises using available technologies will need to be further investigated to promote the generalizability of the programme to the whole stroke population.

Change of needs and preferences over time?

Although stroke survivors' needs and preferences were identified in this study, people's needs and preferences are likely to change over time. With the change of health services, and system and policy for stroke community rehabilitation, their unmet needs may be satisfied or increased. Stroke survivors may have different needs and preferences at different age and time, with the change of rehabilitation services, and the advancement of new technologies. The regular review of stroke survivors' and their carers' needs for health and social care is recommended in national guidelines (NICE, 2013, DH, 2007b). This reflects the importance of reviewing their needs for self-managing exercises for physical rehabilitation over time. The identified needs and preferences in this study could only illustrate their needs and preferences at the moment.

6.7 Implications

The view of individual stroke survivors is the main concern and opportunity for self-management after stroke (Jones et al., 2013b). There has been a very limited amount of research in stroke that has explored the issue of helping stroke survivors to self-manage their own physical exercises for their functional physical rehabilitation with the use of available ICTs in the community. Therefore, this study has contributed new information from a stroke survivors' perspective in relation to engaging them to self-manage their own exercises and use available technologies to

do so. The findings imply the determinants needed to form a self-managed exercise manual supported with the use of ICTs from a user's perspective.

The participants indicated a list of difficulties that they have encountered in their physical functional recovery in this study. In addition, stroke survivors suggested goals important to them regardless of their age; include recreation and leisure, hand and arm use and walking, moving around in different locations indoor, changing basic body position and doing housework.

With regards to the help that stroke survivors think they may need to enable them to self-manage their own exercises, a list of considerations and possible help was required for them to self-manage their own exercises. However, further research is needed to understand the detailed content of the help required within a self-managed exercise manual. For instance, the provision of *external support & feedback to enhance self-confidence* was reported as an important requirement to all participants, it will be useful to identify the contents of the encouragement and support that should be provided.

This study also indicates that improving education and learning skills was regarded as important to enable stroke survivors to self-manage. However, there is no known education theory and learning skills not reported in the current studies of stroke specific self-management programmes (Jones and Riazi, 2011, Lennon et al., 2013) (see figure 2.3.9 in chapter 2).

This study informs preferred choices and considerations in using ICTs to deliver self-management support to stroke survivors. The findings of this study provide new insights for selecting and using ICTs to address the needs of stroke survivors to self-manage exercises.

More studies to investigate the features, relationships and the influence of the identified attitudes to stroke survivors' participation in managing their own exercise in the longer term are warranted. The perceptions and needs of individuals may differ at different time after stroke. Perceptions may also vary between individuals, which may influence their attitudes and decision on technology in different ways. Thus, studies will need to investigate the impact of the individual's attitudes and rationale

on the outcomes of stroke rehabilitation to understand how their perceptions and beliefs may affect the continued management of their own rehabilitation exercise with the use of technology for their ongoing recovery.

The additional themes provide insights to assist clinicians to deploy their interpersonal skills to communicate and collaborate with stroke survivors to decide personalised contents when prescribing an exercise manual to address individual's needs. Understanding stroke survivors' attitudes and rationale may enable researchers and clinicians to see how the individual survivors think. This may help to identify the preferable methods to enable them to actively participate in the intervention instead of asking them to follow general information alone. Thus, the findings of these two themes suggest insights for clinicians to establish a smooth rapport with individual stroke survivors. In addition to better personalise an exercise intervention for each patient, this may promote the sense of ownership and control over the prescription of the individuals when deciding the contents using their views.

However, questions remain about how to formulate a practical manual beyond the insights from patients' perceptions alone. Clinicians' opinions are also required to develop a practical manual for clinical use. The details are provided in the next chapter. Research is still needed to determine what strategies and concepts may help to develop an alternative way to enable stroke survivors to manage their own exercise with the support of using available ICTs for the prescription and maintenance of the exercise. This is detailed in chapter 8a.

6.8 Limitations

The findings of this study are preliminary which may not be generalised to the whole stroke population. This is partly due to the limited numbers of participants and the fact that they were all recruited from one area of the United Kingdom.

The interviewed stroke survivors were relatively physically active, since 17 out of 18 of them continued to practise physical exercises since their discharge from specialist stroke services. The collected information may, therefore, be biased with the views of physically active stroke survivors. This may be improved by including more

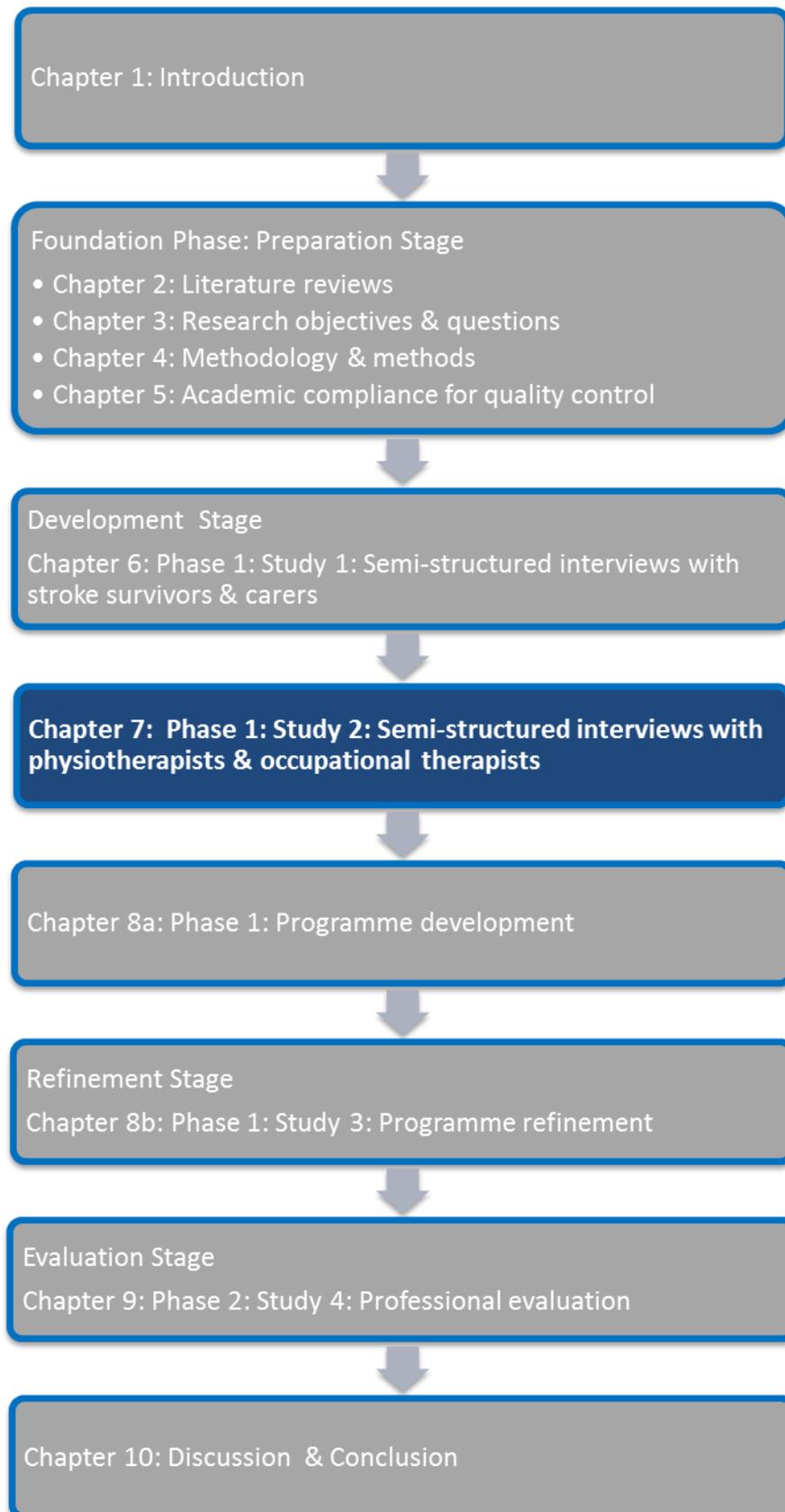
inactive stroke survivors to explore their experiences and needs at different activity and fitness levels in future studies.

A diverse range of personal characteristics may need to be considered in future research of assessing stroke survivors' needs and preference for self-management practice, such as social class, socioeconomic status, education level, cultural background and religion; in order to better understand the potential influence from different demographic factors to help tailoring self-management services for individual user. This may help to generate different components to develop a programme for individuals with different activity levels.

In this study, only 1 stroke survivor had experience of using available ICTs for their physical stroke rehabilitation. Thus, the information about the issues of selecting and using available ICTs may be limited by the understanding, perception and ability of the participants with relatively less experience in using available ICTs to receive health services for physical stroke rehabilitation. Further studies may be improved by recruiting more stroke survivors with experience in using available ICTs to receive physical stroke rehabilitation. This may help to gain more rich information from stroke survivors across the spectrum, perception and ability of using available ICTs for physical stroke rehabilitation.

6.9 Summary

This study helped to extract a range of components to inform the development of a new stroke exercise manual to promote self-managed rehabilitation from a stroke survivor perspective. It suggests multiple factors need to be addressed to enable stroke survivors to manage their own exercise with the support of preferred technology from their views for their ongoing functional recovery needs. This provides components to design a new intervention. This study also provides insights about stroke survivor's attitudes in managing their own exercise and their rationales for choosing suitable supporting technology to do so. This contributes additional factors to develop a personalised manual using stroke survivors' viewpoints.



Phase 1 ----Study 2

Chapter 7: Semi-structured interviews with physiotherapists and occupational therapists

Chapter summary

This chapter details the study design, method, procedures, analysis and findings from the semi-structured interviews with physiotherapists (PTs) and occupational therapists (OTs). The findings were further analysed and used to develop a remotely supported self-managed physical exercise manual together with the findings in the previous chapter.

7.1 Introduction

In view of health needs assessment, the findings of the interviews with stroke survivors and carers could only reflect the felt and expressed needs²⁵ of individual stroke survivors (Robinson and Elkan, 2000). It is equally important to explore the normative need²⁶ and opinions from clinicians' perspective to develop a clinical programme.

Although a self-care strategy and self-management skills were emphasised in guidelines for stroke rehabilitation (NICE, 2013, ISWP, 2012, SIGN, 2010), little is known about therapists' consideration in prescribing self-managed stroke exercise manuals supported with ICTs.

Whilst stroke exercises have been included in some existing stroke self-management programmes and technology system for the recovery of motor function (Lennon et al., 2013, McKenna et al., 2013, Mawson et al., 2013, Huijbregts et al.,

²⁵ Felt need: It is equated with want. People are asked whether feel they need a service when assessing their need for it. It embodies the values of individuals (Robinson and Elkan, 2000)

Expressed need: It is felt need turned into action. It is commonly used by health service planners. (Robinson and Elkan, 2000)

²⁶ Normative need: It is what the expert or professional or administrator defines as need in particular situations. It reflects the value judgements of professionals and experts. (Robinson and Elkan, 2000)

2010, Jones, 2008, Zheng et al., 2007), little was known about therapists' consideration in helping their clients to self-manage their own exercises in the community. Little was known about what clinicians consider important for patients to select and use available ICTs to self-manage exercise.

The assessment of impairment of body functions, activity and participation restrictions have been highlighted for planning and delivering rehabilitation in guidelines for stroke rehabilitation (NICE, 2013). However, the items that should be included in a personalised and self-managed exercise for functional stroke rehabilitation has yet been unspecified.

Goal-setting was reported a common component for stroke self-management interventions in related literature (see table 2.3.5 in chapter 2). Whilst goals for stroke rehabilitation are recommended to focus on activity and participation and be achievable (NICE, 2013, ISWP, 2012), it remains unclear which items that clinicians can use to set such goals with their patients to prescribe a self-managed exercise manual for functional stroke rehabilitation. Additionally, little is known what exercises that therapists consider useful and safe to be included in a self-managed exercise manual for their clients to attain their functional goals for rehabilitation.

In addition to the user's perspective in chapter 6, it is equally important to consider clinicians' view to develop a clinical programme. Thus, this research aims to develop a programme that is intended to be used in clinical practice. The information from related professionals may also help to understand the normative needs about self-management of exercise supported with the use of available technologies for functional stroke rehabilitation.

Physiotherapy and occupational therapy are important for physical functional stroke rehabilitation (Black and Gruen, 2005, Bonetti and Johnston, 2008). While a degree of overlap may exist between PT and OT for the provision of stroke rehabilitation services, they are still distinct professions (van Velden et al., 2005). Thus, the perceptions of both professionals are needed for stroke rehabilitation to obtain relatively comprehensive information to design a programme to be delivered by both professions.

Aim

The purpose of this study was to explore the professional perspective to identify the components required to formulate a self-managed exercise manual.

Objectives

The followings were the objectives of this study:

- Explore the common factors which limit stroke survivors' daily physical functions
- Identify daily physical functional goals that professionals deem important for physical functional recovery of stroke survivors
- Identify safe and clinically useful physical exercises for stroke survivors to self-manage
- Explore professional considerations to enable stroke survivors to self-manage their own physical exercises
- Identify what assistance therapists consider useful to facilitate stroke survivors to self-manage their own exercises
- Explore professional considerations about using available information and communication technologies (ICTs) to support stroke survivors to self-manage their own exercises

7.2 Methods

Semi-structured interviews were conducted with PTs and OTs in this study. The interviews were transcribed and managed with Nvivo9 software, then analysed with the qualitative content analysis approach described in chapter 6.

7.2.1 Study design

7.2.1.1 Design of topic guide for interviews with therapists

The interview questions aimed to identify requirements to develop the programme from the therapists' perspective. The interview questions were grouped to ensure the sequence and content of the questions facilitated the natural flow of the interview.

Relevant prompts and probes were prepared as supplementary questions to facilitate the participants to generate in-depth information for a better understanding of their viewpoint (Gillham, 2005, Bryman, 2012, Silverman, 2010).

Interview questions & rationales

The following interviews questions were designed according to the objectives of this study. The questions and corresponding rationale are detailed in table 7.2.1.1 below.

Table 7.2.1.1: Question and rationale for interviews with therapists

	Main interview question	Rationale
1	“What are the common goals of functional stroke rehabilitation for daily physical activities?”	To identify the kinds of targets in terms of functional recovery to perform day-to-day physical activities that therapists considered common to most stroke survivors
2	“What do you perceive are the most common daily functional difficulties of stroke survivors?”	To identify types of day-to-day functional difficulties that therapists deemed most common to stroke survivors
3	“What types of physical exercises do you think are safe and clinically useful for the daily functional activities of stroke survivors?”	To identify types of physical exercises that therapists considered safe and clinically useful for stroke survivors to practise for their day-to-day physical functions
4	“What advice would you give to help stroke survivors to safely and effectively manage these physical exercises for their functional physical recovery?”	To identify the potential considerations that therapists may have for stroke survivors to safely and effectively manage their own physical exercises
5	“What do you think your role as a therapist should be in initiating and supporting stroke survivors to self-manage the exercises in the longer term?”	To understand the kinds of professional assistance that therapists considered safe and effective to help stroke survivors to manage the identified physical exercises for the purpose of their physical functional recovery in the long-term
6	“What do you think about using technologies that people have in their homes to remotely support stroke survivors to manage their physical exercises after discharge?”	To understand the kinds of considerations that therapists deemed important for stroke survivors to use available information and communication technologies to manage their own physical exercises after discharge

7.2.1.2 Validation of topic guide

To ensure the rigour of the qualitative data collection in this research, validation and verification of the topic guide were conducted before the main interviews. It was conducted with the same procedures described in chapter 6.

Stage 1: Validation

Interview questions and wordings were checked by a specific panel that included 8 members. It included 1 physiotherapist and 1 occupational therapist who were working in the NHS in Sheffield, 2 stroke researchers experienced in conducting stroke research in the community, who are also experienced healthcare professionals in providing physical stroke rehabilitation by background (1 physiotherapist and 1 occupational therapist). Two supervisors experienced in providing stroke rehabilitation and conducting stroke research in the community, and 2 lay native English speakers (1 below and 1 above 65 years old) were consulted to ensure the contents and questions were appropriate and clear for native English speakers in different age groups. Each member was given 2 to 4 weeks to read and make comments, before they sent their feedback to the researcher for amendment.

Stage 2: Verification: pilot interview

A preliminary interview was carried out with a stroke specialist occupational therapist experienced in providing physical functional rehabilitation for stroke survivors in the community. The therapist has worked clinically to provide stroke services in Sheffield for 10 years. The topic guide was verified with this pilot interview.

7.2.1.3 Participants

Eligibility

PTs and OTs were purposively selected with the following selection criteria.

Selection criteria

- Physiotherapist (PT) or
- Occupational therapist (OT)
- Experienced in providing healthcare services to stroke survivors for their physical recovery of daily functional activities within the UK
- Providing day-to-day healthcare to stroke survivors for at least last 12 months

Recruitment procedure

I contacted the managers of stroke rehabilitation department of Sheffield Teaching Hospitals and community settings to explain the aim, characteristics and procedures of this study to recruit professionals. I invited the managers to identify eligible PTs and OTs to participate based on the selection criteria. I distributed the information sheets, leaflets and cover letters to the potential participants via the managers and a PT in the community team by email.

It took 3 months to recruit adequate numbers of participants. This was due to limited number of such specific type of therapists in the local area at that time and the difficulty of having time within their busy work schedules.

7.2.1.4 Procedures of data collection

Interview procedure

I first explained the process to each therapist at the beginning of each interview. Then, I answered any questions they had about the study and the interview process. I ensured they understood the information about this study and the interview process, before making sure they were willing to participate. Then, each participant and I signed a consent form.

After using the demographic sheets to collect basic information from the participant, I used the topic guide to carry out the interview. Probe questions were used to facilitate the participants to elaborate their own experience and opinions.

Each interview lasted for 1 to 2 hours. The audio recording from the interview were transcribed and analysed below.

Ethics approval & R&D governance

Research ethics approval was granted for this study (Reference number: 0524/CAO). This research had been registered in the NHS at Sheffield Teaching Hospital (STH) trust (Registration number: STH16588). NHS governance permission was also granted by the research and development (R&D) of STH. Copies of the approval letters are attached in appendix 1 and 2.

7.3 Data analysis

The procedure for data analysis of professional interviews was in the same as in chapter 6.

Coding framework

The coding framework illustrated in figure 7.3 was established to organise, analyse and differentiate data from the interviews with therapists, as described in chapter 6.

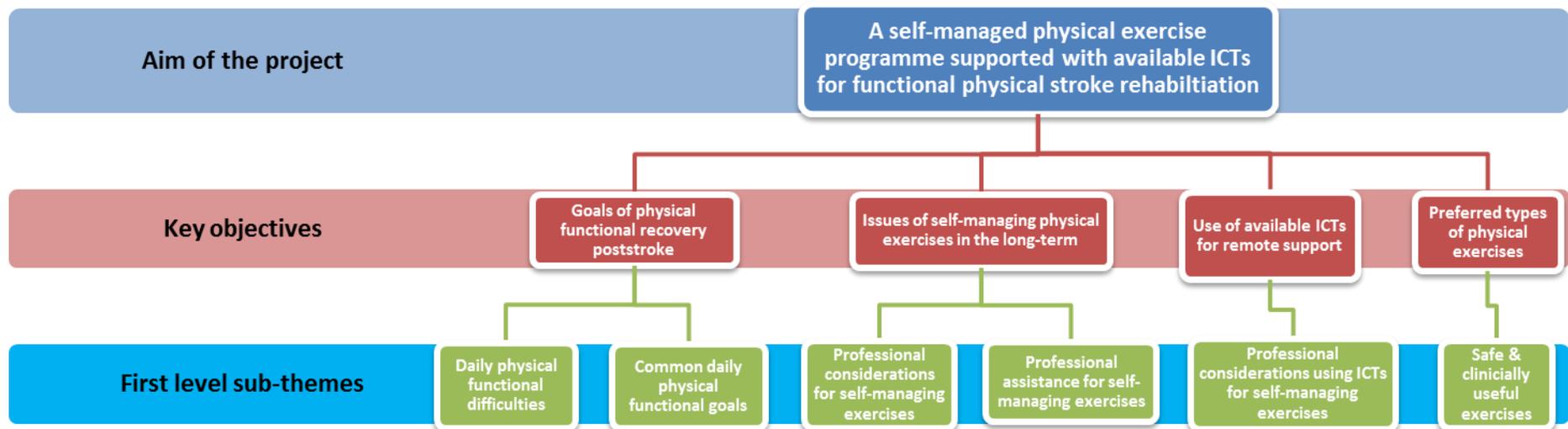


Figure 7.3 Hierarchical coding framework showing the categories of the interviews data collected from physiotherapists & occupational therapists

Themes

The following main 6 themes were identified from the data together with the topic guide.

1. Daily physical functional difficulties
2. Common daily physical functional goals
3. Professional considerations for self-managing exercises
4. Professional assistance for self-managing exercises
5. Professional considerations of using ICTs for self-managing exercises
6. Safe and clinically useful physical exercises

Themes were defined for data analysis using the same process as described in chapter 6. The identified themes and their definitions are shown in table 7.3.1 below.

Table 7.3.1: Themes and definition of each theme for interviews with therapists

Theme	Name	Definition
1	Daily physical functional difficulties	The difficulties identified by physiotherapists and occupational therapists that they considered stroke survivors often have due to their physical health conditions poststroke, which restricts their ability to perform a normal purposeful day-to-day physical activity to participate in a given environment
2	Common daily physical functional goals	The explicit targets that physiotherapists and occupational therapists considered common for stroke survivors to achieve for their normal purposeful day-to-day physical activity in a given environment
3	Professional considerations to self-manage exercises	The factors that physiotherapists and occupational therapists deemed important within a physical exercise programme managed by individual stroke survivor after discharge
4	Professional assistance to self-manage exercises	The action that physiotherapists and occupational therapists through could assist individual stroke survivor to enable him/her to manage his/her physical exercise by himself/herself
5	Professional considerations of using ICTs to self-manage exercises	The careful thought of physiotherapists and occupational therapists in response to the use of existing and reachable information and communication technologies (ICTs) to provide support to stroke survivor over a geographical distance
6	Safe and clinically useful physical exercises	The physical exercises that physiotherapists and occupational therapists considered safe and useful for stroke survivors to practise for the purpose of physical functional recovery after discharge

Sub-themes

Sub-themes were further extracted under the identified themes. They provided further descriptions and details of the corresponding themes. This assisted the process of identifying the determinants required to develop the programme from a professional perspective.

Frequencies of themes and subthemes

Absolute frequencies of the numbers of participants supporting each theme and subtheme were presented to show their relative importance.

7.4 Results

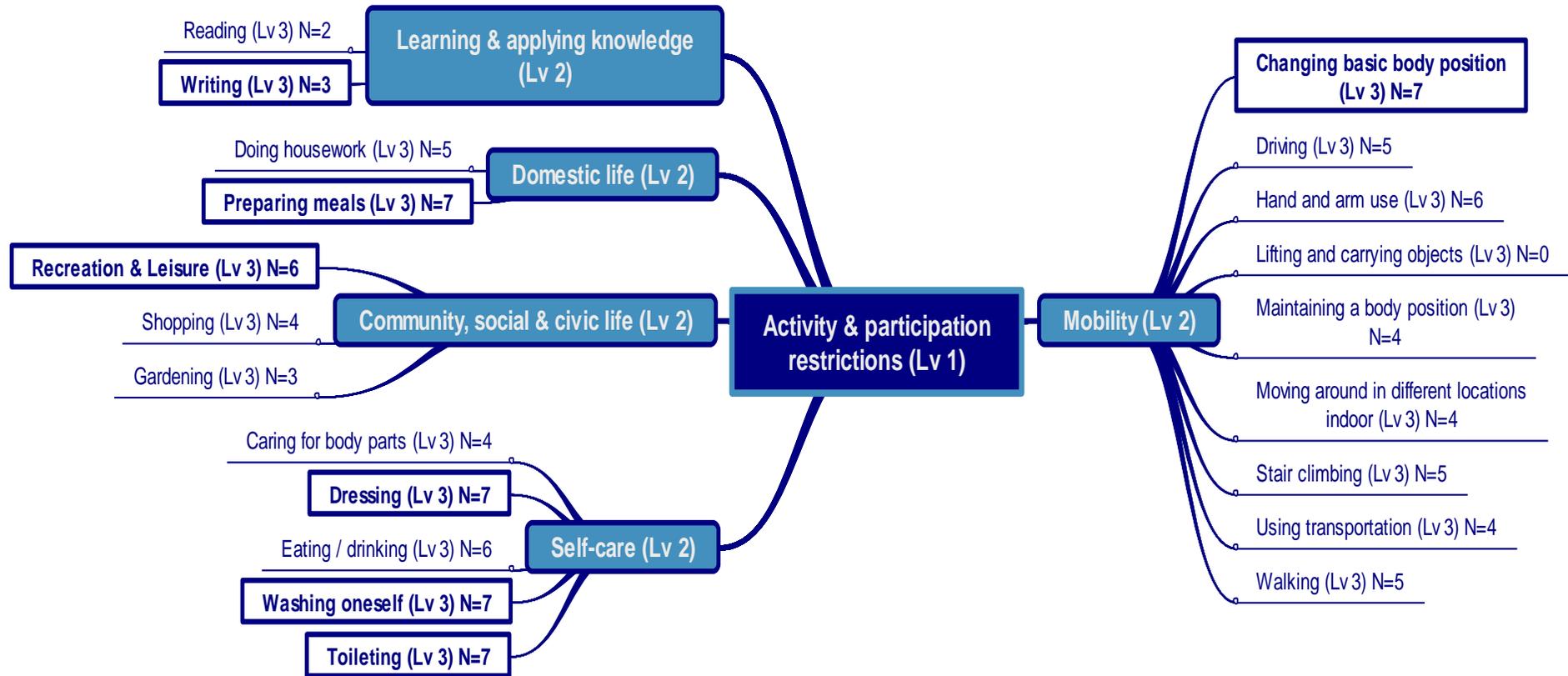
A total of 7 therapists were interviewed for this study including 3 physiotherapists (PTs) and 4 occupational therapists (OTs). The average years of clinical practice in stroke rehabilitation was 8.07. The characteristics of the participants are shown in table 7.4.1 below.

Table 7.4.1: Participant characteristics

The characteristics of the participants are presented in table 7.4.1 below.

Participant code	PT/OT	Agenda for Change (AFC) Band	Years working in stroke rehabilitation	Experience of using self-management programmes for stroke rehabilitation (Yes /No)	Experience of using information & communication technology to deliver stroke rehabilitation (Yes /No)
P001	PT	6	2.5	No	No
P002	OT	7	13	No	Yes
P003	PT	6	5	Yes	Yes
P004	OT	6	4	No	No
P005	OT	8	12	No	No
P006	OT	8	12	No	Yes
P007	PT	6	8	No	Yes
Total	PT: 3, OT: 4	Not applicable	Average (mean): 8 (years)	Yes: 1, No: 6	Yes: 4, No: 3

Theme 1: Daily physical functional difficulties in study 2



Abbreviations: Lv= Subtheme Level, N= Numbers of participants

Figure 7.4.2a: Connective conceptual model of theme 1 daily physical functional difficulties in study 2

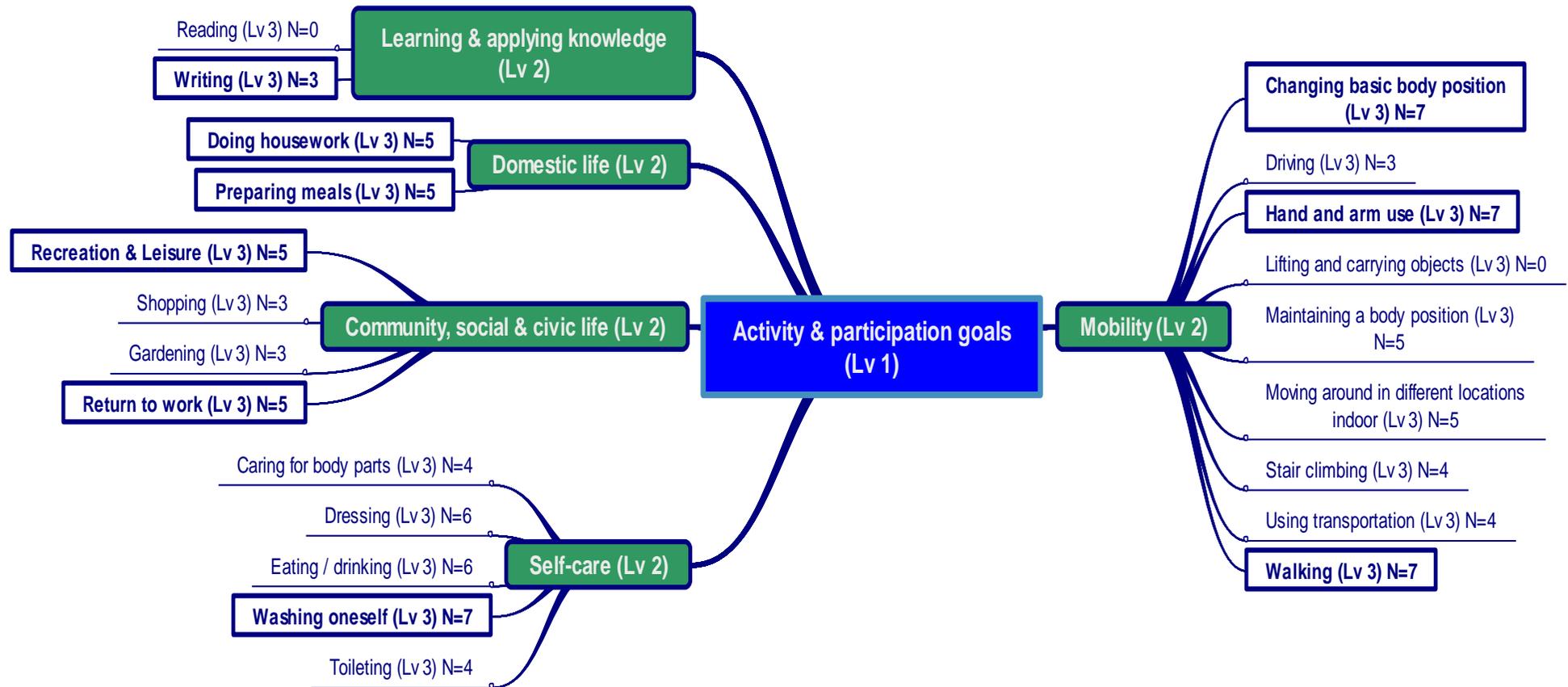
Common daily physical functional difficulties

Activity and participation restrictions were identified in response to the difficulties in physical functioning poststroke by therapists. Five main themes were identified and illustrated in figure 7.4.2a above. Mobility, self-care, community, social and civic life, domestic life, and learning and applying knowledge were the subthemes which emerged from therapists about the activity and participation restrictions. The following table 7.4.2 shows the identified subthemes with illustrative quotations.

Table 7.4.2: Identified common daily physical functional difficulties and quotations

Subtheme (level 2)	Subtheme (level 3)	Quotation
Mobility	Changing of basic body positions (N=7)	“all the transfers getting in and out of bed, on and off a chair” (P005)
Self-care	Dressing (N=7)	“Personal care would be undressing, dressing” (P004)
	Washing (N=7)	“the personal care aspects of life, getting themselves washed” (P002)
	Toileting (N=7)	“Even something like using the toilet” (P005)
Community, social and civic life	Recreation and leisure (N=6)	” they have talked so much about returning to their leisure activities’ (P004)
Domestic life	Preparing meals (N=7)	“To be able to make meals if that’s something they did before the stroke” (P006)
Learning & applying knowledge	Writing (N=3)	“If it’s a dominant hand that has been affected, dominant limb, then they’re not able to write” (P001)

Theme 2: Common daily physical functional goals in study 2



Abbreviations: Lv= Subtheme Level, N= Numbers of participants

Figure 7.4.2b: Connective conceptual model of theme 2 common daily physical functional goals in study 2

Common daily physical functional goals

The common goals of daily physical functioning were identified from professionals. The results are shown in the figure 7.4.2b above. The items of the identified goals are about the same as that of the identified difficulties except the item of “return to work” was mentioned by the therapists as a goal which was categorised into the subtheme of “community, social and civic life” as described in the above diagram. The following table 7.4.3 shows the identified subthemes with illustrative quotations.

Table 7.4.3: Identified common daily physical functional goals and quotations

Subtheme (level 2)	Subtheme (level 3)	Quotation
Mobility	Changing basic body position (N=7)	“Generally speaking after that it’s probably the transfers” (P002)
	Hand and arm use (N=7)	“Hand and arm function” (P003)
	Walking (N=7)	“Be able to walk again” (P001)
Self-care	Washing oneself (N=7)	“Be able to wash independently” (P001)
Community, social and civic life	Recreation and leisure (N=5)	“Pursuing leisure that might actually be more of a common goal amongst them” (P002)
	Return to work (N=5)	“Returning to work, I wouldn't put that in leisure, that’s their occupation isn't it, someone’s job” (P004)
Domestic life	Doing housework (N=5)	“Household tasks, cleaning, laundry” (P007)
	Preparing meals (N=5)	“Being able to cook a meal independently” (P004)
Learning and applying knowledge	Writing (N=3)	“Be able to write” (P005)

Theme 3: Professional considerations for self-managing exercises

Table 7.4.4: Professional considerations for self-managing exercises

Theme	Subtheme	
	Level 1	Numbers of participants
Professional considerations for a self-managed exercise programme	Availability of professional support	7
	External support & reassurance	7
	Motivation	7
	Personalisation of the exercise programme	7
	Relevance to rehabilitation goals & needs & health conditions	7
	Simple & specific instruction	7
	Teaching & Learning how to self-manage exercise	7
	Application of self-monitoring & self-	6
	Physical conditions poststroke	5
	Enjoyable exercises	3
	Self-confidence	3

Professional considerations for self-managing exercises

There were 11 considerations suggested by therapists for stroke survivors to self-manage their own exercises, which are shown in the table 7.4.4.

Motivation, prescribing exercises relevant to goals and needs of daily activities, personalisation of the exercise manual, external support and reassurance, simple and specific instruction, availability of professional support, and teaching and learning how to self-manage exercise were suggested by all clinicians as the considerations for stroke survivors to manage their own exercises.

The quotations related to the above subthemes are shown in table 7.4.4.1 below.

Table 7.4.4.1: Most frequently reported considerations to self-manage exercises and quotations

Sub-theme	Quotation
Motivation (N=7)	“They’ve got to be able to initiate that off their own back for it to be successful, so motivation’s important” (P004)
Prescribing exercises relevant to goals and needs of daily activities (N=7)	“We need to instruct the patients to do those exercises and to achieve their goals by doing those physical exercises or daily activities” (P005)
Personalisation of the exercise programme (N=7)	“Advice can vary quite a lot according to the level of the patient” (P001)
External support and reassurance (N=7)	“They need external feedback, not just from themselves but from some other people so that they know if they are doing it right” (P007)
Simple and specific instruction (N=7)	“Instructions are very, very concise usually, yeah, simple for the layman, yeah we don’t use difficult words” (P001)
Availability of professional support (N=7)	“That is part of the National Stroke Strategy that patients should be able to re-access stroke services” (P003)
Teaching and learning how to self-manage exercise (N=7)	“Giving them lots of teaching before they’re going in to self-management I suppose” (P007)

Theme 4: Professional assistance for self-managing exercises

Table 7.4.5: Professional assistance for self-managing exercises

Theme	Subtheme	Numbers of participants
	Level 1	
Professional assistance for self-managing exercises	Access to relevant resources	7
	Education of knowledge & learning skills to self-manage	7
	External support & feedback to enhance self-confidence	7
	Monitoring, regulation & progress evaluation	7
	Professional instruction & advice	7
	Facilitation for self-motivation	6
	Goal setting	6
	Systematic action planning	6
	Information provision	6
	Safety education	4

Professional assistance for self-managing exercises

Ten different kinds of help were identified to support stroke survivors to manage their own exercises in table 7.4.5. Access to relevant supporting resources, education of knowledge & learning skills to self-manage, external support & feedback to enhance self-confidence, provision of professional instruction and advice, and monitoring, regulation and progress evaluation were proposed by all therapists as important and useful assistance.

The quotations illustrating the above subthemes are shown in table 7.4.5.1 below.

Table 7.4.5.1: Most frequently reported assistance for self-managing exercises and quotations

Sub-theme	Quotation
Access to relevant supporting resources (N=7)	“Would be quite good if they can have access to the healthcare professionals specific to their condition and know their conditions” (P003)
Education of knowledge & learning skills to self-manage (N=7)	“Teaching them with a self-management approach and strategy” (P004)
External support & feedback to enhance self-confidence (N=7)	“Some people like the support and the feedback from carers and family members or people that are important in their lives” (P005)
Provision of professional instruction and advice (N=7)	“Useful to any stroke patient I’m sure if you gave them a number for a professional where they could get support and advice” (P004)
Monitoring, regulation and progress evaluation (N=7)	“In order to do some self-management stuff, they might need like a diary to record their progress in or something like that” (P005)

Theme 5: Professional considerations of using ICTs to self-manage exercises

Table 7.4.6: Professional considerations of using ICTs to self-manage exercises

Theme	Subtheme	
	Level 1	Numbers of participants
Professional considerations of using ICTs to self-manage exercises	Accessibility	7
	Availability	7
	User centred design for personal needs & conditions	7
	Motivation to use ICTs	7
	Perceived ease of use	6
	Perceived usefulness	6
	Age of users	6
	Sustainability & maintenance issues	6
	Technical support	6
	Flexibility	5
	Cost utility of using ICTs	4
	Safety & confidentiality of using ICTs	3
	Confidence in using ICTs	3

Professional considerations of using ICTs to self-manage exercises

Fourteen different considerations for using information and communication technologies (ICTs) to self-manage exercises were identified by therapists as shown in table 7.4.6. Accessibility, availability, motivation of using ICTs, and user centred design for personal needs and conditions were suggested as important for stroke survivors to use ICTs for their own exercises by all interviewed therapists.

Quotes illustrating the above issues are shown in table 7.4.6.1 below.

Table 7.4.6.1: Most frequently reported considerations of using ICTs to self-manage exercises and quotations

Sub-theme	Quotation
Accessibility (N=7)	“I think that probably the telephone and the mobile phone’s probably the most accessible ones for our client group” (P004)
Availability (N=7)	“I think if that was more available that would become more and more useful” (P007)
Motivation to use ICTs (N=7)	“Because most people, if they are that motivated and they want to get in” (P004)
User centred design for personal needs and conditions (N=7)	“the technology needs to be specific, or whatever you offer in the technology, shouldn’t be generic, you know, it should be specific for stroke patients and it should be versatile enough to customise it really to the specific person because they present in very, very different, you know, it’s very, very difficult to find two patients that present in exactly the same way” (P001)

Theme 6: Safe and clinically useful physical exercises

Nine types of safe and clinically useful exercises for physical functioning were suggested by the therapists in table 7.4.7 below.

Table 7.4.7: Identified types of safe and clinically useful physical exercises for physical functioning poststroke from physiotherapists and occupational therapists

Types of safe & clinically useful physical exercises	Numbers of participants
Combined task-oriented functional movements/physical activities	7
Balance	6
Coordination	6
Strengthening	6
Walking	6
Mobilizing	5
Sensory	5
Stretching	3
Aerobic	2

All therapists suggested combined functional movements or physical activities as being essential in the programme for physical functional recovery post-stroke.

“I try to incorporate function as much as I can” (P004)

Six therapists suggested walking, balance, coordination and strengthening exercises (N=6) should be included in an exercise manual for physical functional recovery.

7.5 Discussion

The focus of this study was to explore the key components from professional perspective for the development of a programme intended to be delivered by clinicians. The provision of self-management service has been highlighted in recent clinical guidelines for stroke rehabilitation (NICE, 2013). Information provision, goal-setting, problem solving, and the promotion of self-efficacy have been reported as common components included in existing stroke self-management programmes (Lennon et al., 2013, Jones and Riazi, 2011) (see table 2.3.5 in chapter 2). However, little was known about what clinicians think important to be included to provide a self-managed exercise manual with the support of available technology for functional stroke rehabilitation.

This study identified components that clinicians consider should be involved in the programme to answer the above question. Six themes were identified and are discussed below.

Theme 1: Daily physical functional difficulties in study 2

This theme provides the information to answer the following research question:

“What do clinicians think are the common physical functional difficulties in the community stroke rehabilitation?”

The focus of this theme was to explore the common daily physical functional difficulties in stroke recovery from a professional view as promoting the recovery of these issues. The subthemes of this theme were identified with the ICF model and the core set as to provide a functional oriented structure to analyse and interpret the

opinions collected from therapists. The identified types of common physical functional difficulties were the same as the findings from stroke survivors. Mobility, self-care, community, social and civic life, domestic life, and learning and applying knowledge were identified as the areas to focus on. The same sub-items were identified under each theme. It reflects that both service users and providers considered these items as barriers for functional stroke recovery.

The findings of this theme help to understand the clinical problems that should be managed in a self-managed stroke exercise manual; in view of developing an intervention to promote physical functional stroke rehabilitation.

Theme 2: Common daily physical functional goals in study 2

This theme helps to answer the following research question:

“What are the common goals of physical functional recovery in the community from the clinicians’ perspective?”

The findings of this theme provide an explicit list of items which therapists may consider to use in practice. This may provide clear information for clinicians to determine goals with their stroke survivors when prescribing the programme. Task-oriented goals are suggested for motor learning for physical functional stroke rehabilitation (Krakauer, 2006, Sparkes, 2000). The task-oriented functional goals of stroke rehabilitation in this theme were identified from professional perspective. The items were considered important for functional stroke rehabilitation in a self-managed exercise intervention by clinicians.

The findings reveal that the majority of the identified goals in this study were similar to that from stroke survivors in the previous study. This reflects that both stroke survivors and therapists may share common views on some issues about setting goals in self-managed programme for functional stroke recovery. Thus, the identified items should be used to develop the programme of this research to address the needs of both users and providers.

However, therapists suggested “return-to-work” as a goal for activity and participation which was not found from stroke survivors in the previous study. The issue about return-to-work has been highlighted in clinical guidelines for stroke rehabilitation (NICE, 2013, ISWP, 2012). Since it relates to activity and social participation, this item should be considered in a self-managed programme for functional stroke rehabilitation. Furthermore, the items of “lifting-and-carrying-objects” and “reading” were not suggested by therapists as goals for activity and participation, whilst they were reported by stroke survivors. This indicates that a gap may still exist between clinicians and therapists in view of the perceptions of setting some kinds of functional goals, although other studies reported that professionals perceived they were patient-centred in goal-setting for stroke rehabilitation (Rosewilliam et al., 2011). Thus, it is inadequate to only rely on either professionals or patients for setting functional goals in a self-managed exercise manual for physical functional stroke recovery.

Theme 3: Professional considerations to self-manage exercises

This theme provides the information for the following research question:

“What do clinicians consider important in relation to the self-management of exercise by stroke survivors in the community?”

A list of specific professional considerations about self-managing exercises was identified from therapists’ perspective. This helps to expose what clinicians perceive important to prescribe in a physical exercise manual to be managed by their clients for functional rehabilitation. This study helped to identify the practical challenges that should be overcome to empower stroke survivors to self-manage their own exercises. The identified types of subthemes from therapists were those of stroke survivors in the previous study. Therefore, those are common concerns for both stroke survivors and therapists and should be considered in a self-managed stroke exercise manual. In addition to the common concerns, therapists indicated that external feedback is considered important for self-managing exercises.

Further research will be helpful to determine how to empower clinicians to efficiently address the identified considerations when they deliver community services to their

clients to manage their own exercises. For instance, although motivation has been identified in this theme, the study also reported that physiotherapists indicated lack of confidence and skills in addressing stroke survivors' motivation in providing physical activity intervention for rehabilitation. Training has been suggested to develop therapists' skills to understand and assist stroke survivors to manage their motivation in practising physical activity (Morris et al., 2014).

Theme 4: Professional assistance to self-manage exercises

This theme helps to answer the following research question:

“What do clinicians think can help stroke survivors to manage their own exercise in the community?”

Information provision has been reported as a common component in stroke self-management interventions (Jones, 2013, Lennon et al., 2013, Jones, 2011). The provision of information during stroke rehabilitation can assist stroke survivors to relearn motor skills for physical functions (Orrell et al., 2006). The recent guidelines have recognised the importance of providing support to enable stroke survivors to actively participate in their rehabilitation plans (NICE, 2013, ISWP, 2012). However, little was known about the kind of information and help that therapists can be provided to assist their clients to self-manage exercises for physical rehabilitation. This study helps to identify what clinicians think that can be done to enable their clients to do so. The identified theme provides a list of possible actions that clinicians suggest to be taken to assist stroke survivors to self-manage their own exercises.

Theme 5: Professional considerations of using ICTs to self-manage exercises

This theme provides the information for the following research question:

“What do clinicians consider about using available ICTs to support stroke survivors to manage their own exercise in the community?”

Little was known about what professionals may consider in relation to using available ICTs to support stroke survivors to manage their own exercises, although some kinds of ICTs have already been tested and used to deliver remote support. The

technologies that were tested and reported in current studies were selected by the researchers. Clinicians had no involvement in determining which ICTs should be used whilst they are the key providers of the interventions.

Therefore, the findings of current studies may only reflect the feasibility and influence of using certain selected technology device for stroke recovery. What would therapists consider important for the selection and use of available ICTs to deliver professional support to their patients to manage their own exercises in the community? To develop a clinically usable programme, I explored how service providers' think when choosing and using available ICTs to support their stroke survivors to use the programme.

A list of professional considerations for using available ICTs was discovered in this study. The views of therapists were consistent with stroke survivors' concerns. In addition to the common concerns for using available ICTs, all therapists have emphasised the patient's motivation in using ICTs in this study. Some therapists also have stressed the importance of patients' confidence in using ICTs and the safety and confidentiality of using available ICTs, which are not identified in the previous study. These contribute additional messages required to design an intervention involving the use of ICTs for physical stroke rehabilitation.

Theme 6: Safe and clinically useful physical exercises

This theme helps to answer the following research question:

“What physical exercise would clinicians consider clinically useful and safe for stroke survivors to independently achieve their own functional goals of recovery?”

Although exercises are often included in stroke self-management interventions (Jones, 2011, Jones and Riazi, 2011) (also see table 2.3.5 in chapter 2), little is known about what types of exercises that clinicians consider safe and useful to be included in a self-managed exercise manual. In addition to understanding the exercises recommended in recent stroke guidelines, it remains important to understand what exercises that clinicians would prescribe in a programme intended to be managed by stroke survivors to ensure it is deliverable in practice.

Hence, this study provides a list of exercises that therapists consider useful and safe to be self-managed by stroke survivors for physical functioning in the community. This provides choice of exercises to design the programme. The exercises are in line with the recommendations in recent guidelines for stroke rehabilitation. Therefore, they are generally acceptable according to clinical standard for practice.

7.6 Implications

This study sought to identify the requirements for developing a self-managed and remotely supported exercise manual for functional stroke rehabilitation from a provider's perspective:

Eleven identified clinical considerations:

- availability of professional support, external support and reassurance, motivation, personalisation of the exercise manual, relevance to rehabilitation goals, needs and health conditions, simple and specific instructions, teaching and learning how to self-manage exercise, application of self-monitoring and self-regulation, physical conditions poststroke, enjoyable exercises, and self-confidence.

Ten identified supports for the self-management of exercises:

- access to relevant resources, education of knowledge and learning skills to self-manage, external support and feedback to enhance self-confidence, monitoring, regulation and progress evaluation, professional instruction and advice, facilitation for self-motivation, goal-setting, systematic action planning, information provision, and safety education.

Task-oriented training approach may facilitate motor learning was suggested to be important for neuroplasticity after stroke (Boyd et al., 2010). Clinicians are recommended to encourage stroke survivors to participate in physical activity and task-oriented exercise training according to current guidance for stroke (NICE, 2013, ISWP, 2012). Task-oriented exercises have also been suggested to be beneficial for motor learning process, enhance for motor functions for daily activities poststroke (Langhammer and Stanghelle, 2000, Timmermans et al., 2010). Therapists'

perceptions and suggestions are important to ensure the development of a usable intervention designed to be delivered in clinical situation by them.

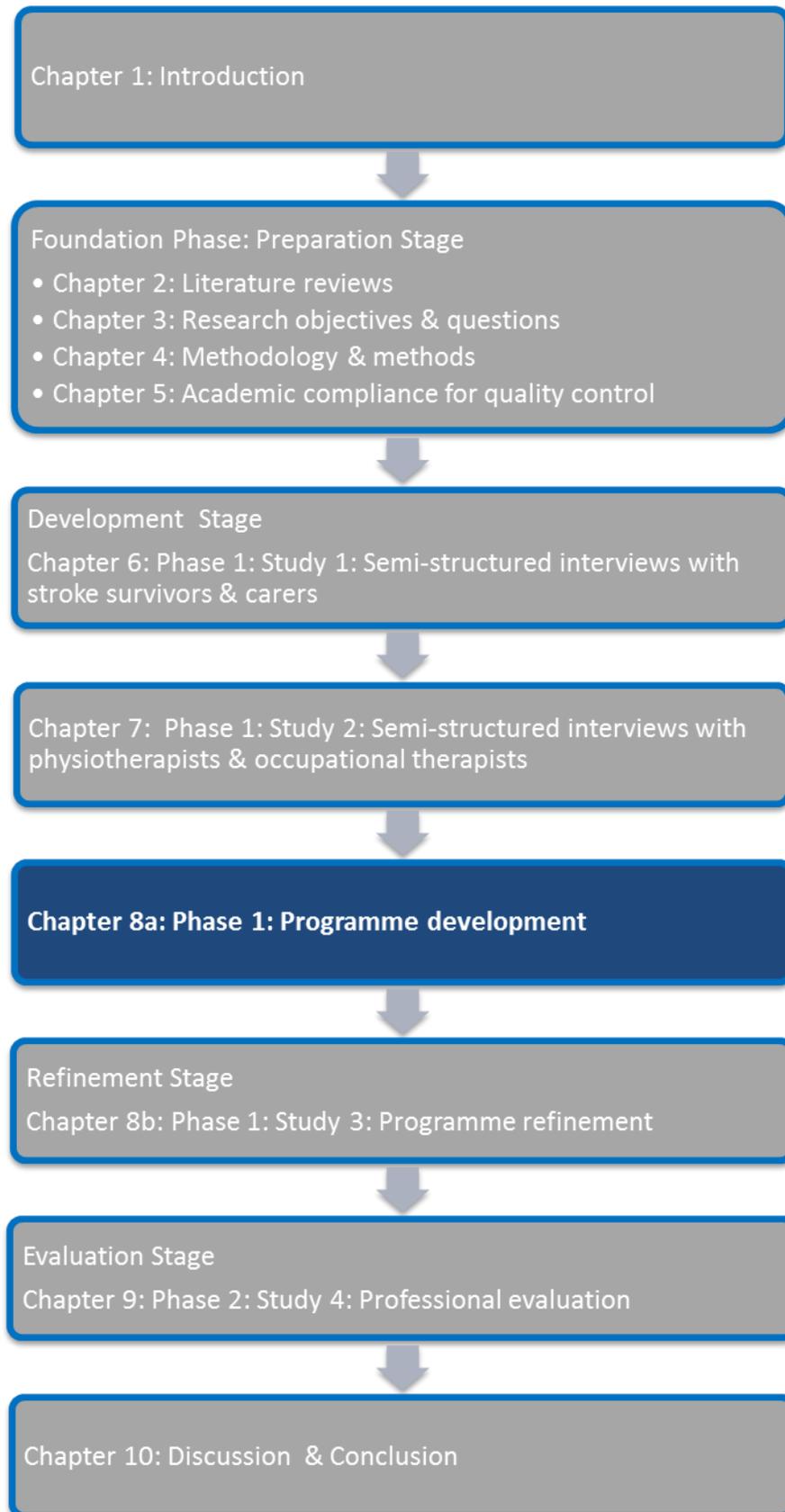
7.7 Limitations

Although representative findings were obtained from both PTs and OTs in this study, it was limited by a small sample size and that the therapists all came from one NHS trust. This may influence the generalizability of the findings to all clinicians in physical stroke rehabilitation.

Only one of the interviewed therapists had clinical experience in using self-management programmes for stroke rehabilitation. This reflected that the use of stroke self-management programme is not common in practice for functional stroke rehabilitation. This may limit the depth of the information about using stroke self-management programme that could be generated from the interviewed therapists due to the limitation of their experiences in using the concepts of self-management for functional stroke rehabilitation. More clinicians with experience in using stroke self-management programme are needed in the future research to collect a wider range of information from therapists with relevant experience.

7.8 Summary

The findings of this study contributed information required to form a self-managed and remotely supported physical exercise manual from a professional perspective. The next step was to combine both stroke survivors' and clinicians' views to form a programme designed for them.



Chapter 8a: Programme development

Chapter summary

Chapter 8 is divided into 2 parts. Part a describes the details about the development of the programme. Part b presents the refinement of the programme.

This chapter details the development process of a personalised, functional oriented, and self-managed physical exercise manual supported with available information and communication technologies. The programme was developed using the data from stroke survivors, carers and clinicians, a conceptual support of a new theoretical foundation established in this research which is called the “Gear Model”, current guidance for stroke rehabilitation and self-management principles.

8a.1 Introduction

Chapter 8a focuses on the development of the programme. The overall development process is illustrated in figure 8a.1.

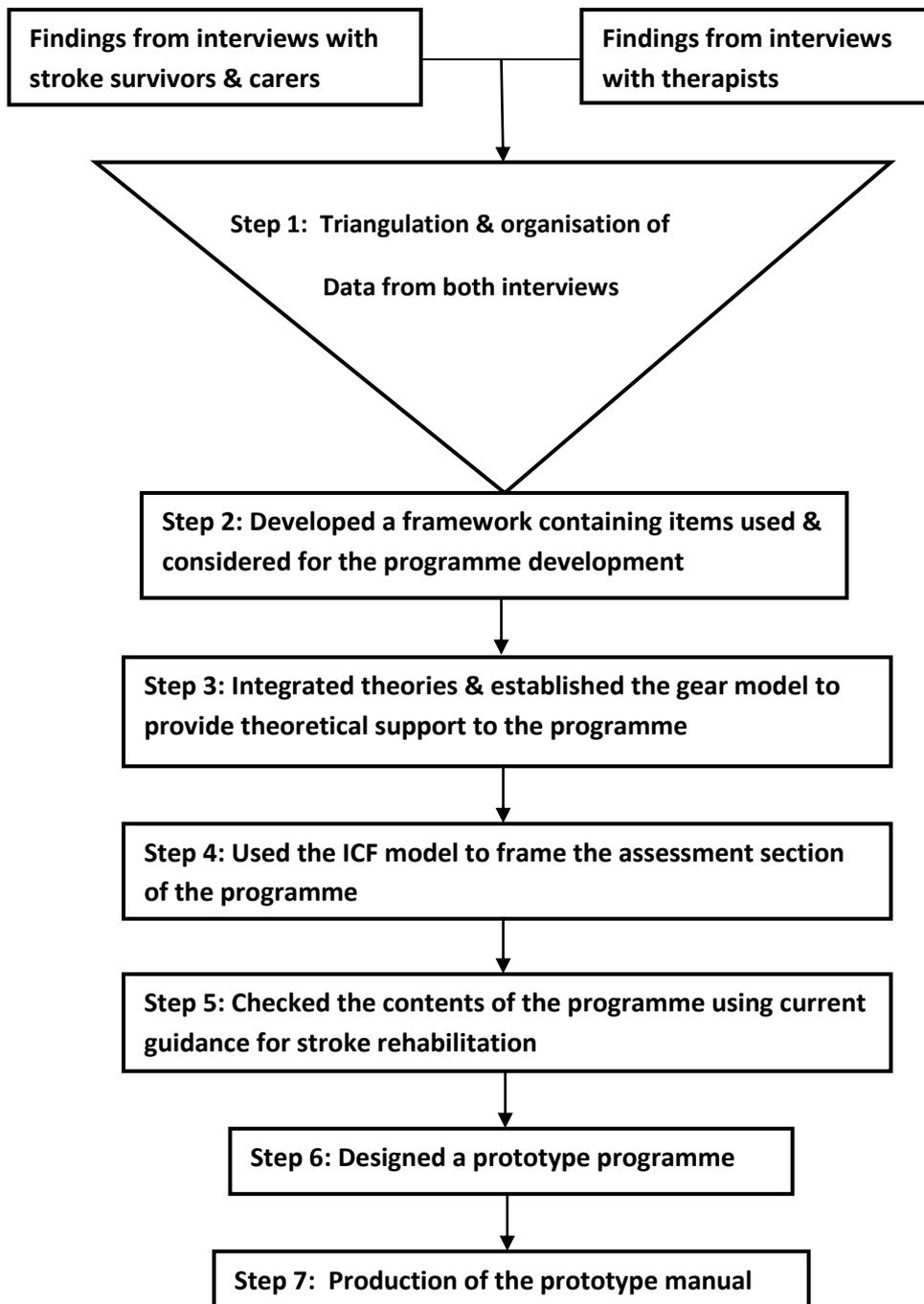


Figure 8a.1: Programme development process

Objectives

The objectives of this chapter as informed by literature reviews and the findings of the interviews with stroke survivors and therapists are listed below.

- Integrate the data from study 1 and 2 to obtain the core components required for the self-managed exercise manual
- Establish a theoretical foundation for the programme
- Formulate a prototype programme using the integrated findings from stroke survivors and professionals, the theoretical underpinnings and current national guidance for stroke rehabilitation

8a.2 Formulation of prototype programme

8a.2.1 Triangulation of Phase 1: Study 1 & 2

Triangulation was employed to establish the trustworthiness of this research as discussed in chapter 3 and to integrate the findings obtained from studies 1 and 2. It involves using more than one method or data source in the research (Bryman, 2012). Data sources and theoretical triangulations were used to generate components required to develop the programme.

An integrated organisational hierarchy framework in figure 8a.2 was used to organize the elements required to formulate the programme. The findings from studies 1 & 2 were triangulated then organised with the framework. Lists of determinants required to form the programme were then synthesised using triangulated findings.

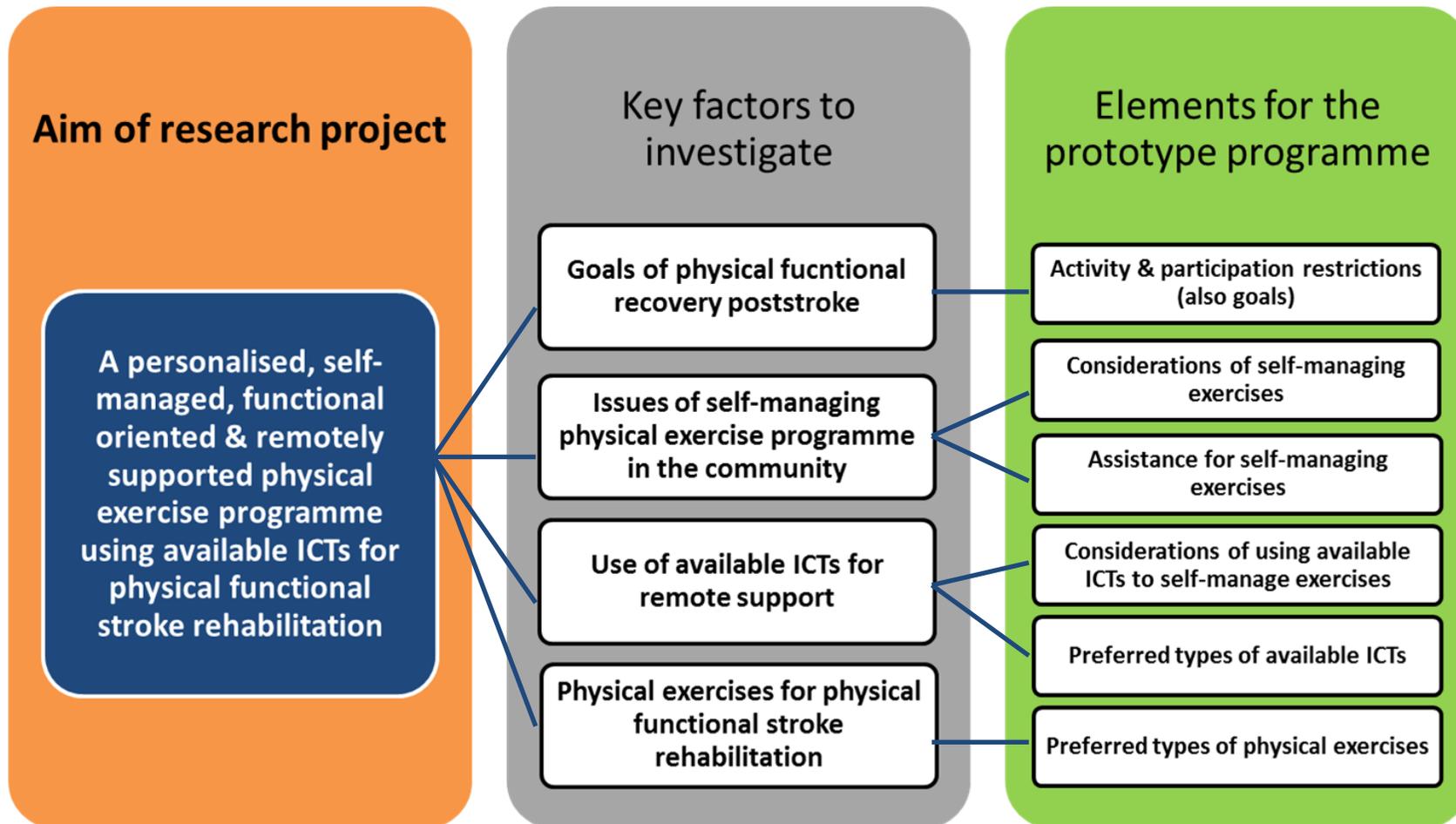


Figure 8a.2: Integrated organisational hierarchy framework of programme development

8a.2.1.1 Data sources triangulation²⁷

The data collected from different types of participants were compared and combined to extract the components to develop the prototype programme. These findings were used to design a manual detailed in the next section.

I first compared and combined the data collected from stroke survivors of different ages using the age subgroups analyses in chapter 6. Then, I compared the data collected from different types of therapists. Finally, I compared and integrated the data obtained from stroke survivors and therapists to elicit lists of factors and components required to develop the programme.

Frequencies of the subthemes were displayed to describe how often a subtheme was coded across the combined data set obtained from the two groups of participants. This was to present the most common ideas of each group of participants for each subtheme.

However, I decided to use all the identified items to formulate the programme to address the different needs of different types of participants, since the viewpoints of each type of participant are equally important for decision-making. Some subthemes have been highlighted in the tables after comparisons for discussion. Table 8a.2.1 and 8a.2.2 present the combined data about stroke survivors' and therapists' views about activities and participation restrictions. Both tables contain similar items since clinical problems and goals are usually closely related in practice.

²⁷ Data sources triangulation involves using different sources of information collected from different persons, or at different times or places in the same research for validation (Thurmond, 2001, Meijer et al., 2002, Hussein, 2009)

A list of activities and participation restrictions

Table 8a.2.1 Triangulation of data from interviews of stroke survivors and therapists on activities and participation restrictions²⁸

Subtheme level 1	Subtheme level 2	Code	Number of stroke survivors raising this subtheme (out of total 18 participants)	Number of therapists raising this subtheme (out of total 7 participants)
Mobility (1)	Changing basic body position	1.1	10	7
	Maintaining a body position	1.2	7	4
	Hand and arm use	1.3	17	6
	Lifting and carrying objects	1.4	7	0
	Moving around in different locations indoor	1.5	12	4
	Stair climbing	1.6	6	5
	Walking	1.7	16	5
	Driving	1.8	6	5
	Using transportation	1.9	6	4
Self-care (2)	Caring for body parts	2.1	11	4
	Dressing	2.2	7	7
	Eating / drinking	2.3	4	6
	Washing oneself	2.4	9	7
	Toileting	2.5	4	7
Community, social & civic life (3)	Recreation and Leisure	3.1	10	6
	Shopping	3.2	5	4
	Gardening	3.3	9	3
Domestic life (4)	Doing housework	4.1	9	5
	Preparing meals	4.2	14	7
Learning and applying knowledge (5)	Reading	5.1	4	2
	Writing	5.2	6	3

²⁸ Green indicates the items raised only by either stroke survivors or professionals.

Table 8a.2.1 details the triangulated findings of activities and participation restrictions recognised by stroke survivors and therapists in view of physical functioning post-stroke. Lifting and carrying objects (code: 1.4) was reported by stroke survivors but not therapists.

A list of activities and participation goals

Table 8a.2.2 Triangulation of data from interviews of stroke survivors and therapists on activities and participation goals

Subtheme level 1	Subtheme level 2	Code	Number of stroke survivors raising this subtheme (out of total 18 participants)	Number of therapists raising this subtheme (out of total 7 participants)
Mobility (1)	Changing basic body position	1.1	10	7
	Maintaining a body position	1.2	9	5
	Hand and arm use	1.3	16	7
	Lifting and carrying objects	1.4	7	0
	Moving around in different locations indoor	1.5	11	5
	Stair climbing	1.6	3	4
	Walking	1.7	14	7
	Driving	1.8	6	3
	Using transportation	1.9	5	4
Self-care (2)	Caring for body parts	2.1	7	4
	Dressing	2.2	3	6
	Eating / drinking	2.3	3	6
	Washing oneself	2.4	4	7
	Toileting	2.5	3	4
Community, social & civic life (3)	Recreation and Leisure	3.1	17	5
	Shopping	3.2	4	3
	Gardening	3.3	6	3
	Return to work	3.4	0	5
Domestic life (4)	Doing housework	4.1	10	5
	Preparing meals	4.2	9	5
Learning and applying knowledge (5)	Reading	5.1	3	0
	Writing	5.2	6	3

The table 8a.2.2 presented triangulated findings of activities and participation goals obtained from stroke survivors and therapists in view of physical functioning post-stroke. It appeared that return to work was suggested by therapists as a goal but not stroke survivors. Conversely, the items of lifting and carrying objects and reading were suggested by stroke survivors as a goal but not therapists. The above highlighted items are further discussed in the discussion section of this chapter.

The items in table 8a.2.1 and table 8a.2.2 were used to form the prototype programme to meet the needs of both groups of participants. They were adopted to design the clinical checklists for needs assessment and goal-setting to individualise the programme in this chapter.

A list of considerations of self-managing physical exercises

Table 8a2.3 Triangulation of data from interviews of stroke survivors and therapists on considerations of self-managing physical exercises²⁹

Subtheme	Code	Number of stroke survivors raising this subtheme (out of total 18 participants)	Number of therapists raising this subtheme (out of total 7 participants)
Motivation	1	14	7
Self-confidence	2	9	3
External support & reassurance	3	18	7
Physical conditions poststroke	4	0	5
Prescribing exercises relevant to goals and needs of daily activities	5	6	7
Personalisation of the exercise programme	6	10	7
Availability of professional support	7	0	7
Simple & specific instruction	8	14	7
Application of self-monitoring & self-regulation	9	12	6
Teaching & Learning how to self-manage exercise	10	8	7
Knowledge of safety & risk	11	9	0
Technical skills	12	5	0
Access to relevant health & social care resources & network	13	5	0
Enjoyable exercises	14	6	3
Suitable environment	15	7	0
Sustainable concept	16	8	0

The table 8a.2.3 presented the considerations recognised by stroke survivors and therapists in view of the self-management of exercise in the community for stroke survivors. External support and reassurance was raised by all participants.

²⁹ Yellow in table indicates the items raised by all participants (both stroke survivors and professionals).

However, physical conditions post-stroke and the availability of professional support suggested by therapists but not stroke survivors as the considerations for stroke survivors to self-manage their exercises. Conversely, knowledge of safety and risk, technical skills, access to relevant health and social care resources and network, suitable and sustainable concept were considered by stroke survivors but not therapists.

The above highlighted items are further discussed in the discussion section of this chapter. The items in the above table were used to form the clinical checklist for the programme in this chapter.

A list of assistance for self-managing exercises

Table 8a.2.4 Triangulation of data from interviews of stroke survivors and therapists on assistance for self-managing exercises

Subtheme level 1	Subtheme level 2	Code	Number of stroke survivors raising this subtheme (out of total 18 participants)	Number of therapists raising this subtheme (out of total 7 participants)
Professional contact & support & feedback (1)		1	17	0
Peer support & feedback (2)		2	18	0
Carer support & feedback (3)		3	5	0
Financial issues & support (4)		4	6	0
Self-management strategies & methods (5)	Access to relevant resources	5.1	14	7
	Facilitation for self-motivation	5.2	15	6
	External support & feedback to enhance self-confidence	5.3	18	7
	Goal setting	5.4	11	6
	Information provision	5.5	16	6
	Monitoring, regulation & progress evaluation	5.6	16	7
	Professional instruction & advice	5.7	18	7
	Systematic action planning	5.8	12	6
Education & Learning skills for self-management (6)	Education of knowledge & learning skills to self-manage	6.1	16	7
	Safety education	6.2	14	4

Table 8a.2.4 demonstrated that external support and feedback to enhance self-confidence and professional instruction and advice were emphasised by all participants as a requirement to help stroke survivors to self-manage their own exercises.

However, professional contact and support and feedback, peer support and feedback, carer support and feedback and financial issues and support were highlighted by stroke survivors but not therapists for helping stroke survivors to self-manage their exercises. The above highlighted items are further discussed in the discussion section of this chapter.

The items in table 8a.2.4 were used to inform the development of the clinical checklist for the programme to allow the users to select the suitable assistance and methods to help themselves to self-manage their own exercise manual.

A list of preferred types of physical exercises for a self-managed stroke exercise manual

Table 8a.2.5 Triangulation of data from interviews of stroke survivors and therapists on types of physical exercises preferred for physical functional stroke rehabilitation

Type of exercise	Code	Number of stroke survivors raising this subtheme (out of total 18 participants)	Number of therapists raising this subtheme (out of total 7 participants)
Mobilizing	1	11	5
Stretching	2	4	3
Coordination	3	5	6
Balance	4	5	6
Sensory	5	0	5
Strengthening	6	12	6
Walking	7	15	6
Aerobic	8	4	2
Combined task-oriented functional movements/physical activities	9	7	7

It appeared that sensory exercise was the only exercise not being suggested by stroke survivors, while all other exercises were proposed by stroke survivors and therapists for a self-managed exercise manual.

The above table was used to summarise the types of physical exercises obtained from triangulation of data from stroke survivors and therapists. This provided a list of physical exercises that were preferred by stroke survivors, regarded to be safe and clinically useful for physical functional stroke recovery by clinicians. The list was used to formulate a section for stroke survivors and therapists to determine suitable exercises in the programme.

A list of considerations in using information and communication technologies to self-manage exercises

Table 8a.2.6 summarises the considerations relating to information and communication technologies (ICTs) used to self-manage exercises obtained from triangulation of data from stroke survivors and therapists. This provided a list of considerations required to determine suitable technology for stroke survivors in the prototype according to stroke survivors' and therapists' perspectives. Motivation to use ICTs, safety and confidentiality of using ICTs and confidence in using ICTs were considered by therapists but not raised by stroke survivors.

Table 8a.2.6 Triangulation of data from interviews of stroke survivors and therapists on considerations in using information and communication technologies to self-manage exercises

Subtheme	Code	Number of stroke survivors raising this subtheme (out of total 18 participants)	Number of therapists raising this subtheme (out of total 7 participants)
Accessibility	1	14	7
Availability	2	14	7
Perceived ease of use	3	15	6
Perceived usefulness	4	15	6
Flexibility	5	9	5
Motivation to use ICTs	6	0	7
Age of users	7	7	6
Safety & confidentiality of using ICTs	8	0	3
Sustainability & maintenance issues	9	7	6
Technical support	10	4	6
User centred design for personal needs & conditions	11	13	7
Cost utility of using ICTs	12	4	4
Confidence in using ICTs	13	0	3

A list of preferred available ICTs

The following table 8a.2.7 was extracted from the interviews with stroke survivors that provided a list of different preferred choices of technologies. This was determined with the UCD principle and the Technology Acceptance Model adopted to support the idea about using available technologies in this research. The following items were used to inform the checklist in the programme.

Table 8a.2.7: Preferred available information and communication technologies

Preferred available information and communication technologies (ICTs)	
Type	Item
Audio-visual technology	TV
	CD
	DVD
	Video recording
Computer	Desktop / laptop computer
	Touch screen computer machine
Internet technology	Internet access to information online
	Online social media and discussion forum
	Online video link
	Electronic record system
	Email
	Interactive videoconference
Telephone communication technology	Apps on touch screen computer
	Computer games
	Landline telephone call
Mixed multimedia technology	Mobile phone call
	Mobile phone text message
	Mixed multimedia technology

Framework of items used or considered for programme development

The figure 8a.2.2 illustrates a framework which summarises the items used or considered for the development of the programme after combining the data generated from both interviews with stroke survivors and professionals. This is to yield a group of components to be used to design the programme based on stroke survivors' and therapists' opinions.

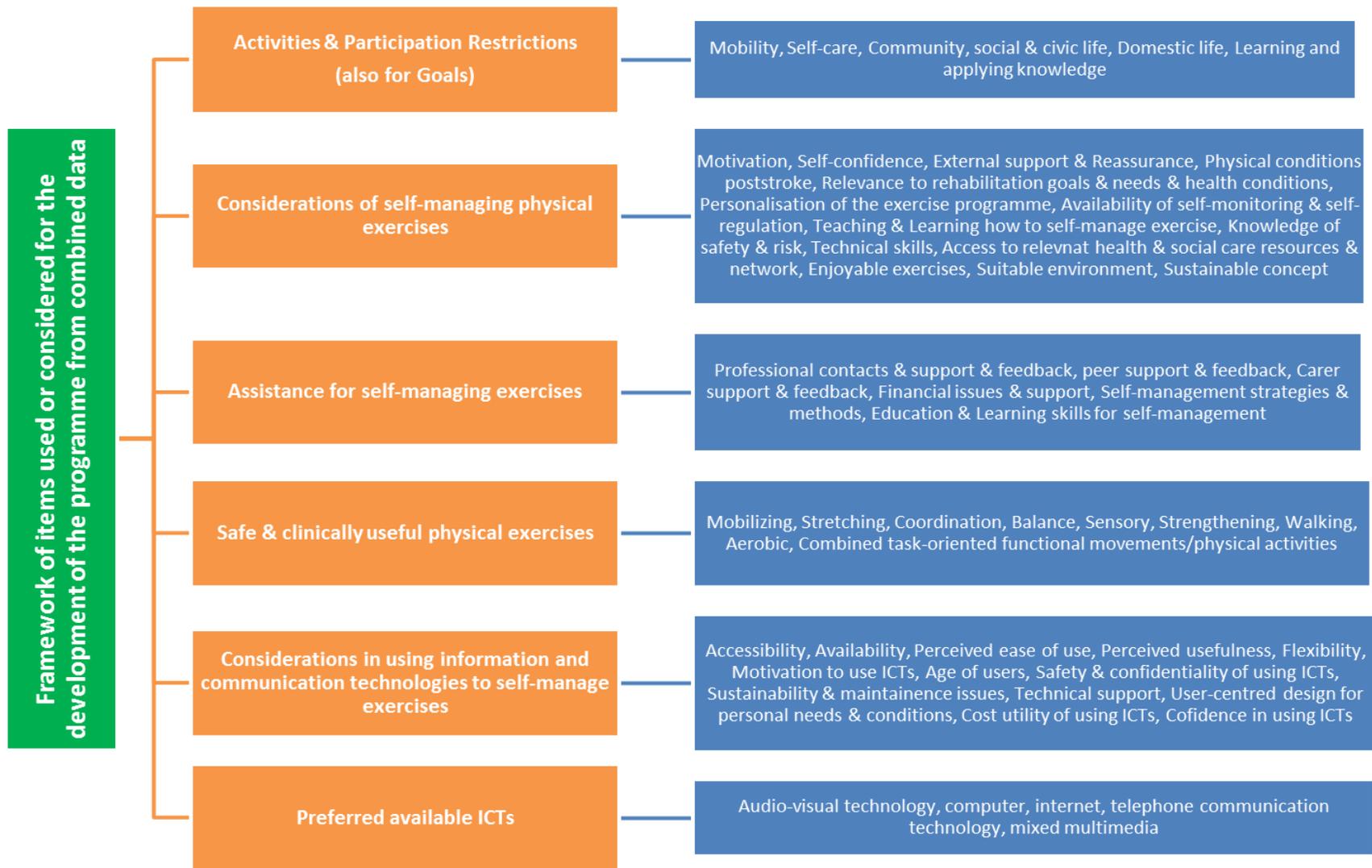


Figure 8a.2.1 Framework showing items used or considered for programme development

8a.2.1.2 Theoretical triangulation

Theoretical triangulation³⁰ was adopted to develop the programme. A novel theoretical foundation was generated to provide a conceptual base to support the programme. There are different theoretical bases used in the existing stroke self-management programmes (see figure 2.3.9 in chapter 2). A home-based telehealthcare model has been proposed for chronic care of stroke patients (Kuo et al., 2011) and a conceptual matrix has been suggested for using assistive technology for a computerised and personalised self-management system for stroke rehabilitation (Mawson et al., 2013, Nasr et al., 2009). However, there is a lack of specific theoretical underpinnings to support therapists in guiding their clients during the assessment, decision-making and prescription processes for the provision of a personalised and self-managed exercise manual with the use of available ICTs. There was no single theory which could provide the underpinning required to develop the programme for this research. Hence, it was necessary to integrate related theories and models for the features of different elements of the programme. This is to support different elements of the programme using most multiple theoretical concepts. This may also inform the way to combine theoretical concepts with the practical components identified from users' and clinicians' perspectives

Triangulating theories may help to mediate original strengths and limitations of each theory or model to obtain a more comprehensive view to interpret and utilise the data to design a programme containing multiple elements. I triangulated the findings generated from data sources with a group of theories. This allowed me to interpret the data from different angles to gain deeper understanding.

Establishing an underpinning theoretical foundation

An underpinning theoretical foundation was established shown in figure 8a.2.2 to illustrate this theoretical triangulation process. I triangulated 3 core theories: Social Cognitive Theory (SCT), Learning Theories (LTs) and Technology Acceptance Model (TAM) to interpret the triangulated findings from multiple angles. I compared

³⁰ Theoretical triangulation refers to the application of multiple theories to interpret data in the same research (Denzin, 2009, Thurmond, 2001)

the features and core concepts of each selected theory to the study aim and objectives, to ensure it provided particular conceptual support for the focus of this research before determining the items of the programme.

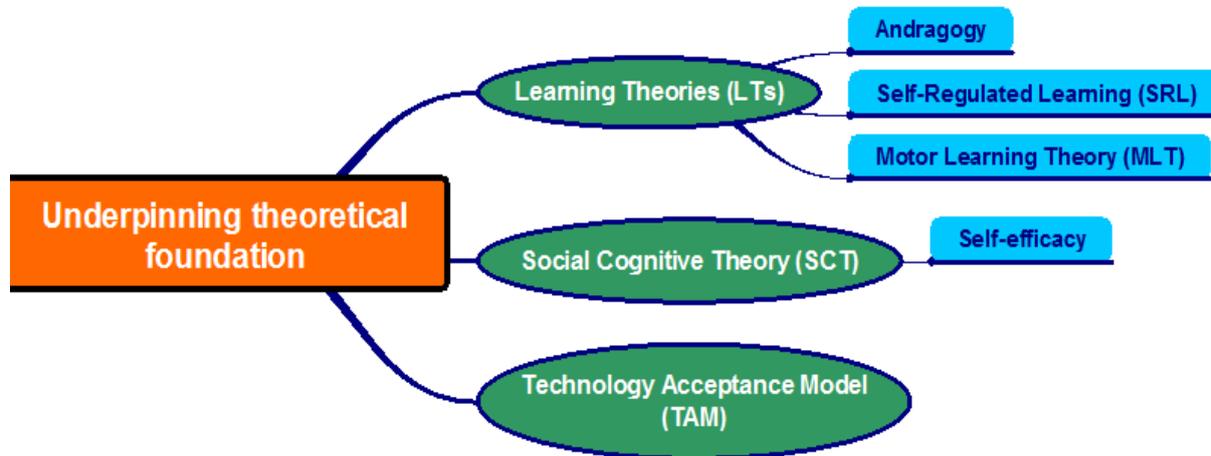


Figure 8a.2.1.2: Underpinning theoretical foundation generated in theoretical triangulation

The underlying thought process that I have gone through to use the theoretical foundation with the combined data is detailed below.

Self-efficacy

Self-efficacy was considered as the key concept driving the formulation process of the programme. It has been proved as an essential factor for stroke self-management since self-management programmes focus on supporting self-efficacy have been shown to be most effective (Jones, 2013, Jones and Riazi, 2011). Physical activity was shown to be improved with increased self-efficacy in studies (Ashford et al., 2010). Studies have reported that self-efficacy is positively correlated and important for building motivation and adherence for physical exercises and activities (Rhodes and Fiala, 2009). In particular, self-efficacy is a key determinant for physical stroke exercise adherence (Bonetti and Johnston, 2008). It is positively correlated with mobility and activities of daily living after stroke in studies (Korpershoek et al., 2011).

The improvement of self-efficacy is shown to be associated with functional improvement for stroke survivors. Positive association between the improvement of self-efficacy and the increase of exercises behaviour for stroke survivors has been reported in studies (Jones and Riazi, 2011, Jones et al., 2009, Shaughnessy and Resnick, 2009, Shaughnessy et al., 2006). Furthermore, the rest of the included elements in the theoretical foundation were also associated and influenced by self-efficacy. Therefore, self-efficacy was regarded as the key elements to develop the programme in this research. Thus, it was used to triangulate with the data collected from the interviews.

Self-confidence was considered as an important factor by both stroke survivors and therapists to self-manage an exercise manual and use available technology to do so. All participants suggested that external support and feedback could help to improve self-confidence to manage their own exercises. The promotion of self-efficacy may also be essential for the improvement of motivation (Zimmerman, 2000), as motivation was considered important for the self-management of exercises. Motivation to adherence of a prescribed intervention can be affected by patient's confidence to follow the interventions (Dreeben, 2010). Feeling confident and having motivation were also reported by stroke survivors as important factors to manage their own exercises. Thus, it is necessary to determine a way to enhance the self-efficacy of the user of the programme. It is important to identify and assist the use of possible sources to promote the self-efficacy of the user.

The provision of feedback on performance by others may promote self-efficacy for physical activity (Ashford et al., 2010). Furthermore, external support is an influencing factor for self-efficacy (Bandura, 2000, Bandura, 1997a). This study indicated that stroke survivors and therapists suggested the need for external feedback from different people to assist the user to self-manage exercises in the programme. Therefore, the provision of feedback from other people should be a component to enhance self-efficacy in this programme. Systematic action planning was identified by both stroke survivors and therapists as a consideration for stroke survivors to self-manage exercises, which has been suggested as potential assistance to facilitate self-efficacy for the promotion of physical activity (Luszczynska et al., 2011).

Motivation and self-efficacy may influence patients' adherence to education (Dreeben, 2010). Stroke survivors' adherence may affect the usage of the exercise manual in the long-term. Hence, it is important to determine ways to empower the users via enhancing and managing their motivation and self-efficacy to facilitate them to learn to self-manage and to enhance their adherence to the programme.

Since self-efficacy has been regarded as important in the findings of the interviews with stroke survivors and therapists and the literature for stroke rehabilitation, I decided to include information related to the sources of self-efficacy in the programme. The four main sources of self-efficacy proposed by Bandura including mastery experiences, vicarious experiences (modelling), verbal persuasion (social persuasion) and physiological feedback (Jones, 2011, Lorig and Holman, 2003, Bandura, 1997a, Bandura, 1997b) presented in figure 8a.2.1.2a were considered in the development of the programme.

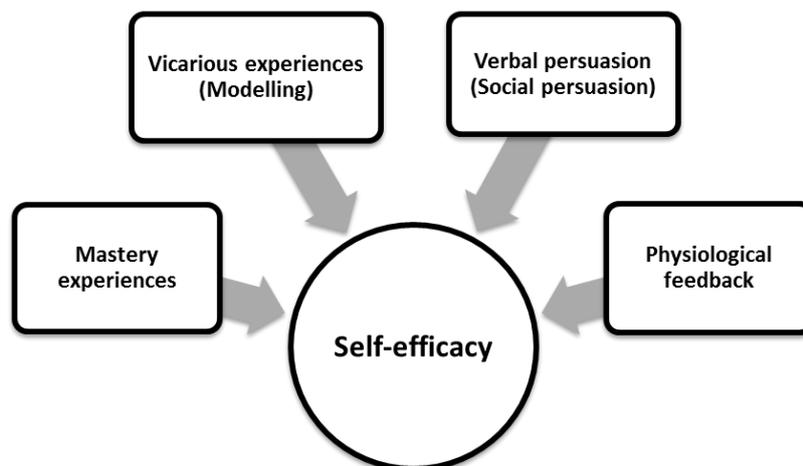


Figure 8a.2.1.2a: Four main sources of self-efficacy³¹

Therefore, the concepts of helping stroke survivors to enhance their self-efficacy by providing the above sources were considered during the development of the programme. For instance, in view of mastery experience, it is important to help the individuals to break the goals of physical functional recovery into small and manageable tasks so as to develop their confidence to achieve the goals they have

³¹ Sources of self-efficacy: There are four common sources of self-efficacy, including mastery experience, vicarious experience, verbal persuasion and physiological feedback (Korpershoek et al., 2011)

set in the programme. This is to allow the stroke survivors to improve their self-efficacy from their successful experiences in a task. Thus, goal-setting and action planning were involved in the programme. With regards to vicarious experiences, it is important to help the users of the programme to enhance their self-efficacy by comparing with and modelling of others who have the same problems and have successfully performed similar tasks. Thus, the users should be given ways to see others' achievement in self-managing exercises and learn the successful experiences from other stroke survivors as they manage their own exercises. They may do so through the use of ICTs. For verbal persuasion, it is necessary to help the individuals to improve their beliefs towards the possibility for them to complete the task so as to increase their self-efficacy. For example, the users of the programme may use ICTs to receive support from others including peers, other stroke survivors, family members and professionals as they manage their own exercises. The verbal support from their carers may also be provided. In view of physiological feedback, it is important to provide feedback about the individuals' own physiological states as they self-manage their own exercises. For instance, it is necessary to allow the individuals to keep progress records of the changes of their physical conditions and functions in the programme. They may do so using printed materials or using electronic equipment; such as taking videos.

Learning theories

Education has been recognised as an important part of any stroke intervention for stroke survivors and their carers, however, the unmet education needs for the recovery of stroke survivors have been highlighted in recent studies (Hafsteinsdóttir et al., 2011). Whilst goal-setting has been emphasised for inclusion in stroke rehabilitation services in clinical guidelines for stroke (NICE, 2013, ISWP, 2012, SIGN, 2010), poor knowledge about stroke recovery of stroke survivors has been reported to be a barrier to setting their own goals for rehabilitation (Laver et al., 2010). Thus, it is important to consider how to help stroke survivors to understand the way to acquire knowledge and skills in order to self-manage for rehabilitation. Education has also been proposed as an important aspect for a computerised self-management system supported by assistive technology for stroke (Nasr et al., 2009,

Mawson et al., 2013). It is reported to be required for users to deliver stroke rehabilitation using technology (Mountain et al., 2010).

Patient education was found to be a common component in self-management interventions in the literature review in chapter 2 of this thesis. Functional physical recovery post-stroke is a learning process to recover and improve functional physical status and abilities via restructuring and adaptation to reintegrate into daily physical role (Gelber et al., 1995, Kwakkel et al., 1999, Burton, 2000, Duncan et al., 2000). However, little was known about how to educate stroke survivors to self-manage their own exercise manual for physical functional rehabilitation in related literature (Lennon et al., 2013, Jones and Riazi, 2011).

Knowledge is regarded as an influencing factor for self-efficacy (Bandura, 1997). Although “information provision” was recognised by stroke survivors and therapists as required for stroke survivors to self-manage exercises, providing information alone is insufficient to ensure knowledge delivery and maintenance to stroke survivors.

Self-management programmes are different from simple patient education or skill training (Jones, 2011). Traditional patient education approaches with information provision alone may not be sufficient for stroke survivors to self-manage over the long-term. However, educational needs of stroke survivors have been highlighted in current evidence of which specific and tailor-made educational interventions are shown to be more beneficial for stroke survivors (Hafsteinsdóttir et al., 2011). The need to educate stroke survivors for their rehabilitation has also been found in the interviews with stroke survivors and professionals in chapter 6 and 7. The provision of patient education appears to be required for self-managing stroke exercises to provide knowledge and skills to stroke survivors in the programme.

The item of “teaching and learning how to self-manage” was recognised by both stroke survivors and therapists as a consideration for stroke survivors to self-manage exercises in the interviews of this research. Furthermore, “education of knowledge and learning skills to self-manage” was identified by both groups as one of the key factors to assist stroke survivors to self-manage exercises. Thus, a set of learning

theories was used to interpret the findings from stroke survivors and therapists to help understanding their needs for learning to self-manage.

It appears that there was no single theory that could underpin all the needs of learning to self-manage exercises for functional stroke recovery. I combined different theories to provide multi-directional support for educating stroke survivors. Three learning theories were chosen in the set of learning theories.

Andragogy and self-regulatory learning are the two adult educational theories selected for this research (see chapter 1). The underpinning philosophical assumptions and constructs of these theories are in line with the core value and purpose of enabling stroke survivors to self-manage their own exercises in this research; since both theories relate to encouraging a person to actively take control over their learning. The features of the selected learning theories also relate to self-efficacy (which has been shown as a key for stroke self-management). Thus, they were chosen to drive the educational side of the programme.

For physical functional stroke recovery, motor learning theory was included in the set of learning theories in this research, in order to facilitate the learning process for stroke survivors to learn and manage their motor skills for physical functioning.

Andragogy

To develop a programme for adult stroke survivors in this research, the features of adult learning³² process and associated concepts were considered in learning theories in this research such as adults' needs to determine what to learn to achieve personal goals, adults' engagement in creating a strategy and resources and implementing the strategy and resources for their own learning to achieve the goals, and adults' evaluation of their own learning (Knowles et al., 2012).

³² Adult learning is defined as the process of adults gaining knowledge and expertise. Learners want to have control over their learning process and learning increases as a result from adult education (Knowles et al., 2012)

Andragogy³³ was used since the targeted users of the developed programme are adults. It is important to consider the concepts related to educate adults learners. Furthermore, stroke education programme was suggested to be based on active interaction, learner's needs, actual problems and experiences, whilst the learner should take the active role (Hanger and Wilkinson, 2001). These factors matched with the fundamental paradigm of andragogy for the adult learning purpose (Sandelowski et al., 2009). The six core principles of andragogy in figure 8a.2.1.2b were used for triangulation and formulation of the programme.

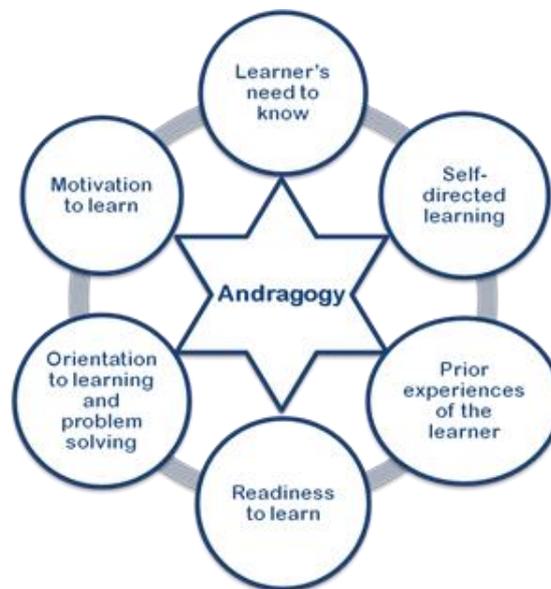


Figure 8a.2.1.2b: Six core principles of andragogy

Motivation and facilitation for self-motivation was recognised as a method to assist stroke survivors to self-manage exercises by both stroke survivors and therapists. In addition, the motivation of using ICTs was identified by therapists as a consideration for stroke survivors to use available technologies to self-manage exercises. In view

³³ Andragogy is an education theory for the process of adult learning. Knowles suggested the following 6 core principles of it: (1) Learner's self-concept: adults have a self-concept of being responsible for their own decisions, for their own lives. They need to be involved in the planning and evaluation of their instruction for their learning (2) Learner's experience (including mistakes): which provides a knowledge base for new learning (3) Readiness to learn: adults become ready to learn when their life situation creates a need to know (4) Orientation to learning and problem solving; adult learning is problem-centred; (5) The need to know: adults need to know the reason for learning (6) Motivation to learn; adults respond better to internal than external motivation (Knowles et al., 2012)

of andragogy, motivation to learn is an element within andragogy. Therefore, it was necessary to consider how to promote the motivation of stroke survivors in order to enable them to self-manage exercises and use available ICTs to do so. Since motivation for learning can be affected by self-efficacy (Severino et al., 2011, Semmar, 2006), it was necessary to also consider how to promote the users' self-efficacy to enhance their motivation to learn as they use the programme which is related to the application of self-efficacy theory discussed in the previous section.

The item of "prescribing exercises relevant to goals and needs of daily activities" was recognised by both stroke survivors and therapists as a consideration affecting stroke survivors to self-manage their exercises. This can be interpreted with the principle of the orientation to learning and problem-solving in view of andragogy. It appeared that they supposed the orientation to learning should be task-centred or problem-centred for the purpose of learning how to self-manage their exercises. Hence, it is necessary to organise the contexts and the structure of the programme of this research based on such orientation.

The subtheme of "application of self-monitoring and self-regulation" was recognised by both stroke survivors and therapists as a consideration affecting stroke survivors to self-manage their exercises. Additionally, they proposed "monitoring, regulation and progress evaluation" as a method to assist stroke survivors to self-manage exercises. These indicated their concept related to "learner's self-concept" in view of andragogy. Thus, it indicates that they considered stroke survivors' responsibility is important for them to self-manage stroke exercises. This reflects the concept about self-directed learning according to andragogy.

The items of "technical skills" and "knowledge of safety and risk" were recognised by stroke survivors as important considerations. Furthermore, the subthemes of "education of knowledge and learning skills to self-manage" and "safety education" were identified by stroke survivors and therapists as the help required for stroke survivors to self-manage exercises. From the view of andragogy, these implied that the concept of "the need to know". This indicates that they need to be aware of certain knowledge to facilitate their learning process whilst learning how to self-manage exercises. Therefore, the concepts of andragogy were adopted in the

programme to teach stroke survivors the way to acquire knowledge and skills to self-manage their own exercises using ICTs.

Self-regulated learning

Self-regulatory behaviour has shown to be associated with and is important for physical activity (Ayotte et al., 2010, Anderson et al., 2006). The importance of helping stroke survivors to self-regulate their own programme has also been emphasised in the interviews with stroke survivors and therapists of this research. Successful learners should organise their work, set goals, seek help when needed, use effective work strategies, and manage their time (Usher and Pajares, 2008, Zimmerman, 2002). Hence, self-regulated learning (SRL)³⁴ theory was adopted to underpin the development of the programme to assist stroke survivors to learn how to control their own exercise manuals in the longer term.

Self-efficacy is suggested, again, a key factor influencing people's SRL. Since it is also related to physical activity, people with higher self-efficacy have more positive views of the outcomes of exercise, perceived fewer barriers, engaged in more self-regulatory behaviour and have more physical activity than those who have lower self-efficacy (Schunk and Zimmerman, 2012, Ayotte et al., 2010, Zimmerman, 2002). Thus, the features of SRL were considered to help the user of the programme to regulate their own programme with regards to the relationship between their self-efficacy and self-regulatory behaviour. The six concepts of SRL in figure 8a.2.1.2c were used for triangulation and programme development.

³⁴ Self-regulated learning (SRL) is a dynamic concept that refers to the learning process guided by metacognition (thinking about one's thinking including the use of feedback), planning, monitoring, and evaluating personal progress to attain personal goals, and motivation to learn. SRL involves goal-setting for learning, focus on instruction, using resources, organizing ideas, positive beliefs about personal abilities and monitoring performance (Schunk and Zimmerman, 2012, Duckworth and Britain, 2009, Zimmerman, 2002)



Figure 8a.2.1.2c: Six elements of self-regulated learning

From the data of the interviews with stroke survivors and therapists in this research, the items of “prescribing exercises relevant to goals and needs of daily activities” and “goal-setting” were recognised as considerations for stroke survivors to self-manage exercises and a method to assist stroke survivors to do so. From the angle of SRL, these may reflect their viewpoint on “goal-setting for learning” for the self-management of stroke exercises. Hence, a goal-setting section should be included in the programme to facilitate stroke survivors’ goal-oriented learning as they learn to self-manage.

The consideration about “application of self-monitoring and self-regulation” and assistance about “monitoring, regulation and progress evaluation” were also proposed by both stroke survivors and therapists. These may imply that the “monitoring performance”, which is a component in SRL, is an influencing factor for stroke survivors to self-manage their exercises. Therefore it was necessary to consider how to enable them to monitor their performance for them to learn how to self-manage their exercises during the development of the programme.

The subthemes of “simple and specific instruction” and “professional instruction and advice” were recognised by both stroke survivors and therapists as a requirement for

stroke survivors to self-manage exercises respectively. These may be related to the concept of “focus on instruction” according to SRL. Thus, to facilitate the learning process for stroke survivors to be able to self-manage their exercises, the provision of instructions was required.

The subtheme of “access to relevant health and social care resources and network” was recognised by the stroke survivors as important. In addition, “access to relevant resources” was recognised by both stroke survivors and therapists as necessary to assist stroke survivors to self-manage their exercises. These indicated the concept of “using resources” for learning based on SRL. Thus, it is necessary to provide resources in the programme for stroke survivors to use to promote their learning process for self-managing exercises.

Both stroke survivors and therapists reported the need for using “systematic action planning” to assist stroke survivors to self-manage their exercises. This may be related to the concept of “organising ideas” in view of SRL. Therefore, it was necessary to help stroke survivors to organise their ideas for the self-management of their exercises with the use of systematic action planning approach to help stroke survivors to self-manage.

Self-confidence and “external support and reassurance” were concerned by both stroke survivors and therapists for stroke survivors to self-manage their exercises. Interviews with clinicians have also indicated that user’s “confidence in using ICTs” is important for them to use technology to self-manage exercises.

Additionally, “external support and feedback to enhance self-confidence” was proposed by both stroke survivors and therapists as a method to assist stroke survivors to self-manage exercises. In view of SRL, these may indicate the concept of “positive belief about personal abilities” for learning. Thus, it is necessary to provide a way to enhance stroke survivors’ self-confidence towards self-managing their own exercises in this programme. Hence, the concepts of SRL were adopted to guide stroke survivors to learn how to regulate their own programmes so as to enable them to control that by themselves.

Motor learning theory

Since the programme is to facilitate the recovery of physical functioning post-stroke, in which motor learning and recovery were the keys, MLT was reviewed to underpin the development of the programme. MLT has also been suggested as consideration for the self-management of stroke using assistive technology (Wolf, 1978).

The focus of motor relearning is on the active participation of the stroke survivor with guidance and feedback for movement correction (Van Vliet and Wulf, 2006, Sparkes, 2000). The provision of feedback is a part of MLT process, in which feedback can provide information on movement improvement and is suggested to be important for motor learning post-stroke. Extrinsic feedback was reported as an important element for maintaining the motivation during learning (Van Vliet and Wulf, 2006).

Current evidence suggested that the provision of extrinsic feedback³⁵ is important to maximise the neuroplasticity and improve motor learning and recovery post-stroke (Subramanian et al., 2010, Cirstea et al., 2006, Van Vliet and Wulf, 2006). The provision of information about movement performance may help motor learning after stroke (Orrell et al., 2006). Thus, it indicated that the provision of feedback is important to for relearning motor skills in functional stroke rehabilitation. It helps to facilitate stroke survivors to relearn physical movements, since it may provide information on errors of movement and suggest ways to correct that. The provision of feedback via Knowledge of Performance (KP) has shown to be more beneficial for the improvement of motor learning and the quality of movement recovery than that of Knowledge of Results (KR) (Subramanian et al., 2010, Cirstea and Levin, 2007, Cirstea et al., 2006), therefore, KP was the main type of feedback considered for provision of this programme.

Extrinsic feedback has been suggested to be a key for maximising experience-dependently plasticity after stroke (Subramanian et al., 2010). Furthermore, learning with personal experiences is an important element for adult learning according to andragogy. Hence, the concepts of both MLT and andragogy were combined to

³⁵ Extrinsic feedback is provided from external environment via the provision of information about knowledge of performance (KP) and knowledge of result (KR)

generate a concept support to enhance stroke survivors to learn from experiences in this programme with the consideration of promoting their motor learning as they learn to manage their own exercises.

The concept of providing feedback for motor learning was adopted in the SMART system for physical stroke rehabilitation. The idea of continuing the provision of feedback with the use of available technologies was suggested to be feasible and beneficial for the recovery of functional activity of stroke survivors in the SMART system with the support of MLT (Parker et al., 2013, Mawson et al., 2013, Mawson and Mountain., 2011, Mountain et al., 2010, Zheng et al., 2007, Zheng et al., 2006). Although studies reported the potential of providing extrinsic feedback to improve motor and functional performance after stroke (Langhorne et al., 2009, Van Vliet and Wulf, 2006), little is known about how to help stroke survivors to choose and use appropriate ICTs to obtain feedback to self-manage their own exercises for their motor recovery for physical functions.

Theories reviewed in this research suggested that the provision of external feedback is important for a self-managed stroke exercise manual. This is also reflected in the findings collected from both stroke survivors and therapists. They suggested the provision of feedback from professionals, peers and carers for helping stroke survivors to self-manage their own exercises in the interviews. Thus, the provision of extrinsic feedback should be involved in this programme to empower stroke survivors to learn how to self-manage their own exercises. The providers of this programme will need to employ both MLT and andragogy to enable the users to learn from experiences as they use this programme.

Combination of learning theories

With the knowledge from the findings from the interviews and the combination of theoretical triangulations, it has been shown that different features of the proposed learning theories may contribute to a different extent to the learning process to enable stroke survivors to self-manage their own exercises with the use of available ICTs. Different learning theories consist of different constructs and characteristics. The combination of them may generate comprehensive support on which to base a

self-management programme for physical rehabilitation with the balance of the strength and weakness between different theories.

Hence, andragogy, SRL and MLT were combined to form theoretical support to drive the learning aspects of the programme. The conceptual relationships between the selected learning theories are shown in figure 8a.2.1.2d.

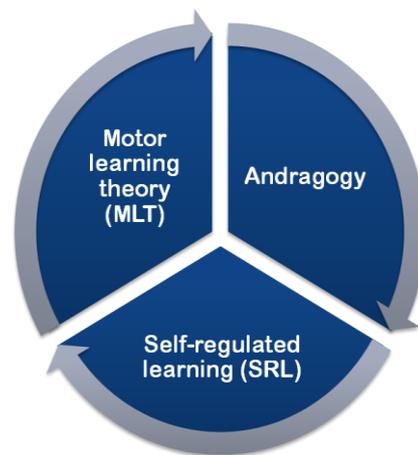


Figure 8a.2.1.2d: Three theories within the gear of the learning theories

Technology acceptance model

Whilst it has been shown to be possible to utilise information and communication technologies (ICTs) as a medium to deliver stroke rehabilitation, little is known about the theoretical underpinning of selecting and using available ICTs in stroke self-management interventions and systems (Mawson et al., 2013, Johansson and Wild, 2011, Kuo et al., 2011, Mawson and Mountain, 2011, Huijbregts et al., 2010, Nasr et al., 2009, Damush et al., 2008, Johnston et al., 2007, Kendall et al., 2007, Lai et al., 2004) (also see table 2.3.7 in chapter 2). How can we match the appropriate and available technologies to individual stroke survivors to support them to manage their own exercises?

Both stroke survivors and therapist's decisions are important for using available ICTs for stroke self-management in practice. The use of different technologies for stroke rehabilitation has been reported in different studies. A list of preferred available

technologies and different considerations for using available ICTs to self-manage exercises were identified in this study.

However, it does not necessarily mean stroke survivors and therapists know how to determine suitable technology options for the self-management of stroke exercises together. How can we guide the thinking process of stroke survivors and clinicians to select and decide on acceptable and available ICTs to self-manage exercises? The theoretical support was required to understand requirements for stroke survivors and therapists to select and utilise available ICTs to facilitate the process of choosing that ICTs that they will and can use.

The technology acceptance model (TAM)³⁶ was the model adopted to provide a conceptual support to address the above questions in this research. TAM was selected to support the programme since the acceptance and intention of the user toward using a technology are important for selecting and using proper ICTs. This was determined according to the value of the user-centred design principle. This decision was also supported with the data of “user-centred design for personal needs and conditions” identified from the interviews with stroke survivors and therapists in this research. The adoption of the concepts of TAM may help to personalise the process of choosing available ICTs to be used to support the individual stroke survivor to manage the programme.

The key constructs of TAM, including perceived usefulness (PU)³⁷ and perceived ease-of-use (PEOU)³⁸ emerged from the findings of the interviews in this research.

³⁶ Technology acceptance model (TAM) is a theoretical model about how technology users come to accept and use a technology. The model suggests that the perceived usefulness and perceived ease-of-use of a technology are the constructs influencing the user’s attitude toward and use the technology. According to Davis, the degree to which a person believes that using a particular system would enhance his or her job performance is the key concept of perceived usefulness, whilst the degree to which a person believes that using a particular system would be free from effort is the core concept of perceived ease-of-use of a technology in the TAM (King and He, 2006, Ma and Liu, 2004, Davis, 1989)

³⁷ Perceived usefulness (PU) is referred to the degree to which a person believes that using a particular system would enhance his / her job performance (Davis, 1993, Davis, 1989)

³⁸ Perceived ease of use (PEOU) is referred to the degree to which a person believes that using a particular system would be free of effort (Davis, 1993, Davis, 1989)

Both stroke survivors and therapists indicated that they considered both “perceived ease of use” and “perceived usefulness” as influencing factors for stroke survivors to use available ICTs to support them to self-manage exercises in the community. This indicated that PU and PEOU were the concepts required to guide stroke survivors and therapists to determine and use available ICTs for this intervention. Thus, TAM was used to frame the underpinning thinking process for stroke survivor and clinician to decide available ICTs in the programme.

The concept of self-efficacy is similar to that of PEOU and PU (Davis, 1993, Davis, 1989). Thus, self-efficacy is associated with TAM. Self-efficacy concept would suggest that PEOU and PU are the fundamental factors in the users’ behaviour for their acceptance of ICTs. Thus, self-efficacy, PEOU and PU were combined to provide a theoretical base to support the process of determining suitable ICTs to provide remote support to the uses in the programme.

In view of TAM, PEOU and PU may lead to the individuals’ actual use of a technology. Hence, in order to facilitate stroke survivors to use ICTs to continue to manage their own exercises; both PEOU and PU were adopted into the prescription process of the programme. This may help the individuals to determine that he/she will and able to use so as to personalise the programme for the individual user.

8a.2.2 A supporting model for the programme: the gear model

A model can be used to represent the process and systems in a simplified communicative form which can help to illustrate relationships between a set of elements (Sanderson and Gruen, 2006). Using a conceptual model³⁹ can assist the development of the relationships between the concepts with a framework to frame underpinning thinking and interpretation processes (Rycroft-Malone and Bucknall, 2011). Therefore, I built a new conceptual model of self-managed physical exercise manual supported with available ICTs for stroke survivors when I formed the prototype programme.

³⁹ A conceptual model is often made up of a set of concepts and suggestions which combine them into meaningful propositions (Rycroft-Malone and Bucknall, 2011)

A set of gears is used to show the architecture showing the relationships between the theories for the programme. The model was used to present the underpinning supporting system to the programme. It was built on the findings from the interviews with stroke survivors and professionals, theories, and related literature. It consists of 3 gears in which each gear represents a theory or a set of theories including self-efficacy, learning theories (includes andragogy, self-regulated learning and motor learning theory), and technology acceptance model. The model was established to articulate knowledge from integrated findings and the concepts of selected theories. It is called “Gear Model” in Figure 8a.2.2 below.

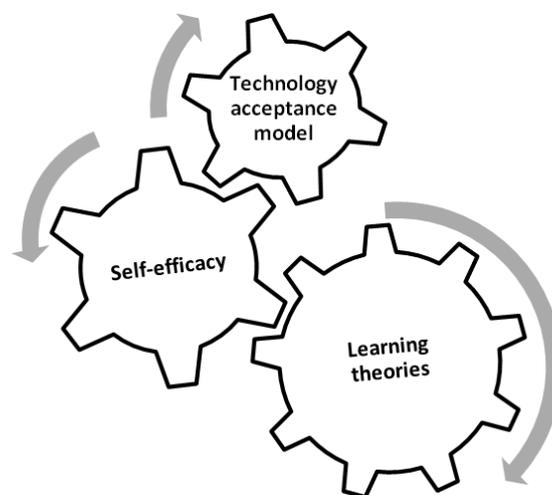


Figure 8a.2.2: The Gear Model

Constructs of the gear model

The gears in the model indicate that those theories are linked to each other and work together to drive the concept of enabling stroke survivors to self-manage their own exercise for their physical functional rehabilitation with the use of available ICTs. This also reflects the vision of this research.

The model demonstrates a conceptual system showing that how the selected theories are correlated and running together to generate cohesive theoretical support to empower stroke survivors to self-manage their own exercises with available ICTs. The gear of self-efficacy is placed in the middle of the gear set to illustrate its key

role in driving and connecting the entire conceptual system based on related evidence, the findings of the interviews with stroke survivors and therapists in this research, as well as the relationship between self-efficacy to the other theories selected for this research. The gear of learning theories represents the concept of educating stroke survivors to enhance their self-directed learning competence to control the process to learn how to self-manage their own programmes. The gear of technology acceptance model represents the concept of helping stroke survivors to decide suitable and available ICTs that they have, can and would like to use to support themselves to manage their own exercise in the way they like.

Therefore, the configuration of this model suggests the use of self-efficacy concept in conjunction with learning concepts to help stroke survivors to learn to self-manage when using the programme. In addition, this model suggests the use of self-efficacy concept together with the concepts in TAM, In view of using available technology to support a self-managed exercise manual for stroke rehabilitation.

This model also underpins the concept of empowerment⁴⁰ to stroke survivors to enhance their competence to self-manage their own rehabilitation. Empowerment can be referred to a process in which individuals are enabled to take greater control (Jones et al., 2000). The process of empowerment is in line with the reason for developing the programme, which was to find out a way to enable stroke survivors to take control over the management of their exercises for the continued recovery of their physical functioning.

Hence, the model is mainly used to drive the theoretical thinking about empowering stroke survivors to take control over the management of their own exercise. Table 8a.2.2 summarised the roles and functions of each theory/group of theories in the programme. This is to show how each theory in the model is used to provide conceptual support to the programme.

⁴⁰ Empowerment is a delicate process that enables and encourages control on patients' own terms (Jones et al., 2000)

Table 8a.2.2: Roles and functions of the theories in the gear model

Theory/ theories in the gear model	Role	Function
Self-efficacy	- Key wheel driving the gear model - Represent the importance of stroke survivors' self-confidence to manage the programme	-Driving the concept of enhancing stroke survivors' self-confidence to enable them to self-manage their own exercises and use available ICTs to do so
Learning theories:	-Represent the educational aspect in the programme -Represent a group of theories helping stroke survivors to learn how to self-manage their own exercise programmes	-Driving the concept of enabling stroke survivors to learn how to acquire knowledge and skills for the self-management of their own exercises
- Andragogy	-Represent the importance of helping adult stroke survivors to learn during the delivery of the programme	-Driving the concept of teaching adult stroke survivors to acquire knowledge and skills in relation to the management of their own programmes
- Self-regulated learning	-Represent the importance of equipping stroke survivors with the concepts and skills to regulate their own programmes as they are learning how to self-manage	-Driving the concept of teaching stroke survivors to take control over the regulation of the contents in their own programmes
- Motor learning theory	-Represent the importance of motor learning for physical functional stroke rehabilitation in the programme	-Driving the concept of facilitating stroke survivors to learn for the improvement motor functions for their physical rehabilitation
Technology acceptance model	-Represent the aspect about the application of available ICTs to support stroke survivors to self-manage their own exercises	-Driving the concept of helping stroke survivors to choose and use the ICTs that they have, would like to and can use to support themselves to continue to self-manage their own exercises

8a.2.3 Framework for programme structure: ICF model

With regards to heterogeneous features resulting from stroke; individual stroke survivors may have different physical consequences, functional needs and abilities post-stroke. Hence, the International Classification of Functioning, Disability and Health (ICF) model was adopted to frame the assessment part of the programme to assess individuals' functional needs and manage personal physical functional rehabilitation. The ICF model has been shown to be useful to develop a patient-oriented educational intervention for stroke survivors (Sabariego et al., 2013, Neubert et al., 2011). It helps to direct the prescription process towards setting more

patient-centred goals for physical functioning. The followings present how the ICF was used to frame the programme together with the combined data.

Environmental and personal influences have been considered by the participants in relation to enabling stroke survivors to self-manage their own exercises with the use of technologies from in terms of the individuals' life situation from the angle of the ICF. Suitable environment was suggested as a requirement by stroke survivors. This reflects their concern about environmental factors towards the self-management of exercises. The issues of "personalisation of the exercise manual" and "enjoyable exercises" were considered by stroke survivors and therapists. They also expressed their concern to "age of users" for the use of available technologies to self-manage exercises. These are related to personal factors in the ICF. Thus, personal and environmental factors were used to design the programme.

Stroke survivor's information about physical functional rehabilitation can be classified using the ICF. This was to assist the therapist to assess and organise the user's personal information, health related needs and conditions for physical functioning and to systematically plan the contents of the programme with stroke survivor. This may help to individualise a programme for physical functional rehabilitation.

8a.2.4 Application of guidelines

The stroke specific guidelines discussed in chapter 1 were referred to ensure the contents of the programme are in line with current health service standard for stroke rehabilitation. I cross checked the triangulated findings with the information about current recommendations for physical stroke rehabilitation in the guidelines when designing the contents to be included into the programme. I referred to the guidelines about stroke specific exercises to determine the choices of exercises to be included the programme in addition to the findings. For instance, I ensured the choices of exercises included in the programme are those recommended in the guidelines. I also ensured sections related to the assessments of impairments, activity and participation limitations and environmental factors, goal-setting and planning for rehabilitation, and the provision of information and resources were included in the programme as these are recommended in guidelines.

The common components of self-management programmes were considered including problem-solving, self-discovery, goal-setting, decision-making, resource utilisation, collaboration, knowledge, take action, reflection on progress (Jones, 2013, Jones, 2011, Lorig and Holman, 2003). This was to ensure the programme can be in line with current expectation and the standards of self-management practice.

8a.2.5 Programme development process

Written materials are commonly regarded as a useful medium to supplement and reinforce verbally delivered information to stroke survivors in studies (Hoffmann et al., 2007, Hoffmann and McKenna, 2006, Eames et al., 2003). Providing an information pack in written format has been recommended to educate stroke survivors and their carers for stroke survivors' functional rehabilitation and community reintegration (Duncan et al., 2005). Hence, the programme was developed in a written format to assist stroke survivors to self-manage. I referred to the findings summarised in the framework of figure 8a.2.2 and the components of the theoretical foundation when I formed the manual designed to help delivering the programme. I also checked the contents of the manual using the recent guidelines. Figure 8a.2.5 shows the core process to form the programme based on practical and theoretical considerations.

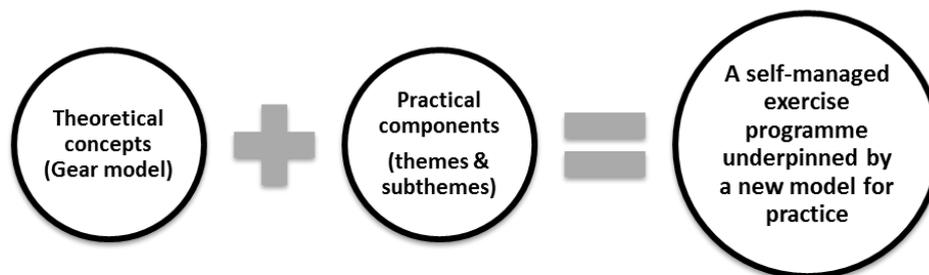


Figure 8a.2.5 Overall programme development process

Since stroke survivors can have relatively closer support from their therapists before their discharge from community stroke rehabilitation services according to the current stroke pathway, I designed the manual to be prescribed by the therapists when the stroke survivors still receive services from the community unit. This allows the patients to receive professional instruction and advice on their personalised prescriptions, and clarify any issues about the manual with their therapists before

practising alone. The manual was also designed to be used alongside routine community stroke rehabilitation services till the individuals to be discharged from the regular services. It is to provide an alternative method to prepare the individuals to continue to manage the exercises that they have been prescribed by their therapists before discharge.

Face-to-face mode was adopted as the delivery method of the manual. It is a commonly acceptable and feasible way to delivery stroke self-management interventions according to the literature. The programme is designed to be provided in one-to-one sessions between the professional and the patient.

From the findings generated of the interviews, it was clear that there was the requirement for a needs assessment in the clinical assessment part of the manual using the ICF model in addition to the components identified in the interviews.

Design of the new stroke exercise manual

This section describes how the information obtained in the reviews 2.2a and 2.2b were used to inform the development of a new stroke exercise manual together with the findings from interviews with stroke survivors. Whilst understanding stroke survivors' and therapists' needs and perceptions are important, there are many variations in practice. Hence, the information from relevant evidence, manuals and guidelines were used together with the findings from the interviews to design a clinically acceptable manual for stroke rehabilitation.

First, a list of evidenced-informed exercises was obtained from the reviews of clinical trials and systematic reviews about the effects of exercise for physical functional stroke rehabilitation. Then, the existing stroke exercise manuals and guidelines were reviewed to determine the types of exercise to be included in order to form the exercise prescription sections of the manual.

To ensure the contents and format of the manual are based on user's and provider's perspectives, the findings from the interviews with the community-dwelling stroke survivors with physical disabilities, and community physiotherapists and occupational therapists were combined to generate a framework containing factors required to

develop the manual (figure 8a.2.1, page 257). The items in the framework were used to inform the core parts of the manual.

In addition, an underpinning theoretical foundation (figure 8a.2.1.2, page 259) was built to provide a conceptual support to the entire manual. The additional themes (which are those information identified in addition to the themes directly related to the questions in the topic guide) from the interviews with stroke survivors were used to design a supplementary note to assist clinicians to prescribe the manual for individual survivors, which is detailed in section 8a.2.6 (page 286) of this chapter.

The following sections detail the prototype manual. The manual was amended after the refinement with the interviewees. The details are provided in chapter 8b.

Prototype manual

A prototype manual was developed using the components identified by professionals and stroke survivors in the interviews and the selected theories in the gear model, and guidelines for stroke. A manual was formed for the manual which contained three booklets as a package, including a user handbook, clinical checklist (Book A), action planning and prescription record (Book B) and a USB card. (See appendix 9 for the manual)

User handbook

The first section of the programme was a user handbook. It was designed to provide introductory information to the users, including stroke survivor and therapist, to explain how to use the self-management manual. Basic information, including an introduction of the programme and manual, user criteria, a list of contents in the package, steps for guiding prescription and usage, and background to the development were included in this section.

Book A: Clinical checklist

The second section is Book A, which is a clinical checklist. It is a guide for the prescription of the remotely supported and self-managed physical exercise manual for the stroke survivor. It is designed to be used by the stroke survivor and therapist

together. Four sub-sections are included in Book A including needs assessment for physical functioning and goal-setting for physical functional recovery after stroke, personalised stroke specific physical exercise prescription, selection of available ICTs, and support to self-manage exercises (see appendix 9 for Book A). Thus, Book A is designed to plan the details to be included for the individual user.

Needs assessment

A needs assessment section has been included in Book A to systematically identify individual needs for physical functional rehabilitation, in order to decide what and how to make changes to meet the needs. The unmet needs can be highlighted using a health needs assessment to provide clear objectives for the clinician to work towards to meet the needs of the individual patient. Thus, a needs assessment section was included in Book A to systematically identify individual stroke survivor's difficulties and requirements for physical functional rehabilitation. This can help both stroke survivors and therapists to focus on what is needed in the programme.

Goal-setting is a key element associated with stroke rehabilitation and the individual's goals are related to functioning (Wade, 2009, Wade, 1999). The prescription of exercises for the goals and needs of daily activities was recognised by both stroke survivors and professionals important for the self-management of stroke exercises. Therefore, it was essential to include that in the needs assessment in Book A to assist both stroke survivor and therapist to set personalised goals for functional rehabilitation together. This can help to determine the substantial actions and physical exercises or activities required to meet the identified needs to achieve the goals for physical functional rehabilitation.

Lists of choices based on the domains of the ICF: impairment, disability, activity and participation restriction, were provided in Book A for stroke survivors and therapists to select and personalise the programme for the individual stroke survivor. The choices were also the items identified in the findings of the interviews with stroke survivors and therapists. Personal and environmental factors were included as consistent with the ICF. The section was designed according to the principle of andragogy, including adults' need to know the reason for learning and the self-concept for learning.

A section for setting activity and participation goals was included as it is highlighted in current guidance and evidence in which the items were determined with the goals obtained in study 1 and 2 with the reference of ICF core set for stroke. Based on the task-oriented approach for functional stroke recovery (ISWP, 2012, NICE, 2013), and the considerations of personalisation design emerged from the triangulated data; the exercises, available ICTs and support for the programme should be determined according to the goals of performing the tasks that the individual stroke survivor would like to attain.

From the view of andragogy, the self-concept, learner's experience, readiness to learn and orientation to learn were the main concepts considered when formulating these sections. In view of self-efficacy, the stroke survivor will need to determine the goals and other items based on their self-confidence. The stroke survivor will need to select the type of feedback to provide motivation and support.

For the section of selecting ICTs, it was developed with the theoretical support of the TAM and triangulated results. Hence, the user needs to determine the preferred ICTs with the considerations of perceived usefulness, perceived ease-of-use, availability, accessibility, flexibility, sustainability and maintenance issues, technical support, user centre design and cost utility of ICTs.

A list of available ICTs was included in Book A for selection based on the findings collected from the interviews. The items should be determined by both stroke survivor and therapist. The clinician will need to discuss with his client to personalise the prescription of the programme for the individual using Book A. The therapist will need to provide professional information and advice for the patient to consider during prescription process.

Book B: Action planning and prescription record

The third section was Book B, which is an action planning and prescription record. It was designed for planning the details of the programme to meet the stroke survivor's specified and realistic goals for physical rehabilitation. It is also to be used as a personalised record for the patient to manage his/her own exercise manual. It is to provide a personalised prescription to the individual based on the assessment

results in Book A. A self-monitored progress record is included to help the individuals to monitor and regulate his/her own programme (See appendix 9 for Book B).

I first considered the triangulated findings obtained from study 1 and 2, then, I compared the results with the elements within the underpinning theoretical foundation to interpret the findings and check whether the findings could be connected with the proposed theories and models. Then, I checked the stroke guidance to understand the relationship of the findings to current recommended practice and ensure all the included components of the programme matched with the current standard for stroke rehabilitation.

It was designed based on the principles of self-efficacy, motor learning, andragogy and SRL with the support of the triangulated findings discussed earlier in this chapter. Both the clinician and patient are supposed to decide the details in Book B together.

My monthly progress record

With regard to applying the motor learning theory, the provision of extrinsic feedback via providing knowledge of result (KR) and performance (KP) were considered as I designed the monthly self-monitored progress record in Book B. Thus, the users of the manual may obtain feedback in terms of KR and KP reflecting the progress of their motor functional recovery. The record was designed for them to monitor and regulate their own exercises and progress. The user can choose the format of extrinsic feedback that he/she would like. Thus, the individual can choose to receive the feedback of KR and KP by either written texts in the printed manual or visual (or audio) format using the selected ICTs. For instance, he/she can keep video (or audio) records using a smartphone. Then, the video (or audio) records can be saved in a USB memory card affiliated with the manual to provide feedback.

USB memory card

A USB memory card was attached with each manual (See appendix 12). It contains a copy of printed manual which allows the user to have the flexibility to use an electronic version of the manual to monitor and manage own exercises. It also allows the users to have flexibility to use different kinds of available ICTs. They can also

use the card to keep the records of their own performance so as to provide feedback on their own achievement and changes. The user can also save in his/her own desktop or laptop computer, on their own email account, or share with their family members or friends on any e-forum or social media; such as facebook® or twitter®. The user may also use the memory card to keep video records to receive visual feedback from which to review and learn from the precise changes in his/her own skills in performing functional activities in addition to written records. For instance, they can use their smartphones to take and keep video records of the changes of their own physical functions and the progress of doing different types of exercises or activities. Then, they can choose to review their progress on the phone or transfer the videos to their own computers or share that to others using internet as they like.

The user can also save exercise video, information about their exercises and rehabilitation, professional advice from their doctors and/or therapists, and stories from other stroke survivors in relation to managing their own exercises and activities. They may also use the USB card to keep exercise videos or information about physical rehabilitation which they have found online; such as Youtube. The card allows them to discuss with their carers and peers to receive external support and feedback with their own records. They can also use it to keep visual and written records to show to their own family doctors and/or therapists to seek for professional advice or feedback whenever they are in doubt or have any discomfort with their exercise and activities.

8a.2.6 Additional factors

The combined findings suggest that other factors may influence stroke survivors to self-manage exercises in addition to the data discussed in theoretical triangulation. Learning from individual's experiences can inform and help to develop appropriate self-management programmes (Jones, 2011). Although some factors were not directly linked to the selected theories, they reflected the diversity of needs to self-manage exercises and to use ICTs to do so from both user's and provider's perspectives. Hence, I also considered those factors as I designed the programme.

Further items were considered as I formed the programme. For instance, “personalisation of the exercise programme” was identified as a consideration for stroke survivors to self-manage exercises. This was considered due to the concerns about “flexibility”, “age of users” and “user-centred design for personal needs and conditions” for stroke survivors to use available ICTs to self-manage exercises. As “financial issues and support” has been suggested by stroke survivors to assist them to self-manage their own exercises, the users and providers of the programme are recommended to choose the ICTs that are already available to them. This is to minimise additional cost to stroke survivors when they use the programme. A USB card containing the electronic version of the manual is also provided for reuse. This was to reduce the cost for stroke survivors. This also addresses stroke survivors’ concern about the “sustainable concept” for self-managing exercises.

The findings reflected the importance of taking user’s personal preferences and needs into account for the programme design. Hence, a personalised design concept was adopted to ensure the contents and structure of the manual can fit the user’s needs in order to encourage them to use the programme in longer term.

Supplementary note for instructor

A supplementary note was designed to provide information to assist the instructor of the manual to better personalise the contents of each manual for the individual stroke survivor (in appendix 11). The following 3 sections are included in this note:

1. Stroke-specific exercise manual for physical functional recovery

It suggests a list of evidence-based exercise components for the clinician to consider for when prescribing exercise. The therapist may still need to personalise the contents for the individual exercise manual according to the findings from the Book A and Book B of the manual. A table suggesting components for a rehabilitation exercise manual is summarised from the recent evidence and guidelines and provided in this note.

2. Suggestions for clinician to identify the stroke survivors' attitudes toward taking control of the management their own exercise to facilitate the delivery process

Stroke survivor's attitudes toward managing their own exercise may influence the individual to take control of the exercise manual. The instructor is encouraged to consider the following factors in addition to the concepts provided in the instructor's handbook including self-efficacy and self-regulatory learning when deciding the contents with the each survivor. The following possible useful attitudes were informed by stroke survivors with physical disabilities:

- Independent
- Determined
- Positive

3. Suggestions for selecting suitable available technology with stroke survivors

It aims to suggest criteria to therapists to consider when selecting suitable technology with individual survivor. This section suggests what the patient may consider when choosing technology for supporting the self-management of their own exercise. This may assist the clinician to better communicate with the individual to determine suitable technology in the decision-making process. Factors that may influence individual survivors to decide which technology to use were identified from other stroke survivors with physical disabilities as below:

- Personal preference
- Ease of understanding
- Tailored to the user condition
- Allow easy communication and interaction

8a.3 Discussion

Studies reported that it is possible and beneficial to provide stroke self-management programmes, however, the best method of providing this remains unknown (Lennon et al., 2013, Jones and Riazi, 2011). Despite stroke survivors' and therapists' perceptions of physical activity for rehabilitation have been explored (Morris et al., 2014), little was known about what stroke survivors and professionals consider important in view of helping stroke survivors to manage their own exercises with the use of available ICTs in a self-managed exercise manual.

This chapter elucidates the process to develop a new personalised, functional oriented, and self-managed stroke exercise manual supported with available ICTs based on stroke survivors' and professionals' preferences. The following research question is answered in this chapter:

“What are the components required to develop a self-managed exercise manual supported with available ICTs for physical functional stroke rehabilitation in the community?”

The components and design of the programme were informed by literature reviews, the existing guidelines for stroke rehabilitation and findings from the interviews with stroke survivors and therapists. The findings of the interviews with stroke survivors and therapists were combined in this chapter. This provided a framework containing practical components to inform the design of the programme according to both users' and providers' perspectives.

This study indicates that stroke survivors and therapists share similar views and concerns about the self-management of exercise with the use of available ICTs in the community. This is important to identify their common ideas and concerns to develop an intervention planned to be used by both of them to ensure the programme can meet the perceived needs of both parties. Despite different items and viewpoints were found between therapists and stroke survivors, this study informs components required to form the programme from both views.

Although factors affecting stroke self-management have been suggested: individual capacity, support for self-management and self-management environment (Boger et al., 2014), there was a lack of clarity about specific components required in a self-managed exercise manual supported with ICTs for functional stroke recovery as the stroke survivors' and therapists' perceptions of physical activity participation may diverge (Morris et al., 2014). Clinical guidelines, however, may not include the real experts' views, the adoption and application of guidelines by therapists should take account of individual preferences (Jones, 2010). Hence, I ensured the programme contains the components obtained from stroke survivors' interviews, in addition to therapists' perspective and referring to the recommendations of the guidelines as it was developed to ensure the programme can be used to address stroke survivors' needs and perceptions to self-manage exercises.

Individual stroke survivors may not feel confident enough to self-manage although they know what to do and have a degree of function (Jones et al., 2013b, Jones and Riazi, 2011). Similarly, although lists of items have been identified by stroke survivors and therapists in this research, it does not mean they know how to use those ideas in practice. It is necessary to assist them to think how to manage and to provide a tool for them to use in their own way.

The gear model was generated bringing together a group of theories to support the programme in this research. It suggests a new way to guide clinicians to think how to work with their clients to facilitate them to learn to take control over managing their own exercises. Combining theories provided integrated conceptual support to develop the programme using the features of different theoretical concepts whilst no single theory contains all features for the scope of this research. The model suggests a novel concept to support the self-management of stroke exercises using available ICTs for physical functional rehabilitation in the community.

This chapter is only a starting point for the development of the programme. Further work was required to confirm the contents with stroke survivors and therapists and to understand their perceptions towards the programme.

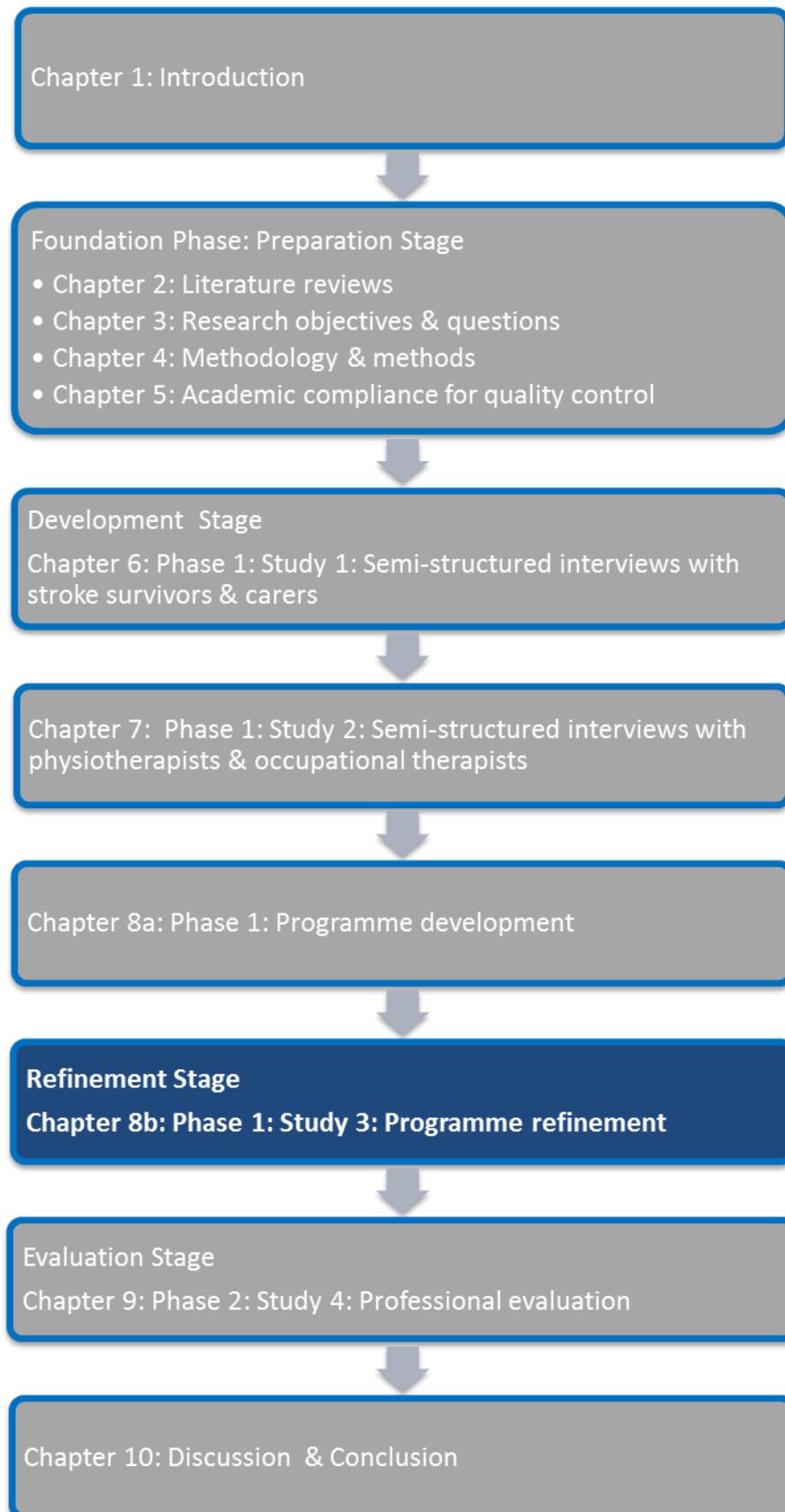
For the design of the manual, Book A was designed to be used to identify the stroke survivor's needs and conditions, which also provides lists of specific choices for the individuals to consider. Both Book A and B were designed to provide aids for the stroke survivor and the clinician to discuss. It also allows the therapist to provide information to teach the patient about managing own exercises. Book B was designed to be used by both the patient and the therapist to review and confirm the contents that they have decided. This is to facilitate the process of collaboration between them using shared decision-making approach to deliver the programme. This is further discussed in the chapter 10 of this thesis.

8a.4 Limitations

Due to the complex nature of consequences after stroke, using the model alone is insufficient to address the multiple needs of stroke rehabilitation, such as nutrition, mood disorders and cognitive issues. Further research may be helpful to explore any additional concepts which may also be useful to enrich the model and advance the theoretical support of the programme. The development of the programme may be limited by the findings collected in this research. The creation of the gear model may also be limited by the findings of the interviews.

8a.5 Summary

A new self-managed, functional oriented and personalised physical exercise manual supported with available ICTs for stroke survivors was developed in this chapter. The gear model was developed to provide a theoretical support to the programme. The findings generated from interviews with stroke survivors and therapists were integrated to synthesis the components required by both parties to design the programme, in addition to the concepts in the gear model.



Chapter 8b: Programme refinement

Chapter summary

This chapter describes the refinement of the programme developed in the previous chapter. An iterative approach was used for the refinement by asking the previously interviewed stroke survivors and therapists to review the programme developed with their inputs using two surveys. Questionnaires were designed for data collection and piloted prior to distribution. The results of the surveys are reported in this chapter. The programme was amended with this information.

Study 3: Programme refinement

8b.1 Introduction

An iterative approach was adopted to verify the programme by the informants. Therefore, the previously interviewed stroke survivors and clinicians were invited to review the programme in this study. This study was divided into 2 parts containing 2 surveys for 2 groups of participants. A mixed methods research approach was adopted in which both quantitative and qualitative data were collected and integrated to investigate different attitudes towards the first iteration of the manual. The overall refinement process is shown in figure 8b.1.

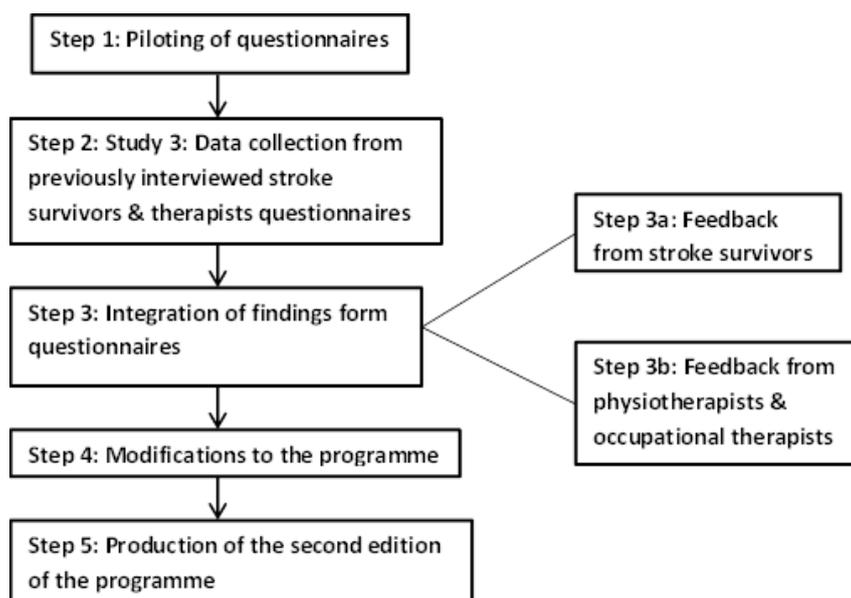


Figure 8b.1: Programme refinement process

Objectives

The objectives of this chapter are listed below.

- Designing and piloting the questionnaires for data collection
- Refining the prototype programme using the opinions and comments from the stroke survivors and therapists who previously contributed to develop the programme to verify and adjust the components
- Modification of the prototype using the opinions collected from the interviewed stroke survivors and therapists to produce a new edition of the programme

Aim

The purpose of study 3 was to understand what stroke survivors and clinicians thought about the usability of the prototype manual, and to check ways in which it could be improved to better reflect their needs and support the use of the programme.

Study design

Using both quantitative and qualitative studies allows generation of knowledge that is not available from only one of them by creating a wider picture in a mixed methods study (Creswell and Plano Clark, 2011). Thus, a mixed methods research approach was used to gain a more complete understanding of the respondents' comments and opinions towards the prototype manual in this study. This aimed to inform refinement of the manual with rich knowledge emerging from both types of data (Creswell et al., 2011, Creswell and Plano Clark, 2011, Teddlie and Tashakkori, 2009).

Method

Surveys were used to collect comments and opinions from the stroke survivors and therapists, who had previously contributed their information to develop the programme in this study. The surveys were used to explore whether the contents of each part of the manual could be understood by the respondents. This allowed the

verification of the components of the manual with the participants involved in the development process. Questionnaires were used to collect the data.

Administration methods and procedures

Two types of methods were employed to administer the questionnaires: interviewer-administrated and self-administrated methods for two different groups of participants.

Interviewer-administrated questionnaires were used for the stroke survivors. This was to enable explanation to the stroke survivors for any questions about the questions and manual whenever they needed. This also helped to increase the response rate of stroke survivors via direct face-to-face collection of the completed questionnaires.

I first contacted each participant to explain the purpose of this survey by phone. Then, I arranged a face-to-face session with the stroke survivor. I explained the purpose of the study, survey, the questionnaire and answered his/her questions before going through the whole manual and questionnaire with the stroke survivor and the carer. I also gave them a cover letter, information sheet and copy of the prototype manual. I answered their questions about the programme and the survey. Then, I asked each participant to sign the consent forms before collecting data using the questionnaire. I invited each participant to answer all the questions during the session before collecting the questionnaire at the end of the session.

Questionnaires were self-administered by the therapists. This was to fit in their busy work schedules. This could provide flexibility for them to complete and return the questionnaires at their convenience.

I first explained the purpose of the survey to each interviewed therapist by phone or email. Then I sent a copy of the prototype manual to each therapist. I sent a cover letter, information sheet, consent form and questionnaire to each by email. Each of them was given 2 weeks to read, complete and return the signed consent forms and questionnaire via email or post according to their preferences.

One participant preferred to have a face-to-face session. Thus, I had a 1-hour visit with the participant to explain this survey, sign consent form, and collected completed questionnaire in person instead of using email.

8b.2 Development and piloting of questionnaires

Two steps were involved in developing the questionnaires. The questionnaires were developed before being piloted with a stroke survivor and a therapist.

8b.2.1 Questionnaire development

A series of statements was presented expressing different attitudes and viewpoints toward different parts of the manual. The set of statements was designed to explore their attitudes towards the contents of Book A of the manual, plus another set was designed for the same purpose to Book B. The respondents were asked to rate their agreement with each statement. Statements were structured in positive and negative ways to ensure the respondents answered each question carefully.

Closed and open-ended questions were used. Closed questions were designed to quantify individuals' comments on the usability of the manual. Open-ended questions were designed to explore their views on how the manual could be improved (Wales, 2009, Buckingham and Saunders, 2004, Fink, 2003).

Likert scale was the ordinal level scale used to measure the responses of the participants for the closed-ended questions to assess their attitudes and comments toward the contexts of the manual (Allen and Seaman, 2007, Jamieson, 2004, Likert, 1932). The selection of Likert scale was to measure and categories the level of agreement or disagreement of the respondents towards the contents of the prototype manual via asking them to evaluate a list of statements. The participants were also asked to provide their opinions using open-ended questions, for which, space was given to write down their thoughts and comments about the manual. There was no difference in psychometric properties between different points of Likert scales including mean, reliability and exploratory factor analysis (Leung, 2011).

A 5-point scale was used in this study. This was to provide a range of choices of agreement and disagreement for respondents to select to express the desired levels of their comments whilst keeping the scale simple for the respondents to use. The scale ranging from strongly agree, agree, and disagree to strongly disagree was assigned. The choice of 'uncertain' was included as an option in some questions to collect particular types of responses, since the answers to some questions could be neutral. An example is shown in figure 8b.2.1 below.

There are enough instructions provided for the user to monitor his/her progress with this record	
<i>Strongly agree</i>	<input type="checkbox"/>
<i>Agree</i>	<input type="checkbox"/>
<i>Uncertain</i>	<input type="checkbox"/>
<i>Disagree</i>	<input type="checkbox"/>
<i>Strongly disagree</i>	<input type="checkbox"/>
Please write your suggestion (if any) below:	
<hr/>	

Figure 8b.2.1: An example of a statement used in the questionnaire for refinement

Validation of questionnaires

The following validation procedures performed to validate the questionnaires. Face validity⁴¹ of the questionnaires was considered as it was necessary to ensure the questions could be used to collect the specific opinions and comments to refine the developed programme. In addition, content validity⁴² of the questionnaires was considered to ensure the questionnaires contained questions to achieve the aim of the survey.

The questionnaires were validated with 2 supervisors experienced in stroke rehabilitation and stroke research to check the relevance of the questions. Two lay

⁴¹ Face validity indicates an instrument appears to measure what it is supposed to measure. It is based on subjective judgement (Gravetter and Forzano, 2012, Portney and Watkins, 2009)

⁴² Content validity refers to the extent to which an instrument cover all the elements that reflect the variable being studied (Gravetter and Forzano, 2012, Portney and Watkins, 2009)

native English speakers were consulted to confirm the questions and prototype manual were understandable and clear for English speakers before piloting the questionnaires.

8b.2.2 Piloting the questionnaires

Piloting can help to check how the questionnaires work via examining the logistics of administering the questionnaires to ensure that they are usable in the actual survey. (Boynton and Greenhalgh, 2004, Buckingham and Saunders, 2004, Bowling and Ebrahim, 2005, Rattray and Jones, 2007, Wales, 2009). Hence, the questionnaires were piloted to determine their usability to collect particular opinions from people who were similar to the intended recipients in the main surveys. This helped to identify any detail that may need to be addressed before the surveys to ensure the questionnaires could be used to collect the data from similar target respondents.

I designed the questionnaires for 2 groups of participants: stroke survivors and physiotherapists and occupational therapists. The questionnaire designed to collect data from stroke survivors was piloted with one stroke survivor and the questionnaire designed to collect data from clinicians was piloted with one physiotherapist.

Piloting with a stroke survivor and a carer

Piloting was conducted with a stroke survivor with physical mobility difficulties and his carer. This was to verify the questions and refine the structure and content of the questionnaires for stroke survivor, and the manual from user's view. The carer provided supplementary information to support the stroke survivor whilst completing the questionnaire.

Piloting with a professional

Piloting was conducted with an independent researcher, who was a physiotherapist and experienced researcher for physical stroke rehabilitation. This was to verify the questions and refine the structure and content of the questionnaires, and the manual.

I first explained the purpose of this study and answered all questions before going through the whole manual and questionnaire with the participant. The participant was given the prototype manual and questionnaires to read and think for 2 weeks.

Results of piloting the questionnaires

These pilots indicated that it was feasible to use the questionnaires to collect comments and opinions from stroke survivors and professionals. It was workable to adopt the methods and procedures to administer the questionnaires for data collection.

The respondents reported some problems with the wording of the questions and manual, including a few spelling errors. They made a few suggestions to simplify the wording. The questions elicited useful information to explore what the individual respondent thought about the usability of the prototype programme.

8b.3 Main studies

Main surveys were conducted with the targeted respondents after amending the questionnaire and manual based on the pilot results.

Participants

For the main surveys, all 18 previously interviewed stroke survivors were invited to participate in this survey. All 7 previously interviewed physiotherapists (PTs) and occupational therapists (OTs) were also invited to participate.

Data analysis

The ordinal data collected with closed questions were analysed to explore the attitudes and comments on the programme. The free text responses to open-ended questions were analysed to yield wider understanding what they thought about the manual. The responses were reported separately in the result section.

Quantitative data analysis

Descriptive statistics were used to provide quantitative summary of the comments and attitudes towards the contents of the manual.

Microsoft Excel 2007 software was used to manage the quantitative data and create bar charts to display results. I coded the collected ordinal data before entering them into the Excel files for analysis. The IBM SPSS statistics version 21 was used to generate descriptive statistical information.

Central tendency⁴³ of the numerical data was measured to describe the distribution of results in the dataset. With regards to the ordinal nature of the data, medians⁴⁴ were measured and reported to illustrate the central tendency of distribution for most of the dataset in this study. This helped to show the overall tendency of attitudes towards each part of the manual. For some statements containing nominal scale data, modes⁴⁵ were calculated to show the distribution of the central tendency of findings.

Qualitative data analysis

The role of the qualitative component in study 3 was to explore the issues emerging from the contents of the free written response provided by the respondents. Qualitative findings helped to expose the reasons of their responses shown in descriptive analysis. This also allowed me to glean further information to identify the items needed to be refined in the manual so as to determine possible solutions for the improvement of the programme based on users' and providers' perspectives.

⁴³ Central tendency is a descriptive statistic representing averages that are representative of a distribution. It provides information about a representative value of the dataset (Portney and Watkins, 2009, Gaur and Gaur, 2006)

⁴⁴ Median is a measure of central tendency of the findings representing 50th percentile in a ranked distribution of scores. It is a middle point of value in a range in which all cases have sorted into ascending or descending order (Portney and Watkins, 2009, Gaur and Gaur, 2006, Buckingham and Saunders, 2004)

⁴⁵ Mode is a measure of central tendency representing the most frequently occurred score in the dataset (Portney and Watkins, 2009, Gaur and Gaur, 2006)

Qualitative content analysis was used to analyse the written answers to the open-ended questions. In particular, thematic analysis was the technique used. This identified and determined the dimensions required for improvement in the manual. The identified themes and subthemes were further analysed to synthesise actions required to amend the programme from the service user's and provider's comments and suggestions. Absolute frequencies of the subthemes were reported to describe how often the issues were being emphasised by the respondents in order to systematically analyse, compare and interpret the data. This helped me to establish a clear understanding of the collected responses.

Data integration

Quantitative data can provide statistical information to describe the overall pattern of the information from the respondents and to verify the contents, whilst qualitative data can help to explore further understanding about the responses. Hence, quantitative and qualitative data were integrated to further analyse the respondents' attitudes and opinions towards the same issue about the manual. This may help to figure out how to refine the programme according to their responses.

8b.4 Ethics approval & NHS governance permission

University research ethics approval and NHS governance permission were granted before this study. The approval letters can be found in appendix 1 and 2.

8b.5 Results

A total of 15 stroke survivors were recruited for study 3a. Three of the previously interviewed stroke survivors were not included in this study as one had a further stroke and was seriously depressed, one did not want to participate due to the change of his post-stroke fatigue, and the third one had moved house and was uncontactable.

A total of 6 therapists, including 3 PTs and 3 OTs were recruited in study 3b. One previously interviewed OT was unable to participate due to maternity leave.

Descriptive statistics of the collected quantitative data are presented below. The results obtained from stroke survivors and therapists were reported to illustrate the findings from each group of respondents. Frequencies are reported to describe the findings from a total of 21 respondents to illustrate the quantified comments and attitudes of the respondents towards different parts of the manual.

Bar charts display the combined results. This helped to describe the details of the quantified attitudes and comments from each group of population in this study. The label “ss” in the following tables and bar charts represents “stroke survivors”, whilst the label “prof” represents PTs and OTs.

The results of the free responses collected with open-ended questions are reported in a separated qualitative section in 8b.5.2.

8b.5.1 Quantitative results

Part 1: Introduction section of the manual

Statement Part1.1:

This introduction provided all the necessary information to understand the programme

The following table was used to analyse the descriptive statistical data for the surveys. The same kind of table was used to analyse the rest of the statements in this study.

Table 8b.5.1.1: Frequency table of statement 1

Descriptive statistics		
Total valid numbers	21	prof: 6 ss: 15
Median	2	
Range	3	Minimum: 1 Maximum: 4
Percentiles		
(1st quartile) 25	1	
(3rd quartile) 75	2	
Frequency		Percent
Strongly agree (1)	9	42.9
Agree (2)	10	47.6
Disagree (4)	2	9.5

Nine (42.9%) and ten (47.6%) respondents strongly agreed and agreed with this statement respectively. The median is 2⁴⁶, which indicated that the overall tendency of total 21 respondents was to agree with the statement. Therefore, they tended to agree that the introduction section provided all the necessary information to understand the programme. However, two (9.5%) respondents disagreed with the statement. This was further investigated in qualitative section. The results are illustrated in figure 8b.5.1.1 below.

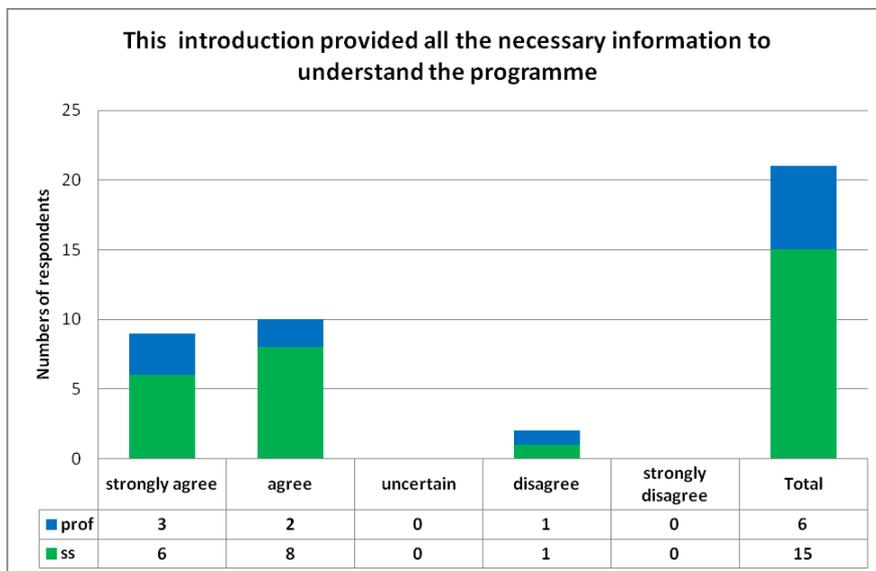


Figure 8b.5.1.1: Combined bar charts showing the numbers of respondents for statement 1

⁴⁶ Coding of median for positive statement: 1=strongly agree, 2=agree, 3=uncertain, 4=disagree, 5=strongly disagree.

Coding of median for negatively structured statement: 1=strongly disagree, 2=disagree, 3=uncertain, 4=agree, 5=strongly agree

Statement 1.2:

This introduction section helped me to understand the background of this manual

All respondents agreed the introduction was helpful for them to understand the background of the manual. There were 9 (42.9%) and 12 (57.1%) respondents strongly agreed and agreed with this statement respectively. The median is 2, which showed that they tended to agree with the statement. The results are illustrated in figure 8b.5.1.2 below.

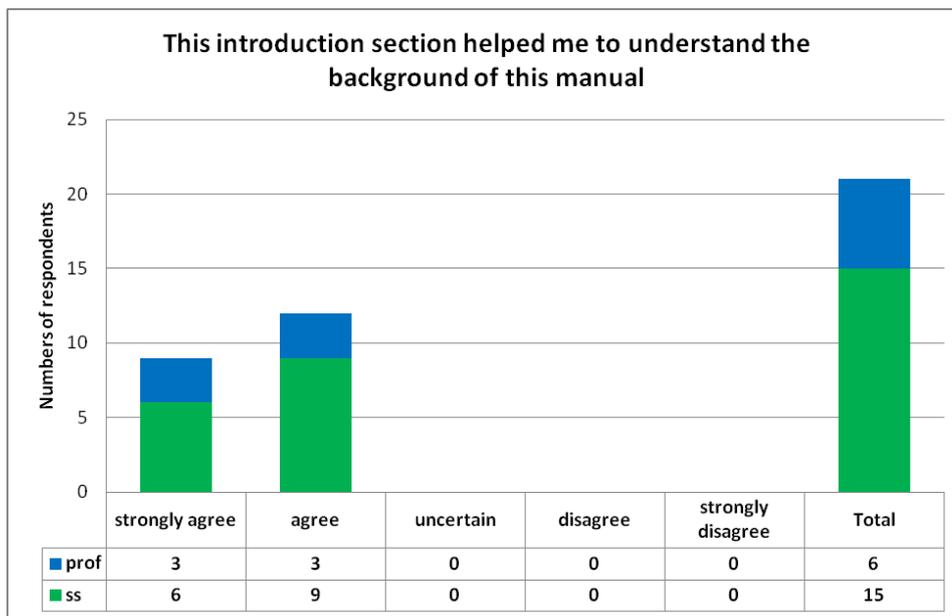


Figure 8b.5.1.2: Combined bar chart showing the numbers of respondents for statement 2

Statement 1.3:

It is difficult to understand something in the introduction

Four (19%) and eleven (52.4%) respondents strongly disagreed and disagreed this statement respectively. The median is 2, which informed that the overall tendency was to disagree with the statement. Therefore, they tended to disagree that it was difficult to understand something in the introduction. However, there were 6 (28.6%) respondents agreed with the statement. The 'difficult' aspects were further analysed and are reported in the qualitative results section This provides the details about the difficulties and what is needed to be modified to make the content easier to understand. The results are illustrated in figure 8b.5.1.3 below.

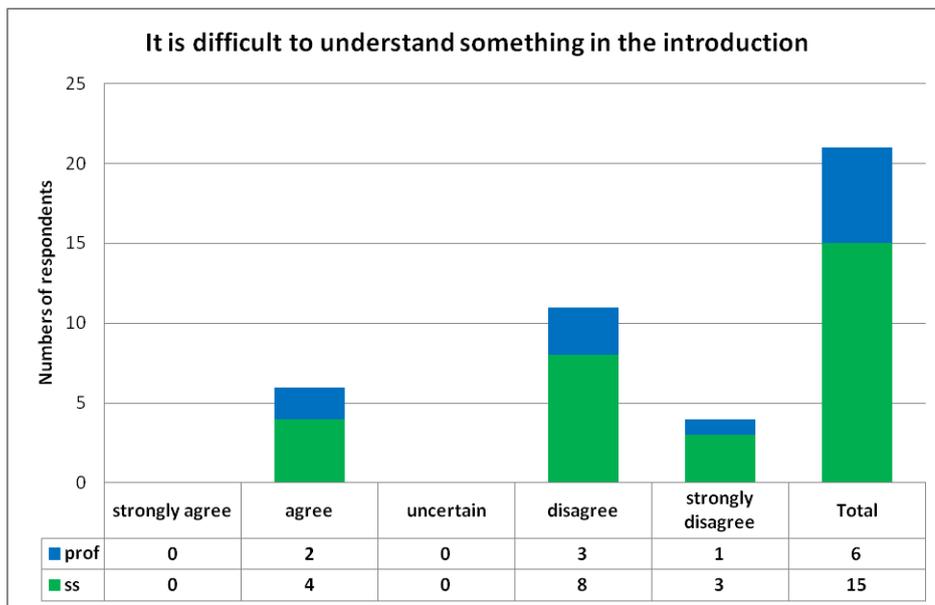


Figure 8b.5.1.3: Combined bar chart showing the numbers of respondents for statement 3

Statement 1.4:

Different parts of the manual have been clearly described in this introduction

Eight (38.1%) and eleven (52.4%) respondents strongly agreed and agreed this statement respectively. The median is 2, which informed that the overall tendency was to agree with the statement. Therefore, the respondents tended to agree that different parts of the manual have been clearly described in this introduction. However, two respondents (9.5%), one stroke survivor and one therapist strongly disagreed and disagreed with the statement. The results are reported in figure 8b.5.1.4 below.

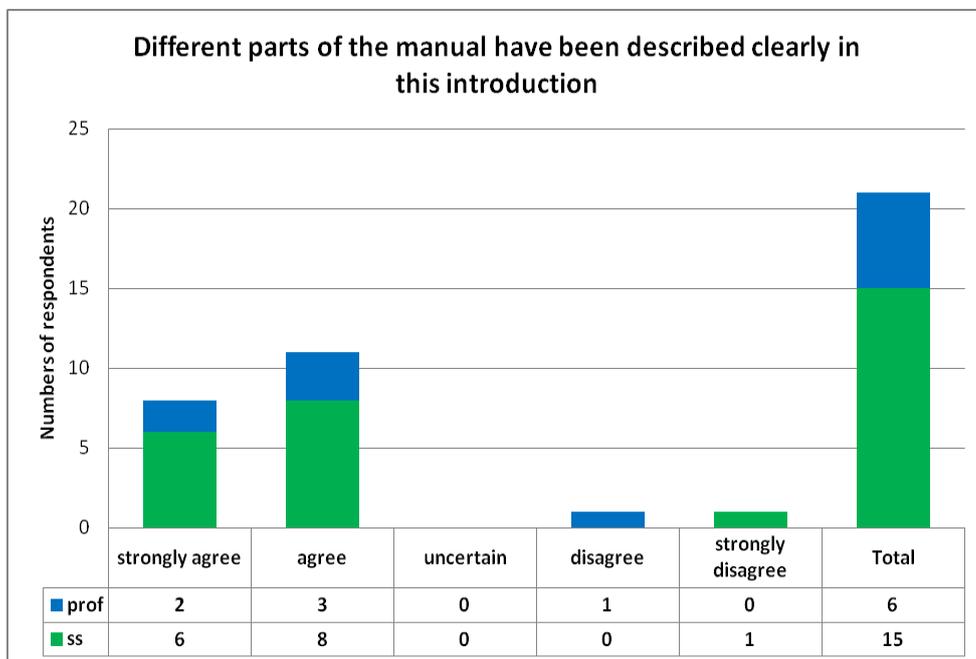


Figure 8b.5.1.4: Combined bar chart showing the numbers of respondents for statement 4

Statement 1.5:

The length of this introduction is appropriate

Six (28.6%) and 13 (61.9%) respondents strongly agreed and agreed with the statement respectively. The median is 2, which indicated that the overall tendency was to agree with the statement. Therefore, the respondents tended to agree that the length of this introduction was appropriate. However, two (9.5%) respondents disagreed with the statement. The results are illustrated in figure 8b.5.1.5 below.

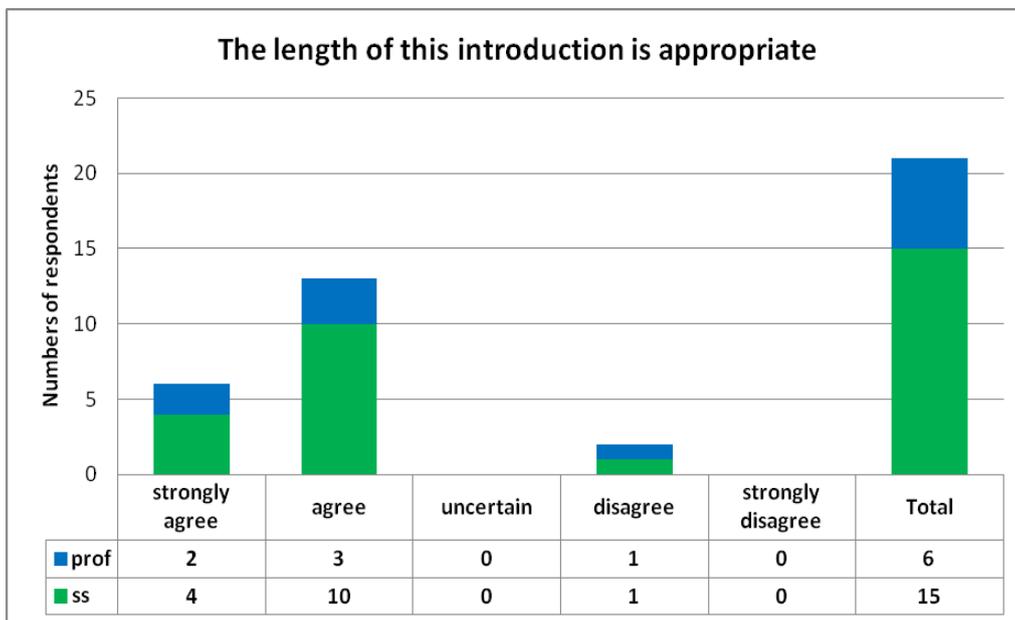


Figure 8b.5.1.5: Combined bar chart showing the numbers of respondents for statement 5

Statement 1.6:

Is something in the introduction that could be better?

Twelve (57.1%) respondents reported “Yes” for this statement. The mode for this statement is 1, which indicated that the majority of the respondents suggested that the introduction should be improved. The results are illustrated in figure 8b.5.1.6 below. The details of their suggested improvements are reported in the qualitative section of this chapter.

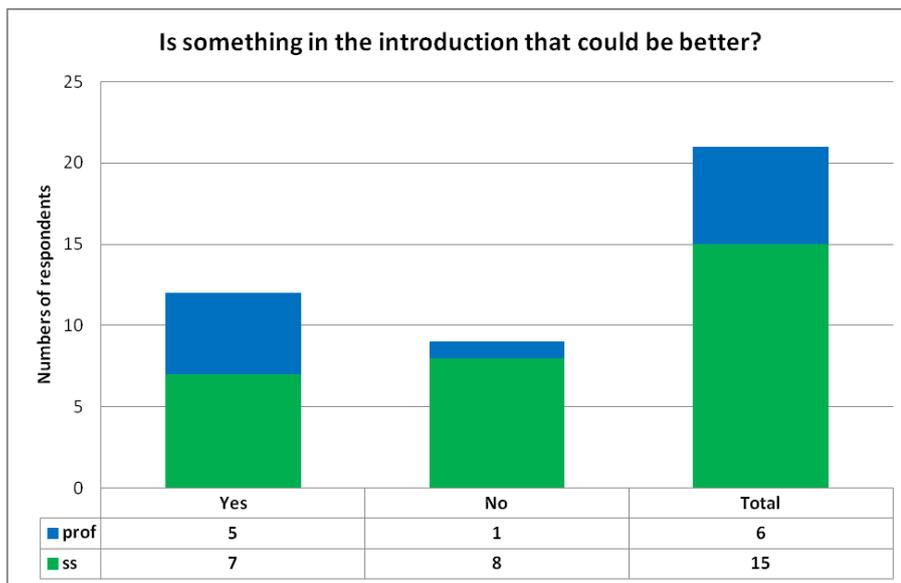


Figure 8b.5.1.6: Combined bar chart showing the numbers of respondents for statement 6

The results of central tendency implied that the respondents generally agreed the introduction provided necessary information for them to understand the programme (median: 2⁴⁷, 90.5%), it helped them to understand the background of the manual (median: 2, 100%), different parts of the manual were described clearly (median: 2, 90.5%), the length of it was appropriate (median: 2, 90.5%), and the contents were not difficult to understand (median: 2, 71.4%). However, over half of the respondents suggested it could be improved (mode: 1⁴⁸, 57.1%).

⁴⁷ Median=2 indicates the respondents generally agreed with the statement.

⁴⁸ Mode=1 indicates the majority of the respondents reported “Yes” to the statement.

8b.5.2 Part 2: Book A: Clinical checklist

Statement Part 2.1:

I could understand the contents of this checklist

All respondents agreed the checklist was understandable. Eight (38.1%) and thirteen (61.9%) respondents strongly agreed and agreed this statement respectively. The median is 2, which indicated that the overall tendency was to agree with the statement. The results are illustrated in figure 8b.5.2.1 below.

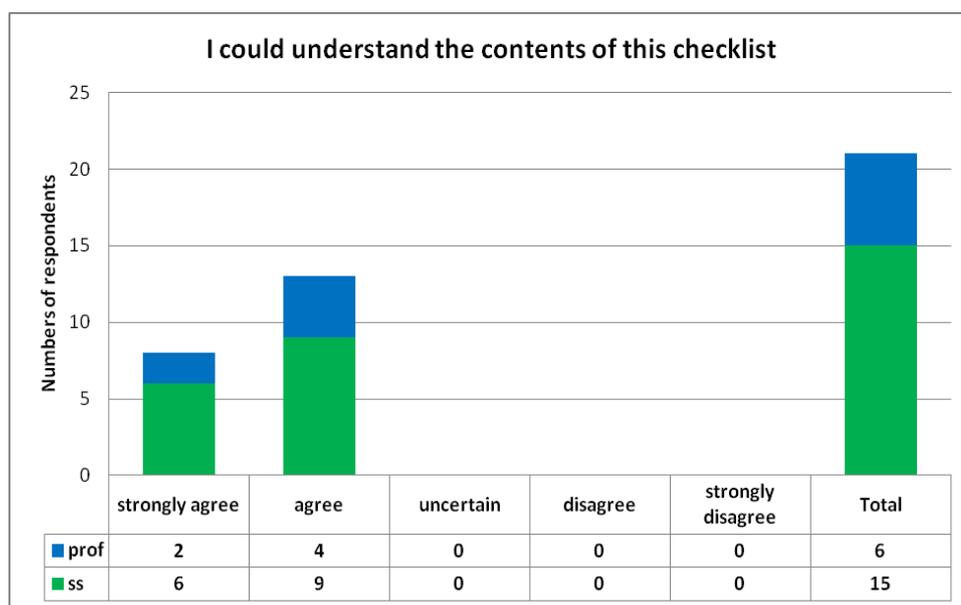


Figure 8b.5.2.1: Combined bar chart showing the numbers of respondents for statement 1

Statement 2.2:

There are enough instructions for me to understand how to use this checklist

Five (23.8%) and fifteen (71.4%) respondents strongly agreed and agreed with this statement respectively. The median is 2, which shows that the overall tendency was to agree with the statement. Therefore, the respondents tended to agree that there were enough instructions for them to understand how to use the checklist. However, one (4.8%) respondent disagreed with this statement. The results are illustrated in figure 8b.5.2.2 below.

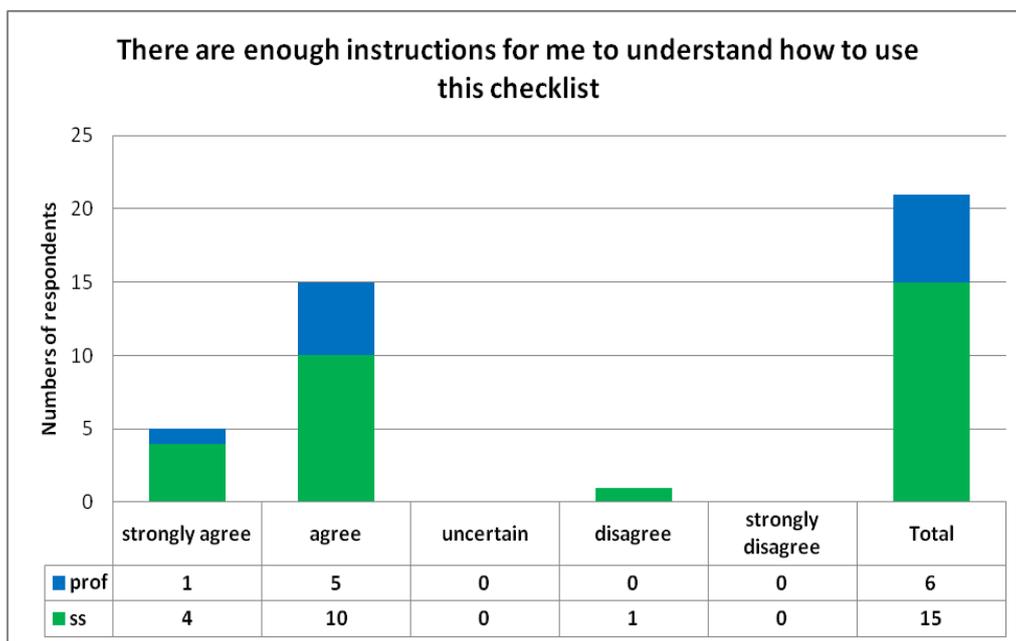


Figure 8b.5.2.2: Combined bar chart showing the numbers of respondents for statement 2

Statement 2.3:

This checklist provides enough items to decide necessary items in a personalised and self-managed physical exercise programme for a stroke survivor to practise after his/her discharge

All respondents agreed the checklist provided sufficient items to determine necessary components for a personalised and self-managed physical exercise manual for stroke survivors to practice after discharge. Nine (42.9%) and twelve (57.1%) respondents strongly agreed and agreed that respectively. The median is 2, which implied that the overall tendency was to agree with the statement. The results are illustrated in figure 8b.5.2.3 below.

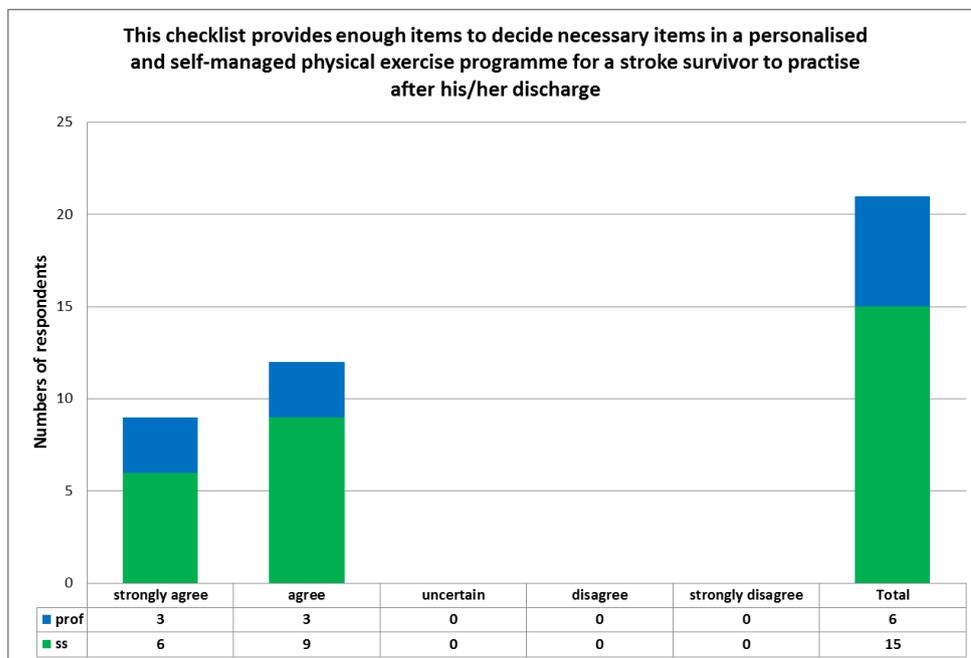


Figure 8b.5.2.3: Combined bar chart showing the numbers of respondents for statement 3

Statement 2.4:

This checklist provides enough items required to decide on the suitable and available information and communication technologies for this programme

Nine (42.9%) and eleven (52.4%) respondents strongly agreed and agreed with this statement respectively. The median is 2, which indicated that the overall tendency was to agree with the statement. Therefore, the respondents tended to agree that the checklist provided enough items required to decide on the suitable and available information and communication technologies for this programme. However, one (4.8%) respondent disagreed with this statement. The results are illustrated in figure 8b.5.2.4 below.

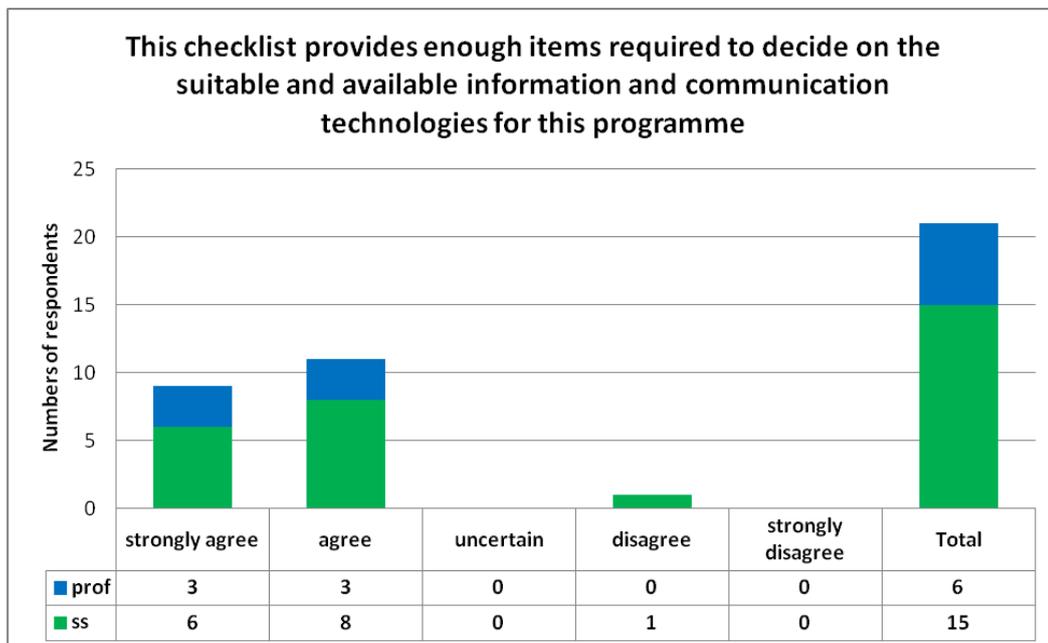


Figure 8b.5.2.4: Combined bar chart showing the numbers of respondents for statement 4

Statement 2.5:

This checklist is suitable to be used by both a stroke survivor and a physiotherapist/occupational therapist to set down a personalised and self-managed exercise programme

Seven (33.3%) and ten (47.6%) respondents strongly agreed and agreed with this statement respectively. The median is 2, which showed that the overall tendency was to agree with the statement. Therefore, the respondents tended to agree that the checklist was suitable to be used by both a stroke survivor and a physiotherapist/occupational therapist to set down a personalised and self-managed exercise manual. However, one (4.8%) and three (14.3%) respondents were uncertain or disagreed with the statement respectively. Details of their concerns and suggestions for improvements were further analysed and reported in the qualitative section. The results are illustrated in figure 8b.5.2.5.

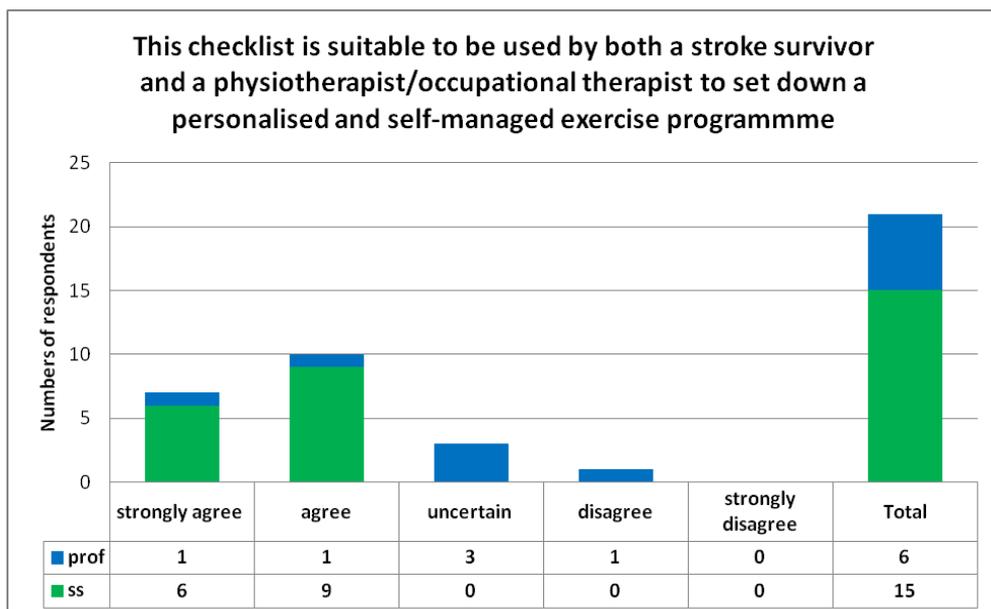


Figure 8b.5.2.5: Combined bar chart showing the numbers of respondents for statement 5

Statement 2.6:

It is difficult to understand something in this checklist

Four (19%) and fourteen (66.7%) respondents strongly disagreed and disagreed with this statement respectively. The median is 2, which implied that the overall tendency was to disagree with the statement. Therefore, the respondents tended to disagree that the checklist was difficult to understand. However, three (14.3%) respondents disagreed with this statement. This was further analysed in qualitative section. The results are illustrated in figure 8b.5.2.6.

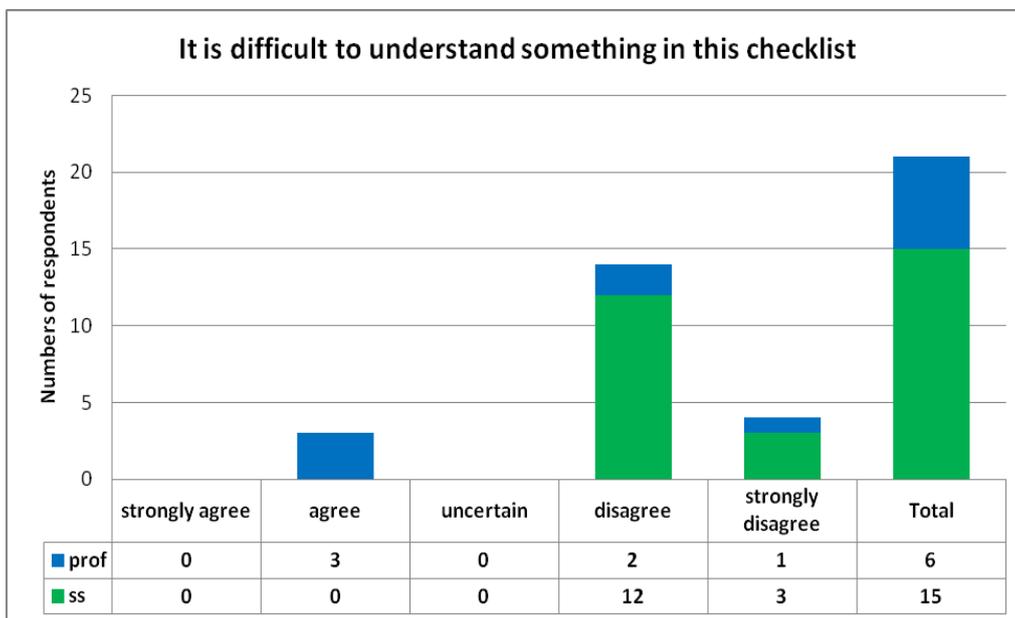


Figure 8b.5.2.6: Combined bar chart showing the numbers of respondents for statement 6

Statement 2.7:

Is there something in this checklist that could be better?

Eleven (52.4%) respondents reported “Yes” to this statement. The mode for this statement is 1, which indicated that there were more respondents suggesting the checklist could be better. However, the frequencies of both views were similar. This was further analysed in qualitative section. The results are shown in figure 8b.5.2.7.

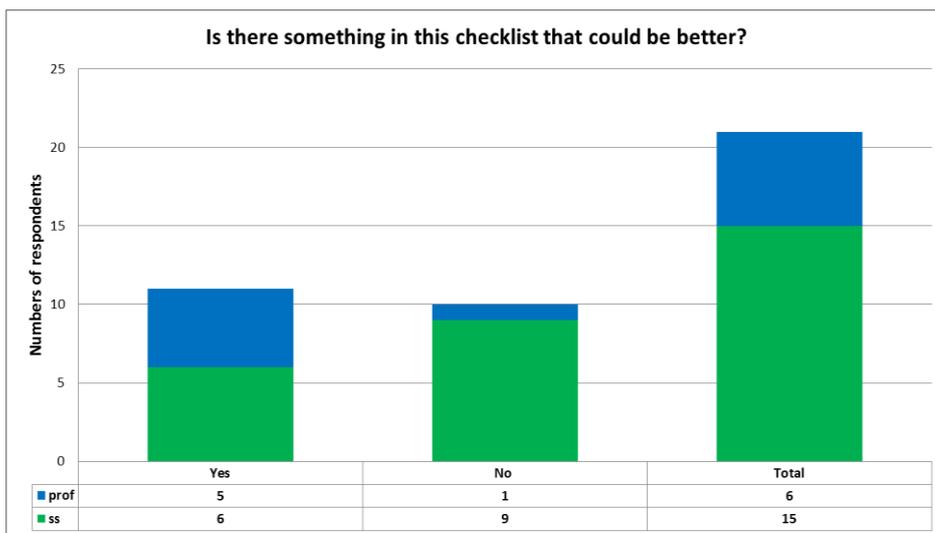


Figure 8b.5.2.7: Combined bar chart showing the numbers of respondents for statement 7

The results indicate that respondents generally agreed that the contents of Book A were understandable to them (median: 2, 100%), the instructions were sufficient for them understand how to use it (median: 2, 95.2%), it contained enough items for them to decide necessary components within a self-managed and remotely supported exercise manual for stroke survivors (median: 2, 100%), and it included sufficient items for them to determine available technologies to support stroke survivors to manage their own exercise manuals (median: 2, 95.2%). They also agreed that Book A was suitable for stroke survivors and therapists to design personalised and self-managed exercise manuals (median: 2, 80.9%).

However some respondents were uncertain or disagreed with the suitability of using it. Although they generally agreed that it was not difficult to understand the contents in Book A (median: 2, 85.7%), there were still over half of the respondents indicated that it should be improved (mode: 1, 52.4%).

8b.5.3 Part 3: Book B: Action planning & prescription record

Statement Part 3.1:

I could understand the contents of this record

All respondents agreed that the contents of the record were understandable. Four (19%) and seventeen (81%) respondents strongly agreed and agreed with this statement respectively. The median is 2, which indicated that the overall tendency was to agree with the statement. The results are illustrated in figure 8b.5.3.1 below.

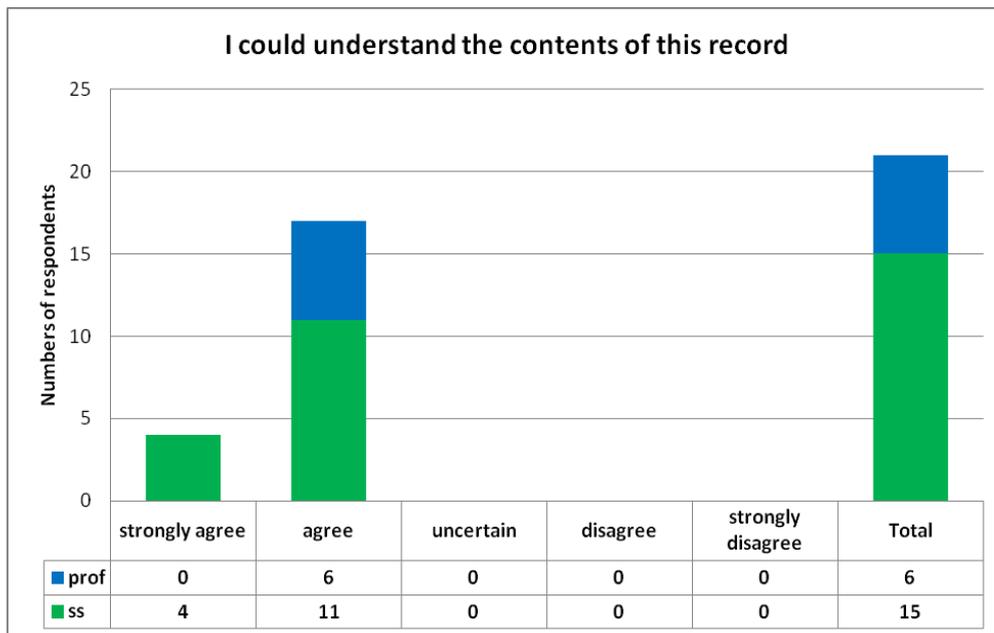


Figure 8b.5.3.1: Combined bar chart showing the numbers of respondents for statement 1

Statement 3.2:

There are enough instructions provided for me to understand how to use this record

Three (14.3%) and sixteen (76.2%) respondents strongly agreed and agreed with this statement respectively. The median is 2, which indicated that the overall tendency was to agree with the statement. Therefore, the respondents tended to agree that there are enough instructions provided for them to understand how to use this record. However, two (9.5%) respondents disagreed with the statement. This was further analysed in qualitative section. The results are illustrated in figure 8b.5.3.2 below.

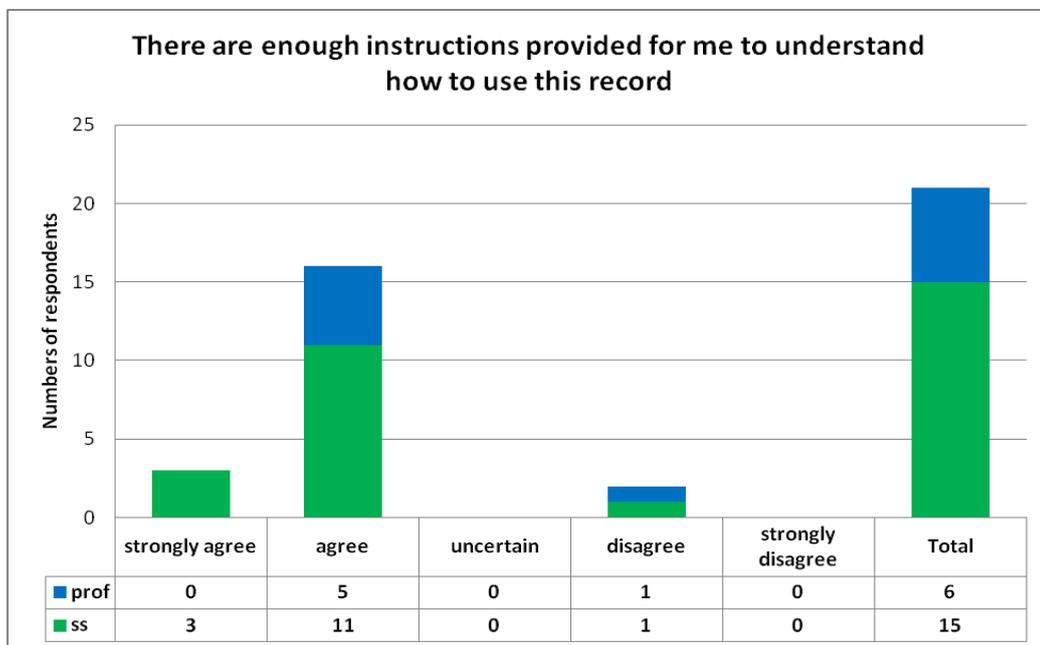


Figure 8b.5.3.2: Combined bar chart showing the numbers of respondents for statement 2

Statement 3.3:

This record contains enough necessary items for a stroke survivor to manage a personalised exercise programme supported by available technologies

Six (28.6%) and eleven (52.4%) respondents strongly agreed and agreed with this statement respectively. The median is 2, which showed that the overall tendency was to agree with the statement. Therefore, the respondents tended to agree that the record contains enough necessary items for a stroke survivor to manage a personalised exercise manual supported by available technologies. However, one (4.8%) and three (14.3%) respondents were uncertain and disagreed with the statement respectively. This was further analysed in qualitative section. The results are illustrated in figure 8b.5.3.3 below.

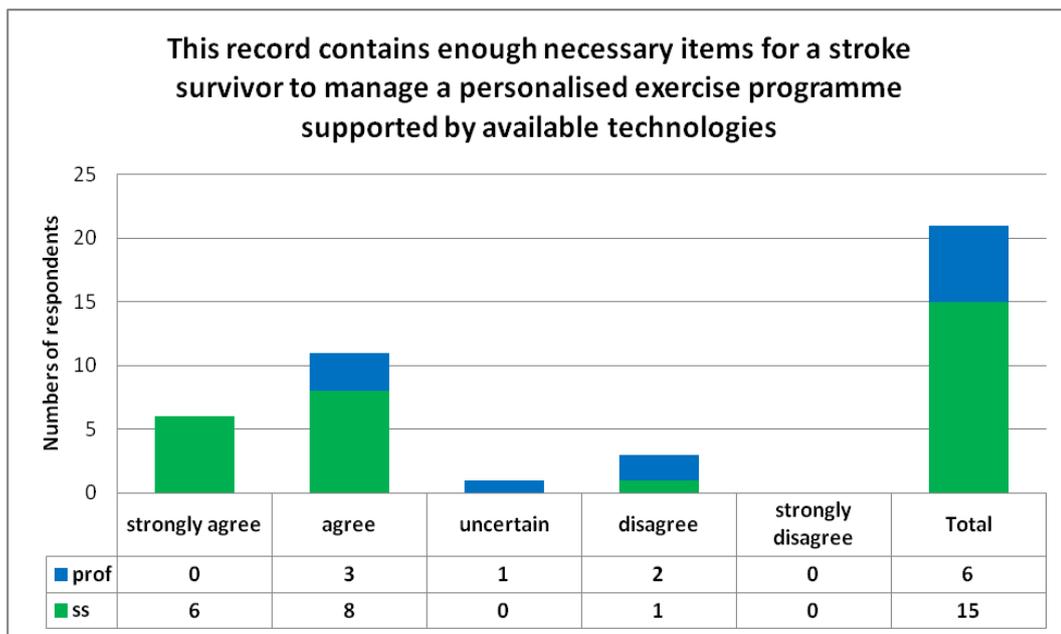


Figure 8b.5.3.3: Combined bar chart showing the numbers of respondents for statement 3

Statement 3.4:

I feel this record is suitable to be used by a stroke survivor alone after discharge

Five (23.8%) and eight (38.1%) respondents strongly agreed and agreed with this statement respectively. The median is 2, which indicated that the overall tendency was to agree with the statement. Therefore, the respondents tended to feel that the record was suitable to be used by a stroke survivor alone after discharge. However, five (23.8%), one (4.8%) and two (9.5%) respondents were uncertain, disagreed and strongly disagreed with the statement respectively. This was investigated in qualitative section. The results are shown in figure 8b.5.3.4 below.

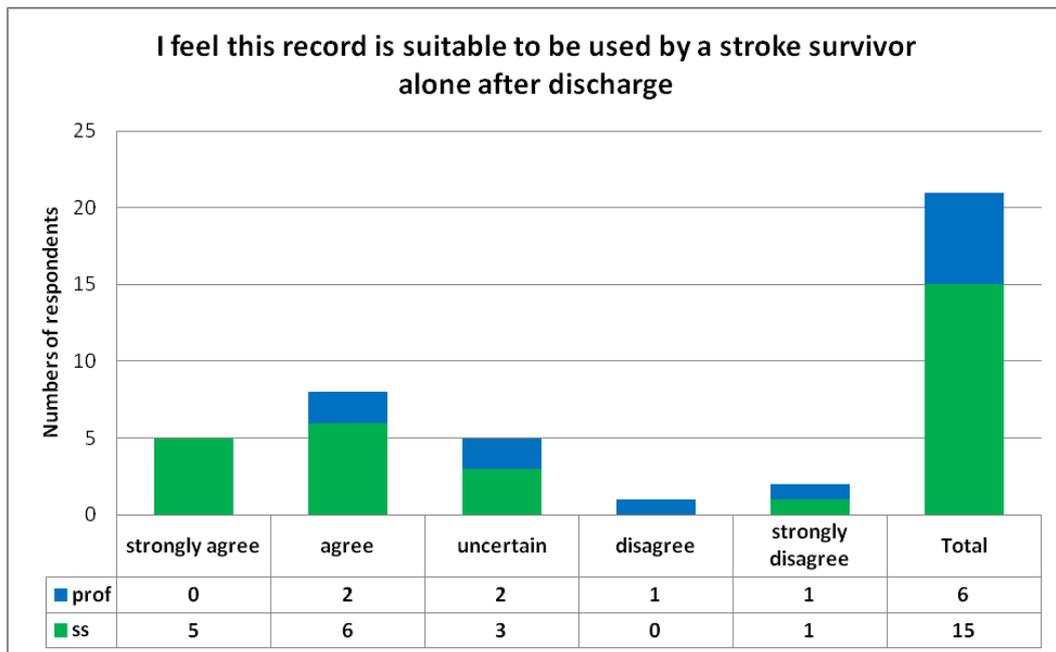


Figure 8b.5.3.4: Combined bar chart showing the numbers of respondents for statement 4

Statement 3.5:

There are enough instructions for the user to monitor his/her progress with this record

Five (23.8%) and twelve (57.1%) respondents strongly agreed and agreed with this statement respectively. The median is 2, which demonstrated that the overall tendency was to agree with the statement. Therefore, the respondents tended to agree that there are enough instructions for the user to monitor his/her progress with the record. However, four (19%) respondents were uncertain about the statement. This was further investigated in qualitative section. The results are illustrated in figure 8b.5.3.5 below.

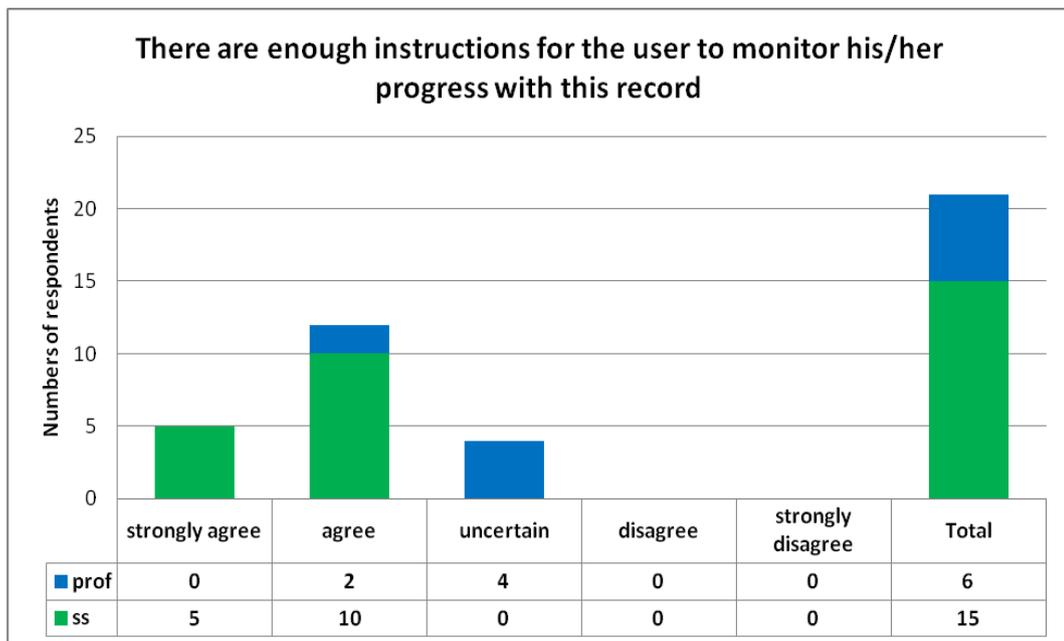


Figure 8b.5.3.5: Combined bar chart showing the numbers of respondents for statement 5

Statement 3.6:

It is difficult to understand something in this record

Five (23.8%) and thirteen (61.9%) respondents strongly disagreed and disagreed with this statement. The median is 2, which indicated that the overall tendency was to disagree with the statement. Therefore, the respondents tended to disagree that the record was difficult to understand. However, three respondents reported differently in which one (4.8%) from each was uncertain, strongly agreed or agreed with the statement. This was further investigated in qualitative section. The results are illustrated in figure 8b.5.3.6 below.

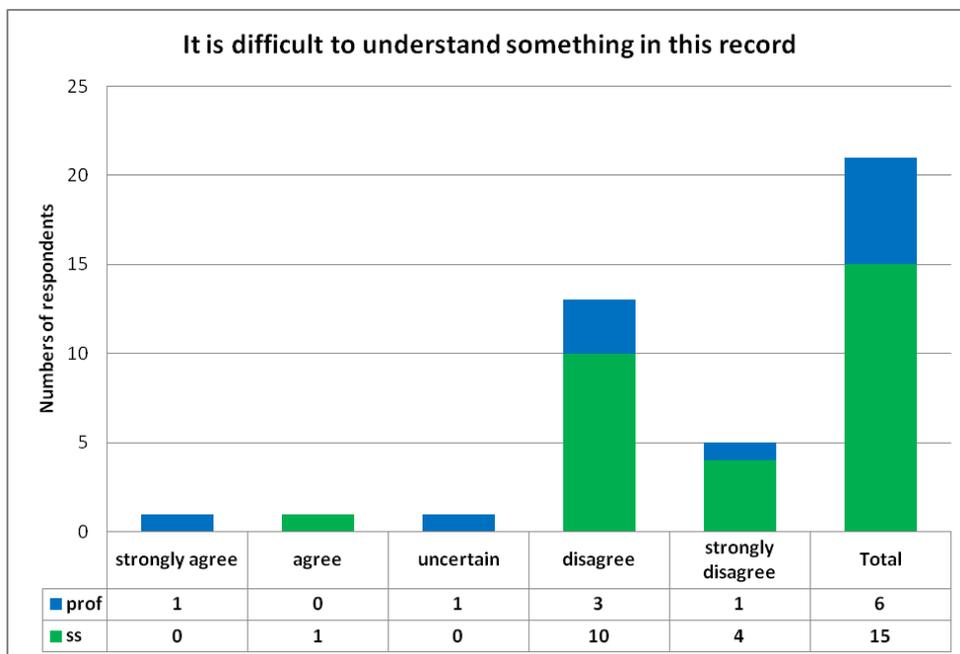


Figure 8b.5.3.6: Combined bar chart showing the numbers of respondents for statement 6

Statement 3.7:

Is there something in this record that could be better?

Fourteen (66.7%) respondents reported “Yes” for this statement. The mode for this statement is 1, which showed that the majority of respondents suggested that the record could be improved. The results are illustrated in figure 8b.5.3.7 below.

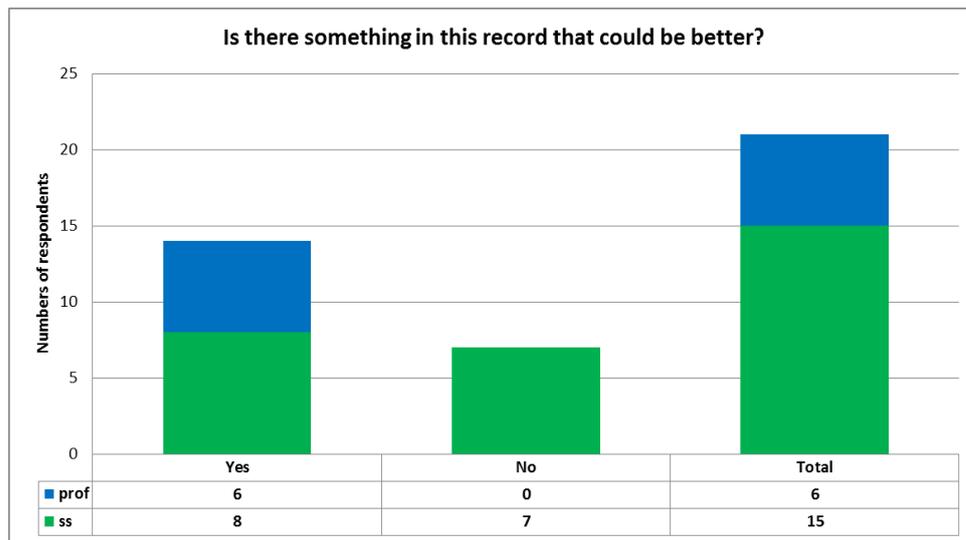


Figure 8b.5.3.7: Combined bar chart showing the numbers of respondents for statement 7

The results informed that the respondents generally agreed the contents of Book B were understandable to them (median: 2, 100%), the instructions were sufficient for them understand how to use it (median: 2, 90.5%), it contained enough items for them to manage a self-managed and remotely supported exercise manual for stroke survivors (median: 2, 80.9%). However, some were uncertain and disagreed.

The respondents generally agreed that Book B was suitable to be used by stroke survivor independently after discharge (median: 2, 61.9%). However, some of them were uncertain and disagreed with the suitability for stroke survivors to use alone.

They generally agreed sufficient instructions were provided for stroke survivors to monitor their own progress using Book B (median: 2, 80.9%). The data shows the respondents tend to agree that it was not difficult to understand the contents of the manual (median: 2, 85.7%). However, the majority of them suggested that Book B should be improved (mode: 1, 66.7%).

8b.5.4 Part 4: Overall comments on the contents of the manual

Statement Part 4.1:

The contents of this manual are understandable to stroke survivors without cognitive impairment

Seven (33.3%) and nine (42.9%) respondents strongly agreed and agreed with this statement respectively. The median is 2, which informed that the overall tendency was to agree with the statement. Thus, the respondents tended to agree that the contents of the manual were understandable to stroke survivors without cognitive impairment. However, three (14.3%) and two (9.5%) respondents were uncertain and disagreed with this statement respectively. This was investigated in qualitative section. The results are shown in figure 8b.5.4.1 below.

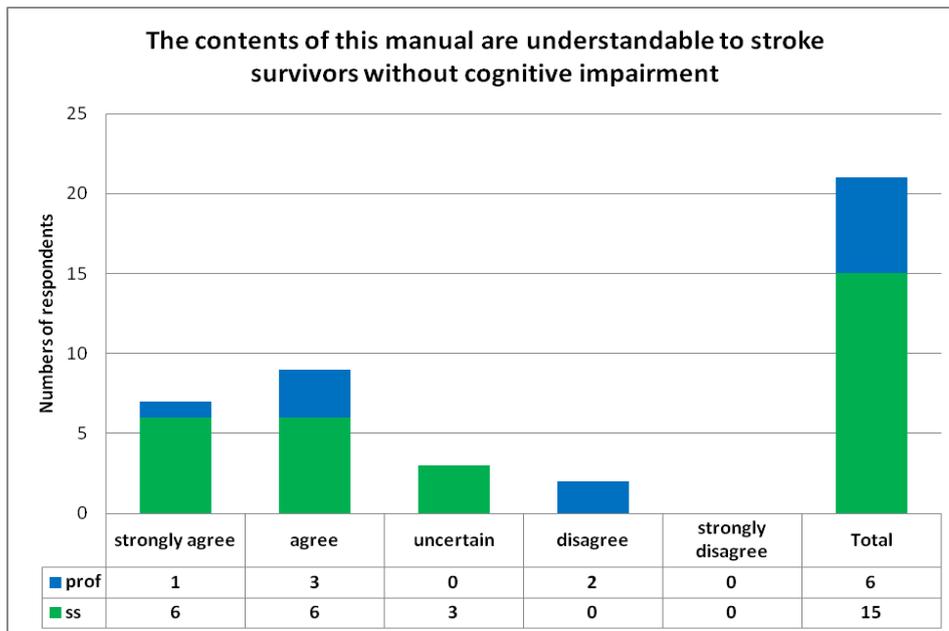


Figure 8b.5.4.1: Combined bar chart showing the numbers of respondents for statement 1

Statement 4.2:

The contents are suitable for helping stroke survivors to manage their own physical exercise programme for their continued physical functional recovery after discharge

All respondents agreed the contents of the manual were overall suitable for helping stroke survivors to manage their own exercise manual for their continued physical functional recovery after discharge. Six (28.6%) and fifteen (71.4%) respondents strongly agreed and agreed with this statement respectively. The median is 2, which indicated that the overall tendency was to agree with the statement. The results are illustrated in figure 8b.5.4.2 below.

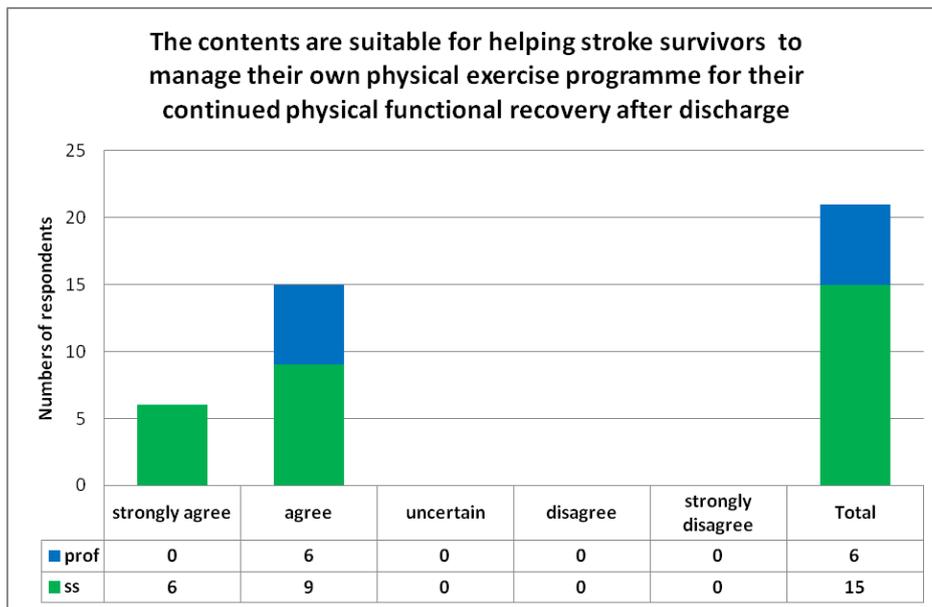


Figure 8b.5.4.2: Combined bar chart showing the numbers of respondents for statement 2

The results show that respondents generally agreed that the contents of the manual were understandable to stroke survivors who without cognitive problem to understand written material (median: 2, 76.2%). However, some of them were uncertain and disagreed with that. In addition, they all agreed the contents were suitable for stroke survivors to manage their own exercises (median: 2, 100%).

This implied that they tend to agreed that the contents of the programme were understandable and suitable for stroke survivors to manage their own exercise with information and communication technologies.

8b.5.5 Part 5: Additional suggestions

Statement Part 5.1:

Is there anything about the manual that should be changed to improve it?

Thirteen (61.9%) respondents reported “Yes” for this statement. The mode for this statement is 1, which indicated that the majority of respondents suggested that the manual should be improved. The suggested improvements were analysed in the next section. The results are illustrated in figure 8b.5.5.1 below.

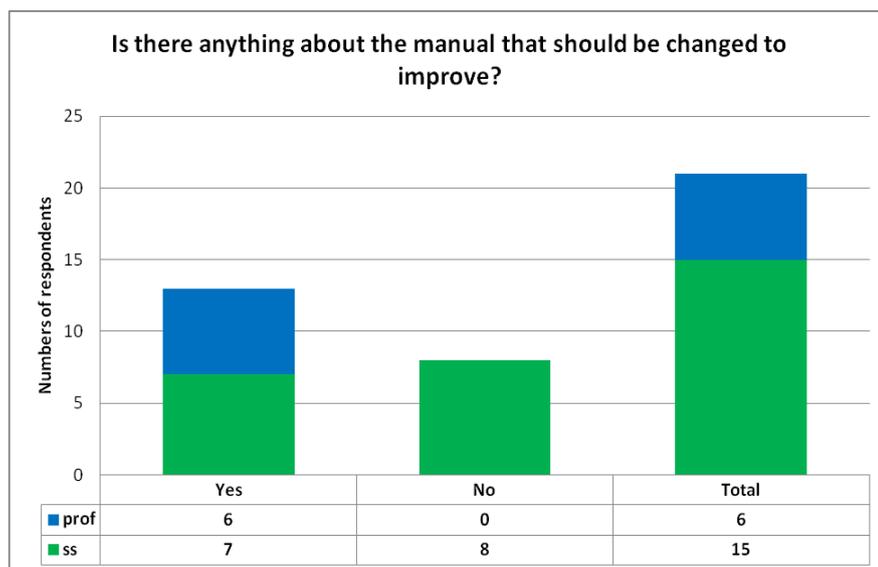


Figure 8b.5.5.1: Combined bar chart showing the numbers of respondents for statement 1

The results indicate that over half of the respondents suggested the overall manual should be changed to further improve (mode: 1, 61.9%).

8b.5.2 Qualitative results

The themes and subthemes emerging from the free responses were analysed and reported below. This reflects the details of the concerns and alternative suggestions from users' and providers' perspectives to determine how the manual should be refined. The findings were categorised for interpretation and integration with quantitative findings. The duplicated items were reduced after comparisons of the integrated findings across data sets.

I present the coding frequency of each subtheme together with a corresponding quotation to help me to check and understand the underlying meanings of the integrated findings. I highlight the relatively more frequently reported subthemes to help remind me that they were more often of concern to the respondents. This helped to modify the manual with an understanding of their major concerns. I decided to refine the programme with the opinions from both types of respondents, so as to ensure the new edition was formed with the opinions of users and providers

The label "SS" refers to "stroke survivors" and "Prof" refers to "PTs" and "OTs" in the following tables. The following tables provide lists of items considered and used to refine each part of the manual identified from stroke survivors' and professionals.

Part 1: Introduction

Table 8b.5.2.1 shows themes and subthemes of the suggestions for improvement of the introduction of the manual. Three themes and fourteen subthemes were identified from their responses about how to improve the introduction.

Table 8b.5.2.1: Suggestions to improve the introduction section⁴⁹

Themes	Sub-themes	Codes	Number of respondents			Quotations
			SS	Prof	Total	
Additional information required (1)	Information about information & communication technologies	1.1	0	1	1	"It could be expanded including more information for the clinician on media and softwares etc available and how to find them" (P001)
	Information about the purpose of each section	1.2	2	0	2	"Purpose? Explain each section" (S008)
Understandability issues (2)	Clear instructions	2.1	1	2	3	"It is not clear how and how often the therapist would be involved in monitoring and reviewing the patient" (P001)
	Clear explanations of the contents	2.2	2	1	3	"The contents maybe difficult for some stroke survivors to understand" (S001)
	Clear descriptions of the terms	2.3	1	1	2	"Glossary or terms" (P006)
	Simplify wording	2.4	2	0	2	"Some people may have problems to understand, so need to have a more simple way to understand it" (S008)
	Simplify the contents	2.5	4	0	4	"the introduction could have been simplified" (S014)
	Provision of working examples	2.6	1	1	2	"A working example would consolidate understanding" (P004)
Design issues (3)	Clear colour codes	3.1	2	1	3	"No colour code matching of books A and B with 8 steps diagram" (S004)
	Clear titles & subtitles	3.2	0	1	1	"Could have titles of the books in capital letters and the 4 sections could be tidy up" (P003)
	Improve readability of the words	3.3	1	1	2	"The fonts could be larger for stroke survivors to read" (S001)
	Add pictures & diagrams for explan	3.4	1	0	1	"...would prefer a few pictures or illustrations" (S002)
	Reduce words	3.5	2	0	2	"A bit too wordy for some sections" (S010)
	Shorten the contents	3.6	4	0	4	"Needs compacting down" (S016)

⁴⁹ S= Stroke survivor, P=Professional

Part 2: Book A

Table 8b.5.2.2 indicates themes and subthemes about the suggestions for the improvement of Book A of the manual. Three themes and fifteen subthemes were identified from their responses about how to improve Book A.

Table 8b.5.2.2: Suggestions to improve Book A

Themes	Sub-themes	Codes	Number of respondents			Quotations
			SS	Prof	Total	
Additional information required (1)	Self-management related information	1.1	1	0	1	"All aspects of self management in one general section" (S017)
	Information about information & communication technologies	1.2	1	1	2	"Could put email or internet access or electric access items on the list" (S008)
	List of alternative interventions	1.3	1	0	1	"Provide alternative therapy choices for different health needs" (S001)
Understandability issues (2)	Clear explanations of the contents	2.1	2	2	4	"Explain the meanings of the items; give examples" (S008)
	Clear instructions	2.2	1	3	4	"A little confusion due to sections, domains, parts etc." (S004)
	Clear descriptions of the terms	2.3	2	3	5	"Some explanation of ICT: glossary" (S004)
	Simplify wording	2.4	2	0	2	"Most patients are not acquainted with most of the terms used in the body function and types of physical exercises sections" (P001)
	Simplify the contents	2.5	3	3	6	"...simple yes , no questions would be more more helpful" (S012)

Themes	Sub-themes	Codes	Number of respondents			Quotations
			SS	Prof	Total	
Design issues (3)	Clear colour codes	3.1	2	0	2	"Color coordination" (S010)
	Encourage stroke survivor to engage	3.2	1	2	3	"May need to encourage older stroke patients to participate in all the sections" (S017)
	Individualise the contents	3.3	1	1	2	"Needs to be more individualistic, more self-analysis regulated by survivor" (S012)
	Add pictures & diagrams for explanation	3.4	1	0	1	"As a stroke survivor it takes time to read, maybe pictures could help" (S002)
	Reduce information	3.5	1	1	2	"Don't need TV as will already have" (S011)
	Reduce words	3.6	0	1	1	"A bit wordy" (P004)
	Simplify the structure	3.7	2	2	4	"Simplify the structure of format in book A" (S014)

Part 3: Book B

The table 8b.5.2.3 shows themes and subthemes about the suggestions for the improvement of Book B of the manual. Three themes and seventeen subthemes were identified from their responses about how to improve Book B.

Table 8b.5.2.3: Suggestions to improve Book B

Themes	Sub-themes	Codes	Number of respondents			Quotations
			SS	Prof	Total	
Additional information required (1)	Information of similar programme	1.1	1	0	1	"Need to compare with other similar services to decide whether this new programme is good and clear or not" (S014)
	More contact details to healthcare resources	1.2	3	0	3	"Provide some contact telephone numbers such as other physio or OT when necessary after discharge" (S001)
	Supporting services for follow-up & support to the users	1.3	0	1	1	"I think at some point they would benefit from a review and update of goals and activities set" (P007)
Understandability issues (2)	Clear explanations of the contents	2.1	3	2	5	"Section b5 not all that obvious what is being asked" (P003)
	Clear descriptions of the terms	2.2	3	2	5	"Explain some terms in further detail" (S010)
	Clear instructions	2.3	2	2	4	"Could always be more instructions for exercises and self-management" (S011)
	Simplify the contents	2.4	4	4	8	"Clearer and simpler information is required on what to do if struggling with compliance to programme" (P001)
	Simplify wording	2.5	2	3	5	"I feel for a lay person to follow it the language needs to be simplified" (P002)

Themes	Sub-themes	Codes	Number of respondents			Quotations
			SS	Prof	Total	
Design issues (3)	Clear titles & subtitles	3.1	0	1	1	"Need different titles for last 2 boxes of summary of progress" (P003)
	Clear colour codes	3.2	2	1	3	"Change colour of text" (S017)
	Encourage stroke survivor to engage	3.3	1	1	2	"Suggest a range of prompts to encourage engagement and maxiing compliance" (S004)
	Individualise the contents	3.4	5	1	6	"Different people different needs" (S011)
	Improve readability of the words	3.5	1	1	2	"Could be made clear by using capital letters" (P003)
	Increase space to provide detailed information	3.6	1	2	3	"There needs to be more space for documenting and giving more information on the action plan, steps for action plan and the exercise prescription" (P007)
	Add pictures & diagrams for explan	3.7	3	3	6	"I would like to see something like a mind map for seting my goals: more visual" (S002)
	Reduce words	3.8	0	3	3	"Less wordy" (P004)
	Simplify the structure	3.9	2	2	4	"Simplify the instrument" (S004)

Part 4: Overall comments on the contents of the manual

Table 8b.5.2.4 indicates themes and subthemes about the suggestions for the overall improvement of the contents of the manual. Three themes and ten subthemes were identified from their responses about overall improvement of the manual.

Table 8b.5.2.4: Suggestions for the overall improvement of the contents of the manual

Themes	Sub-themes	Number of			Quotations
		Codes	respondents	Prof Total	
		SS			
Additional information required (1)	More contact details to healthcare resources	1.1	0	1	"Very helpful to give them links to resources information" (P003)
	Supporting services for follow-up & support to the users	1.2	0	1	" Follow up would be recommended by a clinician to ensure they are correctly carrying out exercises" (P004)
Understandability issues (2)	Clear descriptions of the terms	2.1	1	0	"Define further the meaning" (S004)
	Clear explanations of the contents	2.2	1	0	" Some people may struggle to understand the contents" (S008)
	Clear explanations of the attached USB memor	2.3	1	0	" An explanation of the e-card at the beginning is desirable" (S004)
	Simplify the contents	2.4	2	2	"This booklet requires education above average"(P001)
	Simplify wording	2.5	1	2	"...the presentation, business and wording possibly not. I feel it's too complicated" (P002)
Design issues (3)	Add pictures & diagrams for explanation	3.1	1	0	"...previous comments regarding pictures" (S002)
	Reduce words	3.2	0	1	"But is wordy" (P004)
	Simplify the structure	3.3	1	1	"Keep it simple" (S012)

Part 5: Additional suggestions

The table 8b.5.2.5 indicates themes and subthemes about the additional suggestions for the manual. Three themes and eighteen subthemes were identified from their responses about their additional suggestions to improve the manual.

More access to information related to the topic (N=3) and instruction manual to therapists (N=2) were suggested to be added into the programme in addition to the items suggested in the previous parts. These were considered during the modification of the programme.

Table 8b.5.2.5: Additional suggestions

Themes	Sub-themes	Codes	Number of respondents			Quotations
			SS	Prof	Total	
Additional information required (1)	More contact details to healthcare resources	1.1	1	1	2	"Each patient will require different aids for learning" (S016)
	List of alternative interventions	1.2	1	0	1	"Provide a list of alternative therapies" (S001)
	Supporting services for follow-up & support to the users	1.3	4	0	4	"Direct help from service provider when the stroke survivor using it at least first 6 months" (S014)
	More access to information related to the topic	1.4	2	1	3	"Possible information regarding general living problems and information" (S017)
	Instruction manual to therapists	1.5	0	2	2	"Instructor manual for therapist" (P006)
Understandability issues (2)	Clear descriptions of the terms	2.1	1	1	2	"Glossary for terminology" (P006)
	Clear explanations of the contents	2.2	1	2	3	"Tell them more explanations in the package" (S008)
	Clear instructions	2.3	1	1	2	"How to know when to stop" (P002)
	Simplify the contents	2.4	2	0	2	"Simplicity is a boon for contents" (S012)
	Simplify wording	2.5	2	2	4	"Reducing professional jargon, increasing use of lay-man words" (P001)
	Provision of working examples	2.6	0	1	1	"Examples of answers" (P006)

Themes	Sub-themes	Codes	Number of respondents			Quotations
			SS	Prof	Total	
Design issues (3)	Clear titles & subtitles	3.1	0	1	1	"Progress record could do with a section aht has their goal or at least a prompt to look back at that section for them to consider" (P003)
	Clear colour codes	3.2	3	1	4	"Change colour of text for different sections" (S017)
	Add pictures & diagrams for explanation	3.3	3	2	5	"Pictures, visual prompts" (S002)
	Reduce words	3.4	0	1	1	"Less wordy" (P003)
	Simplify the structure	3.5	2	1	3	"Easy, laminated to tick as and when exercise completed" (S004)

8b.6 Integration of findings for refinement

The quantitative and qualitative findings from stroke survivors and therapists were compared, extracted and combined for integration. The integrated findings of each section of the manual are summarised and embedded into the following mixed methods matrix to systemically yield usable items for further analysis. This helped to inform actions required to modify the programme. Mixed methods matrix was used to integrate quantitative and qualitative data in order to analyse and interpret both data simultaneously.

Two sets of data under the same section of the questionnaire were embedded into one set of data and presented in one matrix during integration. This generated tables showing the results of comments and suggestions elicited from the respondents to generate core items for refinement. The statements used to collect ordinal data and the numbers of respondents answered each statement were listed on the column on the left side of the matrix to illustrate the statistical results obtained from quantitative analysis. Duplicated findings were reduced.

The themes elicited from written information were listed as column headings to illustrate the categorical results elicited from qualitative analysis. The subthemes were listed under each theme providing particular items for the comparison and

integration with the related quantitative results for further interpretation. This provides information about which dimensions required modification, underlying reason and how to refine the manual, in addition to the overall understanding of responses from descriptive data.

The cells containing quantitative and qualitative results were embedded for the integration of two sets of data within one matrix. Lists of domains required for refinement were synthesised from the findings in the matrix. Then, lists of actions required to modify the programme were determined from the lists of domains to guide the modifications of the programme.

Integrated results for introduction

The findings in table 8b.6.1 show the combined results after integrating quantitative and qualitative data from stroke survivors and therapists to refine introduction section.

Table 8b.6.1: Mixed methods matrix of the integrated results for introduction section⁵⁰

QN results			QL results		
No.	Statements	Central tendency of overall agreement	Theme A: Additional information required	Theme B: Understandability issues	Theme C: Design issues
1	This introduction provided all the necessary information to understand the programme	Median: 2 Agree (N=19) 90.5% Disagree (N=2)	Subthemes: Information about information & communication technologies (N=1) Information about the purpose of each section (N=2)	Subthemes: Clear instructions (N=3) Clear explanations of the contents (N=3) Clear descriptions of the terms (N=2) Simplify wording (N=2) Simplify the contents (N=4)	Subthemes: Clear colour codes (N=3) Clear titles & subtitles (N=1) Improve readability of the words (N=2) Add pictures & diagrams for explanation (N=1) Reduce words (N=2)
2	This introduction section helped me to understand the background of this manual	Median: 2 Agree (N=21) 100%		Provision of working examples (N=2)	Shorten the contents (N=4)
3	It is difficult to understand something in the introduction	Median: 2 Agree (N=6) Disagree (N=15) 71.4%			
4	Different parts of the manual have been clearly described in this introduction	Median: 2 Agree (N=19) 90.5% Disagree (N=2)			
5	The length of this introduction is appropriate	Median: 2 Agree (N=19) 90.5% Disagree (N=2)			
6	Is something in the introduction that could be better?	Mode: 1 Yes (N=12) 57.1% No (N=9)			

⁵⁰ QN= Quantitative, QL= Qualitative, N= Total number of respondents suggested that item

Integrated results for Book A

The findings in table 8b.6.2 show the combined results after integrating quantitative and qualitative data from stroke survivors and therapists to refine Book A.

Table 8b.6.2: Mixed methods matrix of the integrated results for Book A

QN results			QL results		
No.	Statements	Central tendency of overall agreement	Theme A: Additional information required	Theme B: Understandability issues	Theme C: Design issues
1	I could understand the contents of this checklist	Median: 2	Subthemes:	Subthemes:	Subthemes:
		Agree (N=21) 100%	Self-management related information(N=1)	Clear explanations of the contents (N=4)	Clear colour codes (N=2)
			Information about information & communication technologies (N=2)	Clear instructions (N=4)	Encourage stroke survivor to engage (N=3)
			List of alternative interventions (N=1)	Clear descriptions of the terms (N=5)	Individualise the contents (N=2)
			Simplify wording (N=2)	Add pictures & diagrams for explanation (N=1)	
			Simplify the contents (N=6)	Reduce information (N=2)	
2	There are enough instructions for me to understand how to use this checklist	Median: 2			Reduce words (N=1)
		Agree (N=20) 95.2%			Simplify the structure (N=4)
		Disagree (N=1)			
3	This checklist provides enough items to decide necessary items in a personalised and self-managed physical exercise programme for a stroke survivor to practice after his/her discharge	Median: 2			
		Agree (N=21) 100%			

QN results			QL results		
No.	Statements	Central tendency of overall agreement	Theme A: Additional information required	Theme B: Understandability issues	Theme C: Design issues
4	This checklist provides enough items required to decide on the suitable and available information and communication technologies for this programme	Median: 2 Agree (N=20) 95.2% Disagree (N=1)			
5	This checklist is suitable to be used by both a stroke survivor and a physiotherapist/occupational therapist to set down a personalised and self-managed exercise programme	Median: 2 Agree (N=17) 80.9% Uncertain (N=3) Disagree (N=1)			
6	It is difficult to understand something in this checklist	Median: 2 Disagree (N=18) 85.7% Agree (N=3)			
7	Is something in this checklist that could be better?	Mode: 1 Yes (N=11) 52.4% No (N=10)			

Integrated results for Book B

The findings in table 8b.6.3 show the combined results after integrating quantitative and qualitative findings from stroke survivors and therapists to refine Book B.

Table 8b.6.3: Mixed methods matrix of the integrated results for Book B

QN results			QL results		
No.	Statements	Central tendency of overall agreement	Theme A: Additional information required	Theme B: Understandability issues	Theme C: Design issues
1	I could understand the contents of this record	Median: 2 Agree (N=21) 100%	Subthemes: Information of similar programme (N=1) More contact details to healthcare resources (N=3) Supporting services for follow-up & support to the users (N=1)	Subthemes: Clear explanations of the contents (N=5) Clear descriptions of the terms (N=5) Clear instructions (N=4) Simplify the contents (N=8) Simplify wording (N=5)	Subthemes: Clear titles & subtitles (N=1) Clear colour codes (N=3) Encourage stroke survivor to engage (N=2) Individualise the contents (N=6) Improve readability of the words (N=2)
2	There are enough instructions provided for me to understand how to use this record	Median: 2 Agree (N=19) 90.5% Disagree (N=2)			Increase space to provide detailed information (N=3) Add pictures & diagrams for explanation (N=6) Reduce words (N=3) Simplify the structure (N=4)
3	This record contains enough necessary items for a stroke survivor to manage a personalised exercise programme supported by available technologies	Median: 2 Agree (N=17) 80.9% Uncertain (N=1) Disagree (N=3)			
4	I feel this record is suitable to be used by a stroke survivor alone after discharge	Median: 2 Agree (N=13) 61.9% Uncertain (N=1) Disagree (N=3)			
5	There are enough instructions for the user to monitor his/her progress with this record	Median: 2 Agree (N=17) 80.9% Disagree (N=4)			
6	It is difficult to understand something in this record	Median: 2 Disagree (N=18) 85.7% Agree (N=3)			
7	Is something in this record that could be better?	Mode: 1 Yes (N=14) 66.7% No (N=7)			

Integrated results for overall comments

The findings in table 8b.6.4 show the combined results after integrating quantitative and qualitative data from stroke survivors and therapists to refine the programme.

Table 8b.6.4: Mixed methods matrix of the integrated results for overall comments

QN results			QL results		
No.	Statements	Central tendency of overall agreement	Theme A: Additional information required	Theme B: Understandability issues	Theme C: Design issues
1	The contents of this manual are understandable to stroke survivors without cognitive impairment	Median: 2 Agree (N=16) 76.2% Uncertain (N=3) Disagree (N=2)	Subthemes: More contact details to healthcare resources (N=1) Supporting services for follow-up & support to the users (N=1)	Subthemes: Clear descriptions of the terms (N=1) Clear explanations of the contents (N=1) Clear explanations of the attached USB memory card (N=1) Simplify the contents (N=4) Simplify wording (N=3)	Subthemes: Add pictures & diagrams for explanation (N=1) Reduce words (N=1) Simplify the structure (N=2)
2	The contents are suitable for helping stroke survivors to manage their own physical exercise	Median: 2 Agree (N=21) 100%			

The details of what aspects required to be changed were elicited from their written responses that were categorised and reported in the matrix. The overall suggestions for the refinement of the manual regarding additional information required, the improvement of understandability of the manual and the design of it were suggested by the respondents that are further discussed later.

8b.7 Modification of the programme

The programme was modified based on the integrated findings obtained in the above section. A list of actions required to refine the manual is presented in table 8b.7.

Actions for programme refinement

Actions were taken beyond the integrated data to modify the programme. The findings from both stroke survivors and therapists were collapsed to synthesis dimensions required to determine the solutions required to refine the programme. This was to ensure the new edition was formulated with the suggestions elicited from both user's and provider's perspectives.

The key issues of the findings and the details of actions taken to change the programme are summarised in table 8b.7.

Table 8b.7: Summary table of the actions for refinement

Sections	Dimensions for refinement	Items from integrated findings	Actions for refinement
Common issues for all sections	Communication	Clearer instructions	Provide examples to describe the meaning. Add an "instructor's handbook" to provide step-by-step guidance to the instructor
		Clearer explanations of the contents	Describe detailed explanations for the content of each section. Provide "tips" to list out the instructions for readers
		Clearer descriptions of terms	Provide a glossary to describe special terms used in the manual
		Simplify wording	Avoid professional jargon and italic font
		Simplify the contents	Put professional terms, concepts and information into instructor's handbook instead of the manual for user. Ask lay persons for feedback on the understandability of the contents
	Design	Clearer colour codes	Provide colour codes to explain the meaning of the colour used in the manual
		Add pictures & diagrams for explanation	Add pictures and diagrams to explain some meanings of the contents
		Reduce words	Use labels to replace written texts
Introduction	Additional information required	Information about information & communication technologies	Add a space for therapist to provide suggestions to assist stroke survivor to use the selected technologies. Provide links to access information and organisations related to problems from using available technologies
		Information about the purpose of each section	Add a short paragraph to explain the purpose of each section
	Communication	Provision of working examples	Add a case study section with real case stories from stroke survivors to explain the concepts about using available technology to remotely support the self-management of exercises in the community. Add examples into each section to demonstrate how to complete that section
	Design	Clearer titles and subtitles	Shorten and enlarge the titles and subtitles. Avoid using italic font
		Improve readability of the words	Enlarge the size and change to clearer font of the words
		Shorten the contents	Shorten the length of contents in each section

Sections	Dimensions for refinement	Items from integrated findings	Actions for refinemmnt
Book A	Additional information required	Self-management related information	Add self-management related information in the manual
		Information about information & communication technologies	Add a space for therapist to provide suggestions to assist stroke survivor to use the selected technologies. Provide links to access information and organisations related to problems from using available technologies
		List of alternative interventions	Provide a space in section 2 about the selection of exercises to allow instructor to suggest and discuss potential alternative interventions after assessing the user's personal needs and conditions
	Design	Encourage stroke survivor to engage	Add reminders in the manual and instructor's handbook to remind the instructor to engage stroke survivor decide components in the manual via discussion
		Individualise the contents	Add reminders in the need assessment section in the manual and instructor's handbook to remind both instructor and stroke survivor to discuss together when determining the items on the checklists
		Reduce information	Reduce professional information in this section and put into a separate instructor handbook for therapists
		Simplify the structure	Reduce words and increase space in each section

Sections	Dimensions for refinement	Items from integrated findings	Actions for refinement
Book B	Additional information required	Information of similar programme	Provide information of existing stroke self-management programmes. Provide a space to allow the instructor to provide the details of similar available and suitable programme
		More contact details to healthcare resources	Add contact details of stroke related healthcare organisations, charity and social service units. Provide a space for instructor to provide additional details about suitable resources to the user
		Supporting services for follow-up & support to the users	Suggest contact details of stroke related organisations to link up with peers and professionals when necessary. Add a section called "tips for users" to provide advice and information for stroke survivor to continue to use the manual. Provide a space to allow instructor to provide additional information and contacts to refer the user to proper services for further follow-up
	Design	Clearer titles and subtitles	Shorten and enlarge the titles and subtitles. Avoid using italic font
		Encourage stroke survivor to engage	Add reminders in the manual and instructor's handbook to remind the instructor to engage stroke survivor decide components in the manual vis discussion
		Individualise the contents	Provide labels to facilitate stroke survivor and therapist to select the mutually agreed items from the list after discussion. Add reminders in the manual and instructor's handbook to remind instructor and stroke survivor to decide the related details in the manual based on personal needs and conditions of the stroke survivor
		Improve readability of the words	Enlarge the size and change the format of words in the manual
		Increase space to provide detailed information	Provide more space for section to write down the personalised information
		Simplify the structure	Reduce words and increase space in each section. Use labels to replace written texts

Sections	Dimensions for refinement	Items from integrated findings	Actions for refinememt
Other additional suggestions for the manual	Additional information required	More access to information related to the topic	Add a section called "tips for users" to provide advice and information for stroke survivor to use the manual. Add contact details of organisations for stroke and disability
		Instruction manual to therapists	Add an instructor handbook to provide specific information about the programme to therapists, including background, criteria to select user, programme contents, prescription flow chart, role of the instructor in the programme, details of supporting theories, tips to instructor and useful resources
	Communication	Clearer explanations of the attached USB memory card	Add a paragraph to explain the use of attached USB memory card for the programme

New edition of the programme

A new edition of the manual was formed after refinement. An instructor handbook has been added to provide background information about the programme and theoretical reasoning for the therapists (see appendix 10). The information in the introduction section was simplified and incorporated into Book B to simplify the overall structure and contents of the programme.

Therefore, the programme is designed to be implemented before discharging stroke survivors from community stroke rehabilitation unit. It is to be delivered by physiotherapist or occupational therapist during home visit to the individuals. The final version of Book A consists of sections for needs assessment, goal setting, selection of physical exercises according to the stroke survivor's abilities, health and personal conditions as well as goals for activity and participation, the selections of available ICTs as well as the options of assistance to self-manage exercises. It is designed to be kept by the clinician as a clinical record.

After using Book A, the therapist and stroke survivor will go on to Book B which is designed to be managed by the individual stroke survivor. It is to be used to summarise the findings obtained from needs assessment in Book A. The clinician and the stroke survivor can it to discuss and decide the details of the goals and action plan to accomplish the goals, decide the prescriptions of personalised

exercises, summarise and determine the details about the selected ICTs, and safety issues about using the programme. The clinician may also information about of the exercises specific to the user's conditions for the individual's learning when using the programme. They can summarise and detail the assistance decided to support the individual to manage the programme. The stroke survivor can learn about how to manage exercises with the use of available ICTs from the case studies provided with the manual or by the clinician according to the individual's situation. This is also to enhance the user's self-confidence to self-manage exercises using ICTs. A monthly progress record is provided in Book B for the user to monitor and regulate his/her programme via reviewing own changes and progress from doing the exercises. Book B also contains practical tips about using the programme, and access to health and social care resources related to stroke rehabilitation as well as access to resources about data protection and security for using ICTs for the user. The contacts of two stroke self-management programmes available in The UK have also been provided in Book B to allow the user to access to related resources.

An instructor booklet has been designed to provide supplementary information for the therapists to understand the features and the theoretical concepts of the programme. Concerning the application of the selected theories, I provided recommendations about how the theories can be applied for the delivery of the programme. Information about how to provide the sources of self-efficacy⁵¹ to the user of the programme is included. I also provided information about how to apply the learning theories to the therapists. For the section about choosing technologies, I have provided recommendations about how to utilise the key concepts about perceived ease-of-use and perceived usefulness in the handbook.

Matching with six-month review policy for stroke

To provide details on “why” and “when” of monitoring as proposed by the quality marker 14 of the national stroke strategy (NICE, 2013, DH, 2007b), in which it is suggested that stroke survivors and their carers to receive regular reviews of their

⁵¹ 4 sources of self-efficacy: mastery experiences, vicarious experiences, verbal persuasion and physiological feedback.

health and social care needs after 6 months and annually thereafter. Hence, the self-monitored progress record of the manual is designed to be monitored by the user for up to 6 months before the post-stroke review. The manual is also designed to contain 6 extra copies of the progress record to allow the stroke survivor to keep a continuous record about his/her own progress and changes before meeting professionals again for re-assessment and further advice in the review. This is to assist the clinician to discuss with the stroke survivor any adjustment to the personalised programme using the information in the personalised records. This is to prepare the programme to be used in line with the future review services for stroke survivors. This is to facilitate the programme to fit into local health service system according to the proposed policy for stroke.

8b.8 Comparing this programme to similar programmes in the UK

Three existing stroke specific self-management programmes were identified in the UK: Bridges Stroke Self-management programme (Bridges) (McKenna et al., 2013, Jones et al., 2009, Jones, 2008), Stroke Workbook programme (Joice et al., 2012, Molloy et al., 2008, Johnston et al., 2007) and Self-Management supported by Assistive, Rehabilitation and Telehealth Technologies rehabilitation system, which is called the SMART system (also Personalised Self-Managed Rehabilitation System, PSMrS) (Mawson et al., 2013, Parker et al., 2013, Mawson and Mountain, 2011, Nasr et al., 2009).

In this section, I compared the above interventions to the programme developed in this research which is named as “Self-managed physical rehabilitation exercise programme for stroke survivors” (SMPRESS) in view of their designs, contents and theoretical base. The details are shown in table 8b.8a below. It is highlighted in green colour in table 8b.8 below. Since self-management interventions may be affected by local contexts including health policy, service system and resources. I only compared those exist in the UK in this thesis.

Table 8b.8a: Comparisons among existing stroke self-management interventions in the UK (about design)

Intervention	Bridges Stroke Self-management programme	Stroke Workbook programme	Personalised Self-Managed Rehabilitation System, PSMrS (built on SMART system)	Self-managed physical rehabilitation exercise programme for stroke survivors (SMPRESS)
Domain				
Design	<p>Designed by Dr Fiona Jones in 2005 in collaboration with a group of stroke survivors in England</p> <p>The programme is presented with a workbook. Each participant will be given one session of up to 1-hour per week for 6 weeks.</p> <p>A booklet is also designed for family and carers of stroke survivors</p> <p>Designed to be prescribed by qualified instructors who are health and social care workers working with stroke survivors</p>	<p>Produced by NHS Lothian in Scotland</p> <p>Designed to be provided by trained facilitator. Registered health professionals are the targeted facilitators to implement the programme</p> <p>A package contains a workbook, diary and relaxation CD</p>	<p>Developed by a group of therapists and engineers across the UK</p> <p>It is built on from SMART rehabilitation system that consists of 3 components:</p> <ul style="list-style-type: none"> - Motion tracking unit (2 inertial sensors connected between the user & the base station via a wireless digital box) - Base station (ICT decision platform consists of a personal computer, a touch screen, & Visual C++ software. It is connected to a central server providing web services to the user from therapists) - Web-server (web-based system via internet) <p>PSMrS consists of a new device:</p> <ul style="list-style-type: none"> - A multi-sensored insole designed to provide feedback on gait, walking & heel strike. It is connected to a touch screen computer 	<p>Developed with a group of stroke survivors, their carers, community physiotherapists and occupational therapists in South Yorkshire</p> <p>A package contains 2 booklets: “Clinical checklist” & “My stroke exercise manual”, & 1 USB memory card.</p> <p>These are designed to be used between therapist and stroke survivor.</p> <p>The memory card contains the electronic version of the programme. It was also used to provide information to tailor personal needs and conditions of the stroke survivor.</p> <p>Instructor’s handbook is included to provide supplementary information for supporting therapists to provide the programme</p>

Table 8b.8a: Comparisons among existing stroke self-management interventions in the UK (about content)

Intervention	Bridges Stroke Self-management programme	Stroke Workbook programme	Personalised Self-Managed Rehabilitation System, PSMrS (built on SMART system)	Self-managed physical rehabilitation exercise programme for stroke survivors (SMPRESS)
Domain				
Content	<p><u>Workshops for stroke practitioners</u></p> <ul style="list-style-type: none"> -Information about skills, theory and research related to stroke self-management -The qualified instructor of Bridges can access the Bridges discussion forum to obtain updated information and share their experience in using the programme 	<p><u>Workbook</u></p> <ul style="list-style-type: none"> -Information about stroke and recovery including basic information about stroke, information for stroke recovery in physical, emotional, speech and language, & cognitive aspects -Tasks to encourage stroke survivors to shift attitude to active -Useful words and quizzes to ensure the information is understood 	<p><u>SMART system</u> consists of 5 modules in the base station:</p> <ul style="list-style-type: none"> Database, interface, decision support, communication & a feedback modules -personal information, individualised questionnaire for safety, patient's rehabilitation history, & instructions/comments from professionals are included in database module -system functions, colour & font size; are provided in interface module -analysis of outcome is carried out in decision support module -transfer of information with the central server is managed in communication module - visual & tabular and graph feedback provided in feedback module 	<p><u>Book A: Clinical checklist</u></p> <ol style="list-style-type: none"> 1.Needs assessment (basic personal characteristics, health conditions, & goal-setting for activity and participation) 2.Select stroke specific physical rehabilitation exercises 3.What technology is available 4.Assistance to self-manage physical rehabilitation exercises <p><u>Book B: My stroke exercise manual</u></p> <ol style="list-style-type: none"> 1.Summary from my therapist 2.What rehabilitation exercises do I need to do 3.Sources of help for me to manage my exercises 4.Learning from other stroke survivors like me 5.How well am I doing---My monthly progress record 6.Tips for user 7.Useful resources and networks

Table 8b.8a: Comparisons among existing stroke self-management interventions in the UK (continued about content)

Intervention	Bridges Stroke Self-management programme	Stroke Workbook programme	Personalised Self-Managed Rehabilitation System, PSMrS (built on SMART system)	Self-managed physical rehabilitation exercise programme for stroke survivors (SMPRESS)
Domain				
Content	<p><u>Personalised and interactive stroke workbook</u></p> <ul style="list-style-type: none"> -Information about stroke -Individual stories & strategies suggested by stroke survivors to manage stroke. Topics ranging from pain, physical disabilities, emotional issues, communication & sleeping. -Section about how to keep active -Section for goals setting -Section to record personal targets and successes <p><u>Carer's booklet</u></p> <ul style="list-style-type: none"> -Information for family and friends using Bridges 	<p><u>Diary</u></p> <ul style="list-style-type: none"> -Plan and set goals -Monitor progress <p><u>Audio relaxation CD</u></p> <ul style="list-style-type: none"> -For survivors and families to practise relaxation exercise 	<p>PSMrS consists of sections tailored to physical needs, goals, activities & specific exercises: <i>My stroke, My goals, My exercises, Today's Exercises</i> and <i>How Am I Doing</i> are the sections included in the computer program</p> <p>Feedback is provided to the user following activities in the page of <i>How Am I Doing</i> (in auditory, visual, & written forms, including motor performance of upper & lower limbs movements)</p>	<p><u>Instructor's handbook</u></p> <ul style="list-style-type: none"> •Background information •Who is the programme suitable for •Programme contents •Exercise prescription flow chart •Your role in this programme •Supporting theories •Tips for instructor •Other stroke self-management programme available •Useful resources

Table 8b.8a: Comparisons among existing stroke self-management interventions in the UK (about theoretical base)

Intervention	Bridges Stroke Self-management programme	Stroke Workbook programme	Personalised Self-Managed Rehabilitation System, PSMrS (built on SMART system)	Self-managed physical rehabilitation exercise programme for stroke survivors (SMPRESS)
Domain				
Theoretical base	Self-efficacy (based on Social Cognitive Therapy)	Cognitive behavioural therapy with the involvement of behaviour change techniques	<p>Motor learning theory (provide extrinsic feedback for knowledge of performance & knowledge of results)</p> <p>A conceptual matrix for a stroke self-managed rehabilitation system was also proposed for the system</p>	<p>A theoretical foundation: The “<i>gear model</i>” consisting of self-efficacy, learning theories (andragogy, self-regulated learning theory, & motor learning theory) & technology acceptance model</p> <p>A conceptual framework to inform the clinical practice of the programme. It consists of the gear model, practical components from identified themes, ICF model, shared decision-making concept, the application of research evidence & guidelines for stroke rehabilitation</p>

The above four interventions are critically appraised by comparing and contrasting them in views of their designs, contents and theoretical bases. The details are presented below.

Design

All of the interventions were designed to help stroke survivors to control their recovery. They were based on user's perspectives, although only PSMrS and SMPRESS clearly stated the adoption of "user-centred design" approach. Health professionals were involved in the design of Bridges, PSMrS and SMPRESS. However, the involvement of stroke survivors, carers and professionals for the design of Stroke Workbook programme is unclear.

Bridges, Stroke Workbook and SMPRESS were designed in written format whereas PSMrS was designed to be operated on a computerised system including the provision of written information and visual and audio feedback and recording. SMPRESS, however, includes both printed and electronic versions of the entire programme. The electronic version is stored in a USB memory card which comes in a package along with the programme. This provides a flexible way for the users to manage their own programmes based on their preferences.

Bridges, Stroke Workbook and SMPRESS have provided supplementary materials for the providers to deliver the programme and to help the users to use it whereas PSMrS does not. However, only Bridges and Stroke Workbook provide training courses for professionals/facilitators so that they are qualified to deliver the interventions. In contrast, SMPRESS does not only provide supplementary materials to the providers, but also provide information to equip professionals with educational concepts to teach their stroke survivors to learn how to self-manage their own programmes. In addition, SMPRESS has provided information to enable professionals to select and decide appropriate technologies for the self-management of personalised exercises with their clients.

The ideas contributed by stroke survivors and therapists to the design of SMPRESS have been clearly stated, in contrast, it was unclear the ideas contributed from stroke survivors and therapists during the design of the other the three interventions.

Although a CD is included in Stroke Workbook for relaxation purpose for the stroke survivors, only PSMrS and SMPRESS have involved the design about using ICTs to operate the programme and deliver support to stroke survivors for self-management. However, the use of PSMrS is dependent on specially designed technology devices

which may not be readily available to stroke survivors and professionals to use. This may limit their access to use technology to self-manage in current practice. In contrast, SMPRESS has included the ideas of using readily available ICTs for stroke survivors to self-manage their own exercises according to their preferences, abilities and available resources. This is to encourage stroke survivors to use technologies to self-manage exercises.

SMPRESS has also included a USB memory card designed to allow flexibility to the users to use different ICTs to receive support, share and store information related to the self-management of exercises according to personal needs and preferences to manage the programme. However, this can only be used when a computer is available to the users since no technology device is provided with SMPRESS. This will limit those without access to computer to use the electronic version. Whilst information on safety and privacy of using ICTs to self-manage exercises has been included in SMPRESS, it has not been mentioned in PSMrS.

Contents

The contents of Bridges and Stroke Workbook programmes cover a wide range of information in addition to physical rehabilitation such as emotion and speech after stroke. In contrast, the contents of SMPRESS are provided specially for the management of physical exercises for physical functional stroke rehabilitation according to the users' physical limitations and health conditions as well as their personal goals of physical functional rehabilitation. This allows the therapists to provide specific advice to address the stroke survivors' specific needs to perform activities and participations for physical functional rehabilitation during prescription. The specific contents can also help the therapists to decide specific exercise prescriptions with the stroke survivors. This is similar to the contents of PSMrS. However, the contents of Bridges and Stroke Workbook programmes may be helpful to provide supplementary information for stroke survivors to self-manage for their overall rehabilitation in the community.

Although goal-setting is a common component in all four interventions, only SMPRESS contains a clinical checklist (Book A). This checklist provides an aid for shared decision-making during personalised needs assessment and goal-setting for

physical functions. It can also be used as a clinical record for clinicians to keep after prescription. This can help clinicians to manage their case records and communicate with their clients when they are in touch to support their clients. This is also to prepare a reference to assist clinicians to review their cases 6 months after discharging their clients according to the 6-month review policy recommended by the government for stroke rehabilitation. In addition, although personalised goal-setting has been involved in all four programmes, only PSMrS and SMPRESS have provided a section for clinicians to provide personalised exercise prescription for the users' physical rehabilitation purpose.

Furthermore, only SMPRESS contains a list of technology options in Book A for clinicians to engage their clients to decide what ICTs that the stroke survivors have and can use, and would like to use to help them to self-manage their own exercises.

Bridges and SMPRESS have provided real stories, which cannot be found in the other interventions. The provision of stories from other stroke survivors can help to provide mastery experience as a source to enhance stroke survivors' self-efficacy to self-manage. In addition to providing mastery experience for promoting the individual's self-efficacy, the cases provided in SMPRESS may help to exemplify how ICTs can be used to support the self-management of exercises for stroke survivors and clinicians to understand how to use the programme.

Theoretical base

Bridges, Stroke Workbook programme and PSMrS were developed using a single theory approach. Bridges is mainly developed with self-efficacy theory. The Stroke Workbook programme is based on cognitive behavioural therapy with the focus on behaviour change. The theoretical base of PSMrS is a conceptual matrix consisting of motor learning theory. In contrast, SMPRESS was developed with the support of a theoretical foundation with multiple theories called the gear model. It consists of three categories of theories: self-efficacy, a group of learning theories built on andragogy, self-regulated learning theory, motor learning theory; and technology acceptance model. This can help to support different elements in SMPRESS.

Education and motor learning theory have been considered in PSMrS, however, only SMPRESS combines a group of educational theories for teaching stroke survivors to

self-manage their own exercises. The idea of using educational theories, including andragogy and self-regulatory learning for the self-management of stroke exercises; has shown to be acceptable, suitable and usable according to stroke survivors' and therapists' opinions.

The concepts of using ICTs are involved in PSMrS and the programme developed in this research, in contrast, only the programme of this research has included a conceptual model specific to the application of technology. This can help to guide both users and providers of the intervention to deal with the technology related in the programme. The use of technology acceptance model may provide conceptual empowerment to the users to take control the use of ICTs for stroke self-management by engaging them to make shared decision with their therapists. The idea of using technology acceptance model for stroke survivors to decide ICTs for the self-management of exercises has shown to be acceptable, suitable and usable according to stroke survivors' and therapists' perspectives. This is reported in the chapter 9 of this thesis.

There are a variety of theories adopted for all four interventions. However, it appears that no approach is superior to others and different theories have different purposes. With regards to the theoretical support for the scope of enabling stroke survivors to self-manage their personalised exercises using available ICTs, the gear model can bring additional concepts to the field of stroke self-management in comparison with the rest of the other interventions. It is a novel concept to combine the features of self-efficacy theory, andragogy, self-regulated learning, motor learning theory, and technology acceptance model to generate a joint theoretical support to a self-managed programme for stroke rehabilitation.

Integrating multiple theories may help to maximise the effects from utilising different characteristics of different theories, instead of relying on a single theory to support a programme containing multiple elements. The use of a single theory or model appears inadequate to satisfy to provide all concepts to guide and support the provision of stroke self-managed exercise manual for functional rehabilitation using available ICTs in the community. Hence, a group of theories were used to support to develop the programme of this research. Additionally, it is new to adopt the ICF model to frame the contents and the design of a self-managed intervention for stroke

rehabilitation. This can help to provide a functional oriented structure to support the programme designed for the rehabilitation of physical functioning.

After all, it appears that different designs, contents and theories have been used in all four similar interventions relevant to the self-management for physical stroke rehabilitation in the UK. However, many stroke survivors may have additional challenges resulting from stroke along with their physical difficulties; such as aphasia, cognitive and visual problems, which may affect them to use the layouts of the existing programmes.

Studies are required to design more accessible layouts to help all stroke survivors to use self-management interventions. It will also be helpful to understand how to use the features of the contents of different programmes to empower stroke survivors to self-manage exercises. Furthermore, it will be helpful to understand any additional concept may be required on the base of the gear model.

The key features and components of the four programmes are compared and summarised in table 8b.8b. A smiling face icon is given if the programme contains the feature described in the row of the table. This is to illustrate what has been added by SMPRESS to the field of self-management for stroke rehabilitation.

Table 8b.8b: Summary of key features and components of the four stroke self-management programmes in the UK

Feature		Programme			
Domain	Component	Bridges	Stroke Workbook	PSMrS	SMPRESS
Theoretical component	Self-efficacy	😊			😊
	Cognitive Behavioural Therapy		😊		
	Motor Learning Theory			😊	😊
	Andragogy (Adult Learning Theory)				😊
	Self-Regulatory Learning				😊
	Technology Acceptance Model				😊
	ICF Model				😊
Focus of self-management	Multiple stroke consequences	😊	😊		
	Specific to physical functional rehabilitation			😊	😊
Method of delivery	One-to-one	😊	😊	😊	😊
Delivery person	Healthcare professional	😊	😊	😊	😊
	Trained instructor/ facilitator	😊	😊		
Format	Printed materials	😊	😊		😊
	Electronic version			😊	😊

Use of technology to manage the programme	Commonly available technologies				
	Special device and software				
	Safety and privacy advice				
Personalisation issue	Personalised goal-setting				
	Personalised exercise prescription for physical rehabilitation				
	Helping the users to decide assistance for self-management				
Other	Access to health and social care resources				
	Clinical record for case management and review				
	Case examples for self-efficacy and learning				
	Materials for instructor/ facilitator				

8b.9 Discussion

An iterative process was employed to refine the prototype manual with the stroke survivors and therapists who provided their ideas to inform the programme. The focus of this refinement study was to ensure the components of the programme were based on both stroke survivors' and therapists' perspectives. This was to ensure the programme could be developed in a way to cater stroke survivors' needs.

The following research questions were answered in this study:

- *“Do stroke survivors understand the programme?”*
- *“Do stroke survivors think the programme is usable?”*
- *“Do clinicians think the programme is understandable?”*
- *“Do clinicians think the programme is usable in practice?”*

Surveys were conducted to explore the extent to which the manual could be understood and agreed to be usable from them. The findings of this study provided information to decide how to better tailor the programme for patients and therapists to use. The programme and its underpinning concepts: the gear model were generally agreed to be usable and understandable by stroke survivors and professionals for the self-management of exercises. Stroke survivors' and clinicians' confidence in trusting the components of the programme is essential, since it was designed to be used by them in practice. This refinement study provides explicit information to understand whether they consider the manual contains what they deem important for the self-management of exercises supported with the use of available ICTs. A new edition of the programme was formed using the data yielded from the surveys.

With regards to the theoretical aspect for self-management, whilst self-efficacy has often been used to form the theoretical basis for many chronic disease self-management programmes and reported to be important factor for stroke rehabilitation (Jones and Riazi, 2011, Korpershoek et al., 2011, Jones, 2006), this research has tried to go beyond using it alone by adding new concepts in the gear model in the field of using self-management for stroke rehabilitation. The findings of this study reveal that the majority of stroke survivors and therapists agreed the programme is understandable and usable. This also suggests that the underpinning concepts are considered to be usable by stroke survivors and therapists.

However, only knowing the tendency of stroke survivors' and clinicians' attitudes toward the agreement or disagreement about the usability of the manual may be inadequate to tailor the programme for them to use. Therefore, qualitative data was also collected to understand how to improve different aspects of the manual to meet their expectations and needs.

The integration of quantitative and qualitative findings helped to facilitate the process to further examine both data on the same issue. This enabled me to understand respondents' attitudes toward the usability of the manual. This also helped to generate solutions to refine it via interpreting both types of information together.

The examination of the relationships between the quantified findings and the reason of the written responses may help to identify practical information for researchers to design and improve a clinical intervention for self-management in the future. In particular, uncertain answers were collected for some questions, and differences between the answers of stroke survivors and therapists were found in the quantitative results. Further research may help to explain the relationships between quantitative and qualitative data of the same subject matter, and the reasons behind different viewpoints of therapists and their patients.

8b.10 Limitations

Although the use of Likert scale could help to quantify and categorise the comments from the respondents for easy interpretation of their attitudes toward the usability of the manual, the ordinal nature of data may limit the further analysis of the detailed level of their agreement or disagreement. The distance between two categories in the scale may not be equivalent.

Although open-ended questions were used to collect the individual's opinions and suggestions to improve the manual, the level of detail of their additional responses is still restricted by the space available for them to write and the pre-determined questions provided in the questionnaire. The responses collected in the survey may be limited to a personal level only, although the respondents could take their time to think their own answers carefully. These limitations may be improved by adding focus group discussion alongside with the surveys in the future. This allows the participants to generate more rich information to improve the manual via sharing and discussing different ideas in groups. However, due to limited resources and time constraints, focus groups could not be conducted in this study.

Bias, however, may exist due to the different administration methods were adopted in this study. Stroke survivors were generally more positive in their responses than therapists. This could be due to the questionnaire being presented to stroke survivors by the researcher who developed the programme, whereas the questionnaire was completed by therapists on their own. Studies will be needed to

understand the reason for the different comments between stroke survivors and therapists towards the programme.

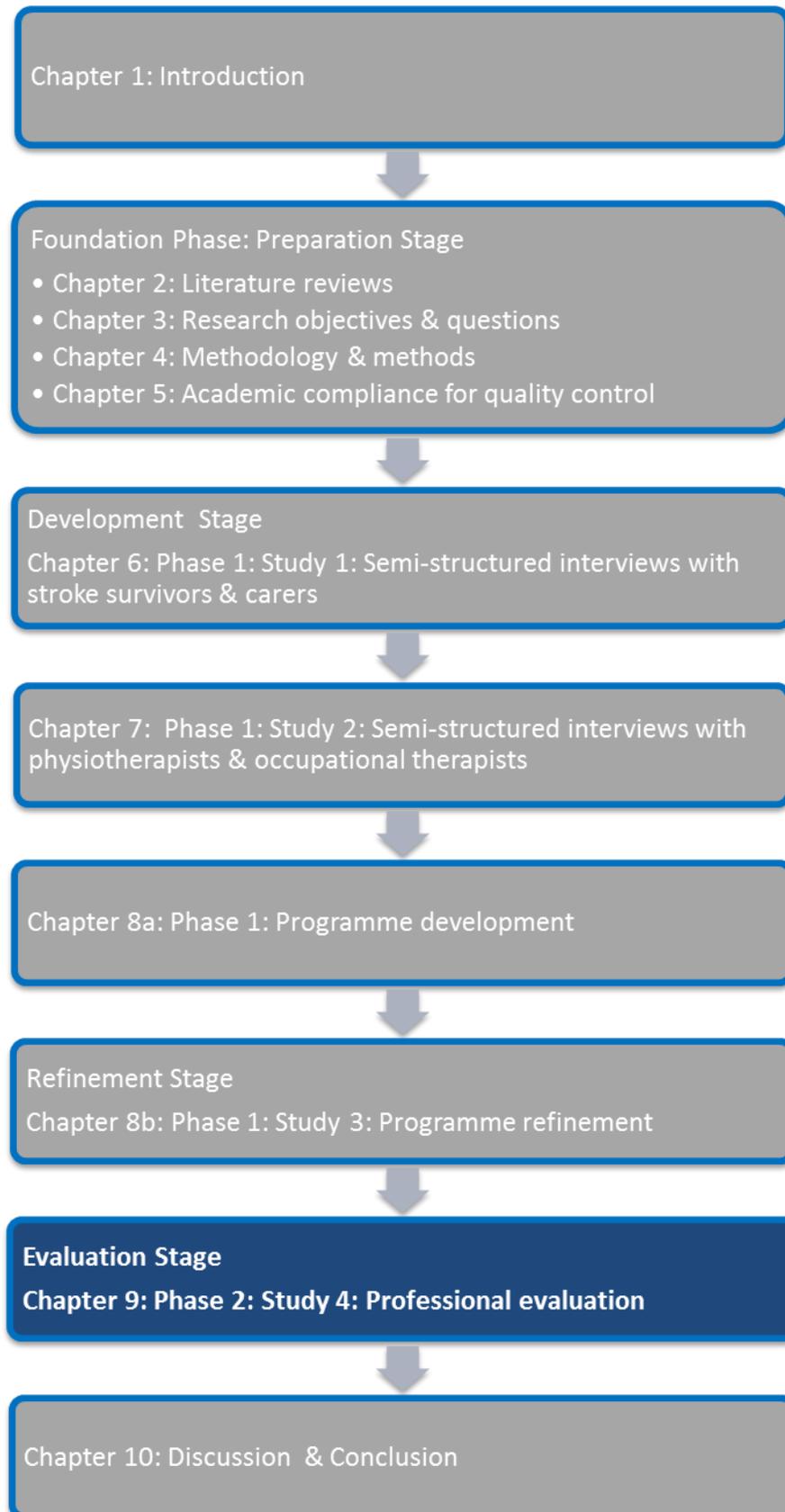
8b.11 Summary

This study sought to refine the programme using stroke survivors' and therapists' views, and a new model. An iterative approach was adopted to refine it with the stroke survivors and therapists who had participated in the development stage.

Findings indicate that the programme is understandable and usable according to stroke survivors' and therapists' perspectives. This study helped to verify the contents with stroke survivors and therapist and provided solutions to amend it.

The programme was evaluated in the next chapter to determine the acceptability, suitability, feasibility and safety of using it for physical functional stroke rehabilitation in the community from a professional perspective.

Section 4: Phase 2: evaluation stage



Chapter 9: Phase 2: Professional evaluation

Chapter summary

The perceived acceptability, suitability and feasibility of the developed programme were evaluated in phase 2, using professional judgement. A survey was conducted with a group of physiotherapists (PTs) and occupational therapists (OTs) who had not been involved in the iterative development of the programme. The method, study design, procedures, analysis and findings from the survey are reported in this chapter. The findings suggest that the programme is acceptable, suitable, feasible and safe to be used in the community from a professional perspective.

9.1 Introduction

With the understanding of stroke survivors' and therapists' perceptions towards the programme developed in the previous study, this study aimed to gain an independent evaluation of the programme to understand its appropriateness and applicability in a clinical setting. The evaluation of healthcare programmes involving the use of technology is recommended by the WHO to facilitate knowledge translation (WHO, 2010).

The information obtained from professionals may help to critically judge the applicability and appropriateness of the programme in practice. Understanding professionals' attitudes towards using the clinical intervention can help to evaluate whether it can be used in a clinical setting. Professionals are often involved in the delivery of stroke self-management interventions (Jones, 2013) (also see table 2.3.6 in chapter 2). In addition, the programme designed in this research was intended to be delivered by therapists in a clinical setting. Thus, professional judgements are used in this evaluation to determine whether the programme can be used to address stroke survivors' needs for their physical functional recovery in practice.

PTs and OTs are involved in this evaluation since they play key roles in prescribing and delivering rehabilitation exercises and activities. They are also the important decision-makers in selecting appropriate clinical interventions for physical stroke rehabilitation, and the targeted providers of the programme.

Aim

This study was to determine the appropriateness, feasibility and safety of using the developed programme for physical functional stroke rehabilitation from a professional perspective.

Objectives

The objectives of this evaluation were to obtain professional judgements for the above aim. Respondents were asked to comment on the acceptability, safety, suitability and feasibility about using the programme. The following key questions were considered in this evaluation:

- Is it acceptable to clinicians who will be the key service providers of this programme?
- Do clinicians think it is suitable to deliver the programme based on the current health service system and policies for community stroke rehabilitation?
- Do clinicians think it is feasible to use the programme in clinical practice?
- Do clinicians think it is safe to use the programme in community setting?

9.1.1 Definitions of terms

In the absence of universal definition for the terms of acceptability, safety, feasibility and suitability for a rehabilitation intervention, the working definitions in table 9.1 were established for the above terms for the purpose of this study. They were used to guide this evaluation and referred to when I designed the questionnaire and analysed the data collected in this study.

Table 9.1 Definitions of acceptability, safety, suitability and feasibility in this study

Terms	Definitions
Acceptability	The extent to which the programme and its contents are agreed to be useful, clinically relevant and safe for the purpose of physical functional stroke rehabilitation. It concerns the willingness of the practitioner to use the programme in a clinical setting.
Safety	The extent to which the programme and its components is free from any danger, harm, risk, injury or adverse effect to the individual who uses it.
Suitability	The ability of the programme and its components to meet the needs of physical functional stroke rehabilitation in the community according to local contexts and standards for services. It focuses on how well the materials of the programme fit into current clinical practice.
Feasibility	The practicability of the programme and its components with the considerations of relevant available resources so as to estimate whether the programme can be used or not. It concerns the ease of administration and delivery of the programme.

9.2 Methods

Acceptability

In general, the acceptability of an intervention refers to the overall evaluation of the procedures. It is related to the judgement about whether the intervention is appropriate for the problem (Kazdin, 1981, Wolf, 1978). For this study, it was important to identify whether the contents of the programme could be accepted to be delivered in a clinical setting. Clinicians' judgements were considered for this evaluation since they are the targeted providers of the programme. A rehabilitation system with technology must be acceptable to therapists involved in the delivery before it is to be adopted by practice (Mountain et al., 2010).

It was important to understand therapists' attitudes towards the acceptability of the programme developed in this research since the application of available technologies is involved in it. The evaluation of the acceptability of the programme in

this study was to understand whether the programme and its concepts are acceptable to be used according to professional judgement.

Safety

Safety of using this new programme was considered in conjunction with acceptability for this evaluation since I considered an acceptable clinical intervention should also be safe to use. From the WHO defines patient safety is the prevention of errors and adverse effects to patients associated with health care (WHO, 2014). The importance of safety has been highlighted for the provision of stroke services and exercises in recent guidelines (Party, 2012, SIGN, 2010, Best et al., 2010). Patients' safety is important in practice. It is essential to ensure the stroke survivors are free from any harm, injury or risk in order to protect their lives and health when they use any intervention. This was a part of the reason for evaluating this programme with clinicians after developing it. It is also important to pay attention to the safety of using technology to deliver stroke rehabilitation (Mountain et al., 2010).

Safety for self-managing exercises was identified from interviews with stroke survivors and professionals in the phase 1. Therapists further expressed their concerns about the safety for stroke survivors to use available ICTs to self-manage their own exercises. Thus, it was necessary to evaluate the safety of the programme overall in response to their concerns. Therapists play the key role to ensure the safe practice of a clinical intervention. Since the developed programme is intended to be delivered by them, their judgements on the safety aspect of applying it are required to determine whether it is safe to be used to ensure safe clinical practice.

Suitability

It is important to evaluate the suitability of written stroke materials by healthcare professionals before they use that with stroke survivors and their carers so as to maximise the potential advantages of using the materials (Hoffmann and Ladner, 2012, Hoffmann et al., 2007). The suitability of written educational material can be regarded as how well it can be understood, perceived as fit for purpose, clear and accepted by the reader (Vallance et al., 2008).

The suitability assessment of materials (SAM)⁵² has been used to evaluate written materials for educational printed materials for physical activity and written educational materials for stroke survivors and their carers (Vallance et al., 2008, Hoffmann and McKenna, 2006, Eames et al., 2003). However, SAM is not designed to evaluate the suitability of using self-management interventions for physical stroke rehabilitation. Hence, it was necessary to design a way to evaluate the suitability of the using the materials of the programme developed in this research to provide physical stroke rehabilitation. The focus of evaluating suitability in this study was on exploring how well the programme fits into the current health service system according to the stroke pathway as a part of community stroke rehabilitation services for physical functioning. This can help to determine whether it is suitable to be used according to local contexts.

Feasibility

Feasibility addresses the wider context in which the intervention is provided and involves deciding whether the intervention can and should be implemented (Evans, 2003). Professionals' judgements from their clinical experiences may provide realistic opinions relating to the potential of using the programme. In this study, the focus of evaluating the feasibility of using the programme was to understand the practicability of it according to practitioner's knowledge and experiences. This can help to understand whether the programme is deliverable in a clinical setting from a provider's perspective.

Three stages were involved in this evaluation: pre-pilot, pilot test and main survey stages. The whole procedure is illustrated in the following diagram figure 9.2. The steps of each stage are detailed in the figure.

⁵² Suitability Assessment of Materials (SAM) is an instrument for the evaluation of health related information materials. It provides a guide to rate the materials in 6 areas to evaluate the suitability of the written materials: content, literacy demand, graphics, layout and type, learning stimulation and motivation, and cultural appropriateness (Vallance et al., 2008, Hoffmann and McKenna, 2006, Eames et al., 2003).

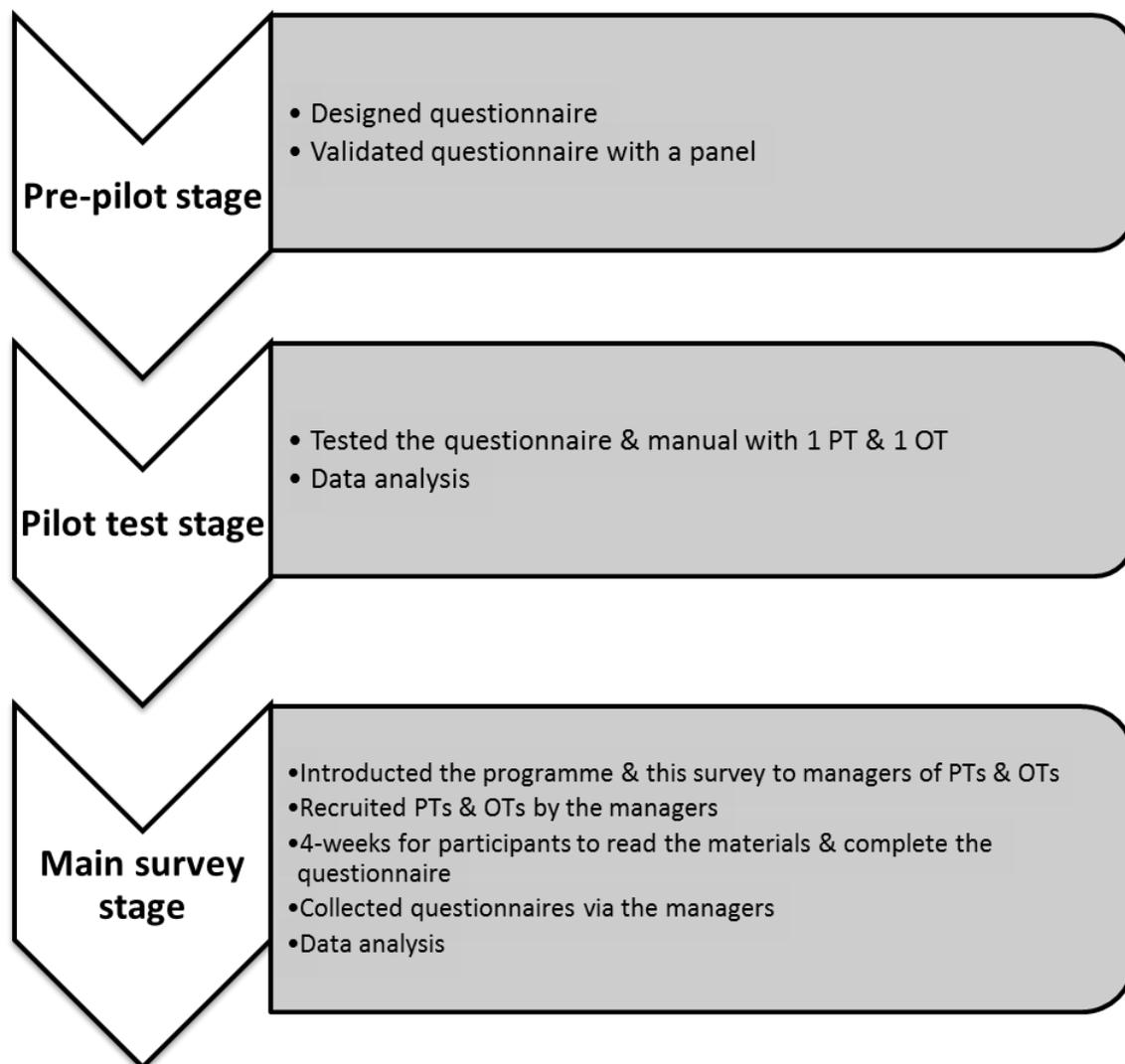


Figure 9.2: Flow diagram of this evaluation

9.2.1 Study design

A questionnaire was used to address the objectives. This allowed me to collect data in a written form. Both open-ended and closed questions were used in the questionnaire to balance the strengths and limitations of each type of question. This allowed me to collect different types of data to explore the attitudes and opinions of the PTs and OTs both quantitatively and qualitatively (Langhorne and Pollock, 2002, Fink, 2003, Boynton and Greenhalgh, 2004, Buckingham and Saunders, 2004, Bowling and Ebrahim, 2005, Rattray and Jones, 2007, Schreier, 2012, Wales, 2009).

Respondents could take time to read and review the new programme and consider their answers before providing specific information to help to critically evaluate it. This allowed me to elicit particular knowledge and experience from each respondent.

The questionnaire was self-administered based on the consideration of the busy working schedules of therapists. They could complete the questionnaires in their own time. The respondents were asked to share their professional opinions to evaluate the acceptability, feasibility and suitability of using the programme in clinical setting. Each section of the manual was precisely evaluated to understand the attitudes of the respondents towards the acceptability, suitability and feasibility of the contents of each section.

9.2.2 Questionnaire design

The questionnaire was designed during the pre-pilot stage. An interval scale with a range of scores from 0 to 10 was used to measure the strength of responses from PTs and OTs in order to understand the extent to which they found the programme acceptable, suitable and feasible using numerical data. The higher the score, the more the respondents considered the programme to have that particular property.

A Likert scale was the ordinal level scale used to measure the responses of the respondents to the closed questions. A series of statements were presented expressing different attitudes and viewpoints toward the context of the manual. The respondents were asked to rate each statement to reflect their agreement or disagreement to show the response that most closely represents his/her viewpoints (Allen and Seaman, 2007, Jamieson, 2004, Likert, 1932). A 4-point scale ranging from strongly agree, agree, and disagree to strongly disagree was employed to explore the respondents' opinions or attitudes. The respondents were allowed to leave a blank if they were uncertain about the answer.

They were also asked to provide their opinions or comments using open-ended questions, and space was given to write down further opinions about the content of its clinical application. This was to allow them to express their opinions spontaneously in their own language to generate additional information about using the programme from them.

Funnel approach was used to structure the questions within the questionnaire in which the sequence of questions is designed from general to particular (Buckingham and Saunders, 2004, Stone, 1993). This helped me to narrow down the scope of the inquiry to glean specific information for this study.

The questions and statements used in the questionnaire were coded to prepare for quantitative analysis. The details about the notation of the questions are provided in the findings section later in this chapter.

9.2.3 Validation of questionnaire

The questionnaire was validated for its face and content validities before being used. Face validity of the questionnaire was considered in order to assess whether it appeared to cover the questions required to collect specific information to evaluate the acceptability, suitability and feasibility of using the programme. Content validity of the questionnaire was also considered to ensure it contained the components required to collect data from PTs and OTs working in community stroke services for this study by reviewing the correspondence between the contents of the questions and the 3 different domains of this evaluation.

The questionnaire designed for this study was validated with a panel. The panel consisted of 2 supervisors of this research, plus 1 PT and 1 OT experienced in providing stroke rehabilitation services and research in the community, to establish face and content validities. They also checked the structure of the questionnaire and the manual to ensure they made sense to clinicians. The PT and OT were not involved in the previous phase of this research to avoid any potential bias or carry-over effect that may result from previous experience in this research. Two lay native English speakers were consulted to check the questions and manual to ensure they were clear for English speakers before the questionnaire was piloted for the same reason described in study 3.

9.2.4 Piloting of questionnaire

One PT and one OT experienced in stroke rehabilitation and research in the community piloted the questionnaire prior to the main survey. They were asked to

evaluate the modified manual using the questionnaire. Face and content validities were also ensured in the pilot. Both participants reported that the questionnaire appears to contain sufficient questions needed to meet the needs for this evaluation. The questions were understandable to professionals with similar background and knowledge as the target respondents within the main survey. It appeared to be feasible to adopt the procedures to administer the survey for this evaluation. I further refined the wording and reduced the duplicated questions in the questionnaire as a result of their feedback. The new version was used in the main survey.

9.2.5 Participants

Since the focus of this evaluation was to obtain professional judgements of the programme for physical functional stroke rehabilitation, PTs and OTs experienced in the provision of stroke rehabilitation for physical functioning were the target participants. The programme was evaluated by a separate group of PTs and OTs who were not involved in the earlier stage of this research. This was to minimise the potential bias during the evaluation. The decision to include both professions was taken for the same reasons discussed in the refinement study.

9.2.6 Procedures

I first visited the managers of PTs and OTs in local hospital trust and explained the purpose and background of the study. I introduced the manual to the managers and answered their questions about the research. Then I invited the managers to help to identify and recruit suitable therapists according to the selection criteria for this survey. This was to minimise the potential selection bias from the researcher. I sent the cover letters, information sheets, informed consent forms, the manuals, instructor's handbooks and questionnaires to the recruited PTs and OTs. The managers helped to distribute the above materials to the respondents. Each participant was given 4 weeks to read the refined manual, and complete the questionnaire before returning it to their managers.

A 1-hour face-to-face session was arranged to meet the therapists working in the stroke unit in their office 2 weeks after distributing the materials by the managers.

The session was organised to answer any questions from the therapists in relation to the programme and this research. It was also arranged for further recruitment.

Each participant was given a package containing a cover letter, information sheet, consents form, a manual of the programme, an instructor's handbook and questionnaire. They were reminded to return the package with a completed questionnaire and signed consents form.

The respondents were asked to indicate their responses by ticking the box beside the answer chosen by them for the closed questions. They could give additional comments regarding different parts of the programme, by writing in the space provided for open-ended questions.

9.2.7 Data analysis

The interval and ordinal data were analysed to explore therapists' attitudes. Descriptive statistics were used to describe quantitative findings and to measures of central tendency of the data. The central tendency of the overall scores measured with an interval scale and of the agreements to the statements measured with ordinal Likert scale were analysed and reported.

The free text responses collected by open-ended questions were analysed to yield wider understanding of their opinions towards acceptability, suitability and feasibility, which were reported separately below. The written texts in the questionnaires were analysed using thematic analysis under the principle of content analysis.

For descriptive statistical analysis, radar charts are used to report the findings of the pilot test and the main survey for this study. Several groups of data representing multiple types of opinions were collected from the respondents in this study. Thus, the use of radar chart can help to display and compare multiple variable data on a single graph (Saary, 2008, Minemawari and Kato, 1999). This helped to present the respondents' tendency in different domains towards to the same issue being evaluated in this study. Therefore, using radar charts allowed me to analyse different aspects of the collected responses simultaneously to gain a relatively

comprehensive understanding in relation to interpreting the acceptability, safety, suitability and feasibility of the programme from multiple angles.

The centre of the radar chart represents total appropriateness and usability of the programme. The spot on the chart represents the mean / median value of the line it belongs to. Each line represents a statement in the questionnaire.

For the radar chart showing interval level data about the overall scores of the evaluation of the acceptability, suitability and feasibility of the programme, the centre represents the lowest score for each dimension. The scale was set from 0 to 10. The centre of the chart was set at 0. The closer the spot is towards the centre of the radar chart, the lower the score of the response was found for that aspect.

For ordinal scale data, which does not have a meaningful zero score; the closer of the spot is towards the centre, the more agreement is with the statement.

Both quantitative and qualitative findings also integrated using a mixed methods matrix for further interpretation. Mixed methods matrix was used to integrate and analyse both quantitative and qualitative findings of this survey simultaneously for further interpretation of the respondents' attitudes towards the programme.

IBM SPSS statistics version 21 was the software used to analyse the quantitative data for this evaluation. Microsoft Excel 2007 was used to create the radar charts and to manage both quantitative and qualitative data.

Coding

The answers in the questionnaires were classified into different categories. This process is referred to as coding (De Vaus, 2002, Buckingham and Saunders, 2004). This was to systematically analyse and present the collected information. Codes were allocated to each of the closed questions in each part of the questionnaires for classification. Responses to the open questions were analysed with thematic analysis technique. The procedures were the same as for the refinement study.

9.2.8 Ethics approval & NHS governance permission

University research ethics approval and NHS governance permission were granted before this study. The approval letters can be found in appendix 1 and 2.

9.3 Results

A total of 7 questionnaires were collected from 5 PTs and 2 OTs. There were 10 suitable therapists identified, however, 1 was on maternity leave, 1 refused to take part due to a personal busy working schedule and 1 moved to work in another place during the survey period. The findings of the main survey are reported below. The quantitative findings are presented before the qualitative data and the mixed methods matrix.

Demographics

The basic demographic characteristics of the respondents are presented in table 9.3.

Table: 9.3: Demographics of respondents

Respondent code	Type of profession	AFC band	Length of time working with stroke rehabilitation (years)
SP001	PT	7	30
SP002	PT	6	1
SP003	PT	7	4
SP004	OT	6	1
SP005	OT	6	3
SP006	PT	6	3
SP007	PT	6	10
Total	PT: 5, OT: 2	Not applicable	Average (mean): 7.4 (years)

9.3.1 Quantitative section

9.3.1.1 Overall evaluation of the programme

The questions and statements about understanding therapists' overall comments and attitudes toward using the programme were grouped together for analysis. The specific findings in relation to each part of the manual are reported in the following section. The codes and corresponding statements are listed below. Particular findings emerging from the data sets are highlighted in yellow.

The codes were also used to represent the statement in the radar chart displayed later in this section. Total overall interval level scores of the acceptability, suitability and feasibility of the programme are set at 10. The scores of each aspect are shown in table 9.3.1a below.

Table 9.3.1a: Overall scores of acceptability, suitability & feasibility of the programme⁵³

	Acceptability score (out of 10)	Suitability score (out of 10)	Feasibility score (out of 10)
SP001	7	7	6
SP002	6	6	5
SP003	7	6	6
SP004	7	8	7
SP005	7	8	6
SP006	6	7	7
SP007	6	7	7
Mean	6.6	7	6.3

A total of three questions were used to evaluate the overall acceptability, suitability and feasibility of the programme in which interval scale scores were collected. A further six questions were used to evaluate different issues relating to the overall acceptability, suitability and feasibility of the programme to holistically evaluate it from different angles.

⁵³ Interval level scale 0-10 was used for the above rating in which 0 is the lowest score and 10 is the highest score

Overall scores of acceptability, suitability & feasibility of the programme

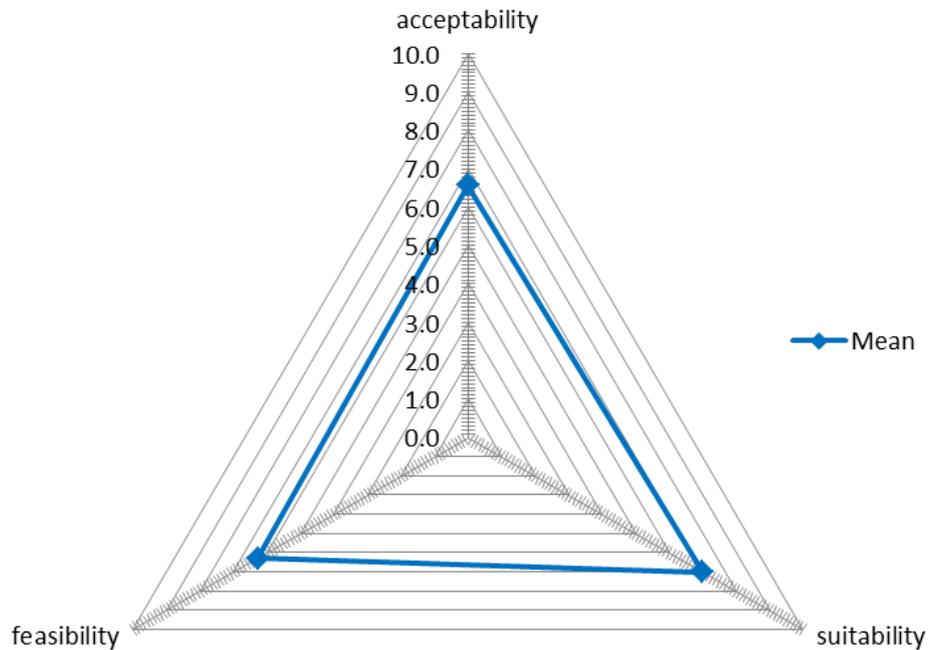


Figure 9.3.1a: Radar chart of overall scores of acceptability, suitability & feasibility of the programme

The findings shown in figure 9.3.1a indicate that the respondents tend to consider the contents of the programme are acceptable (Mean=6.6; out of 10). They tended to think it is suitable (Mean=7; out of 10) to use this programme for clinical practice within the current pathway for stroke rehabilitation in the UK. They also considered that it is feasible (Mean=6.3; out of 10) to use the programme although the score for this aspect is lower, relative to the other 2 domains.

Table 9.3.1b: Overall scores of acceptability, suitability & feasibility of the whole programme⁵⁴

	acceptability	suitability			feasibility	
Statement	The contents of this programme are clinically relevant to address stroke survivors' needs for rehabilitation for activity and participation (pq1b026)	The use of available information and communication technology is a suitable option for helping stroke survivors to manage their exercises for this programme (pq1b027)	It is not appropriate to deliver this programme within the current stroke pathway for community rehabilitation (pq1b028)	The use of this programme can fit for the timing of the provision of community stroke rehabilitation (pq1b029)	It is not feasible to adopt available technology to support stroke survivors to manage their own exercises for activity and participation in the community (pq2a013)	It is not workable to apply this programme in clinical practice to enable stroke survivors to manage their own exercises in the community (pq2a014)
SP001	2	2	2	2	2	2
SP002	2	2	4	2	2	2
SP003	2	2	2	4	2	2
SP004	1	2	3	3	2	2
SP005	2	2	2	2	2	2
SP006	2	2	2	3	2	2
SP007	2	2	2	2	2	2
Median	2 (Agree)	2 (Agree)	2 (Disagree)	2 (Agree)	2 (Disagree)	2 (Disagree)
Total number of respondents of the median score (out of 7*)	7	7	5	4	7	7

⁵⁴ Likert scale used for the positive statement of this survey: 1= strongly agree, 2=agree, 3=uncertain, 4=disagree, 5=strongly disagree

Likert scale used for the negatively structured statement of this survey: 1=strongly disagree, 2=disagree, 3=uncertain, 4=agree, 5=strongly agree

*Combined number of “strongly agree” and “agree” (or “strongly disagree” and “disagree”) for median response

Acceptability, suitability & feasibility of the whole programme

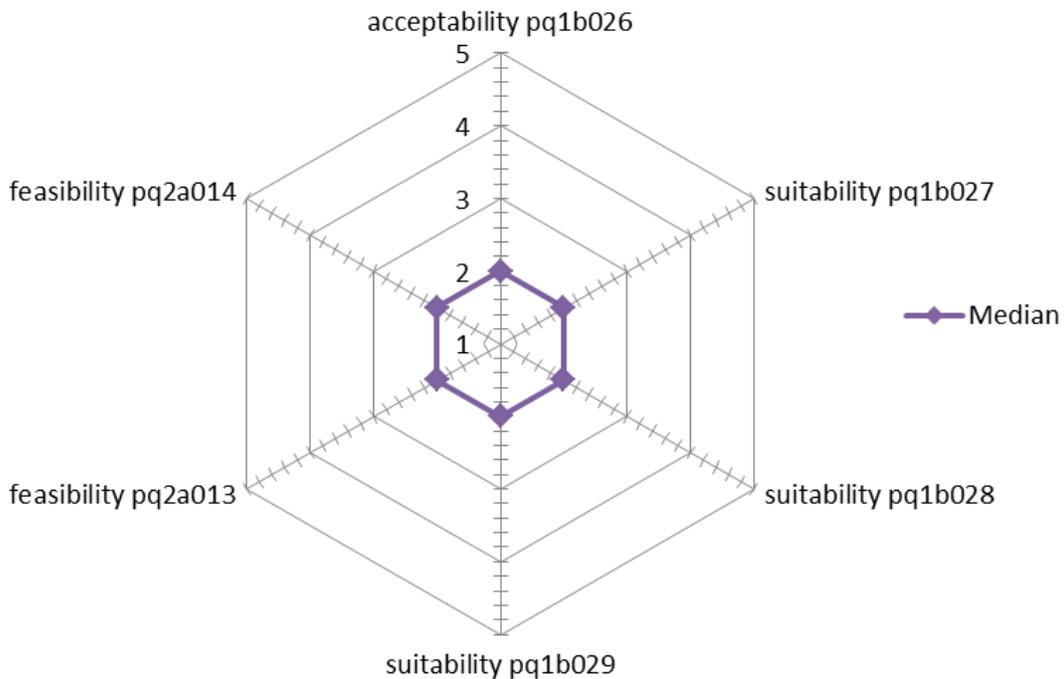


Figure 9.3.1b: Radar chart of overall scores of acceptability, suitability & feasibility of the whole programme

From the angle of acceptability for clinical practice, it indicates that the respondents generally agreed that the programme is clinically relevant (pg1b026) for stroke survivors' needs of rehabilitation for activity and participation (Median=2).

In view of suitability, it shows that the respondents generally agreed it is suitable to use available information and communication technology in the programme (pg1b027) and is appropriate to deliver the programme for community rehabilitation (pg1b028). They tend to agree that the proposed timing of using the programme is also suitable for the provision of community stroke rehabilitation (pg1b029) (Median=2, which indicates they disagree the programme is not suitable).

However, one therapist disagreed that the programme is appropriate to be delivered for community rehabilitation and another one disagreed that the proposed timing of using the programme is suitable for community stroke rehabilitation.

All therapists agreed that it is feasible to use available technology to support stroke survivors to manage their exercises (pg2a013) and apply the programme in clinical practice (pg2a014) (Median=2).

9.3.1.2 Book A: Clinical checklist

The questions were narrowed down to explore specific attitudes towards the contents of *Book A: Clinical checklist*. The findings are reported below. The codes were used to represent the statement in the radar chart displayed below.

A total of 15 statements were used to evaluate the acceptability, safety, suitability and feasibility of *Book A: Clinical Checklist*. Quantitative findings for the evaluation of the Book A are reported in tables 9.3.2a to c below.

Table 9.3.2a: Acceptability & Safety of Book A

Statement	acceptability					safety
	Section 1 (Needs assessment) is acceptable to identify the needs of stroke survivors for their physical functional rehabilitation (pq1a003)	Section 1b (Goal-setting for activity and participation) is acceptable for helping stroke survivors to set their goals for rehabilitation for activity and participation (pq1a004)	It is acceptable to use section 2 (Select stroke specific physical rehabilitation exercises) to determine self-managed physical rehabilitation exercises for individual stroke survivor's activity and participation (pq1a005)	It is not acceptable to use section 3 (What technology is available) to identify useful technology to support stroke survivors (pq1a006)	Section 4 (Assistance to self-manage physical rehabilitation exercises) is acceptable for the identification of useful assistance to help stroke survivors for this programme (pq1a007)	I don't feel safe to use Book A in clinical practice (pq1a012)
SP001	2	2	2	2	2	2
SP002	2	2	2	2	2	2
SP003	2	2	2	4	2	1
SP004	1	1	2	1	2	1
SP005	2	2	2	2	2	2
SP006	2	1	2	2	2	2
SP007	3	2	2	3	2	2
Median	2 (Agree)	2 (Agree)	2 (Agree)	2 (Disagree)	2 (Agree)	2 (Disagree)
Total number of respondents of the median score (out of 7*)	6	7	7	5	7	7

Table 9.3.2b: Suitability of Book A

suitability				
<u>Statement</u>	Section 1 (Needs assessment) is suitable for assessing stroke survivors' needs for rehabilitation for activity and participation (pq1a008)	It is appropriate to use section 2 (Select stroke specific physical rehabilitation exercises) to determine self-managed stroke exercises for functional rehabilitation (pq1a009)	It is not suitable to use section 3 (What technology is available) to determine useful available technology to support stroke survivors to manage their own exercises in the community (pq1a010)	Section 4 (Assistance to self-manage physical rehabilitation exercises) is suitable for identifying useful assistance to help stroke survivors to manage their own exercises according to their conditions in the community (pq1a011)
<u>SP001</u>	2	2	2	2
<u>SP002</u>	2	2	2	2
<u>SP003</u>	2	4	2	2
<u>SP004</u>	1	1	1	2
<u>SP005</u>	2	2	2	2
<u>SP006</u>	2	2	2	2
<u>SP007</u>	1	1	3	2
Median	2 (Agree)	2 (Agree)	2 (Disagree)	2 (Agree)
Total number of respondents of the median score (out of 7*)	7	6	6	7

Table 9.3.2c: Feasibility of Book A

feasibility					
<u>Statement</u>	Section 1 (Needs assessment) is practical for therapists to assess stroke survivors' needs of physical rehabilitation for activity and participation (pq2a002)	It is feasible to use section 1b (Goal-setting for activity and participation) to set the goals for rehabilitation for activity and participation (pq2a003)	I don't think section 2 (Select stroke specific physical rehabilitation exercises) can be used to prescribe self-managed physical rehabilitation exercises for stroke survivors' activity and participation (pq2a004)	It is not practical to use section 3 (What technology is available) to determine useful available technology to support stroke survivors in the community (pq2a005)	Section 4 (Assistance to self-manage physical rehabilitation exercises) is workable for finding useful assistance for helping stroke survivors to manage their own exercises (pq2a006)
<u>SP001</u>	2	2	2	2	2
<u>SP002</u>	2	2	2	2	2
<u>SP003</u>	2	2	2	2	2
<u>SP004</u>	1	1	2	2	2
<u>SP005</u>	2	2	2	2	2
<u>SP006</u>	2	2	2	2	2
<u>SP007</u>	2	2	2	2	2
Median	2 (Agree)	2 (Agree)	2 (Disagree)	2 (Disagree)	2 (Agree)
Total number of respondents of the median score (out of 7*)	7	7	7	7	7

Acceptability, suitability & feasibility of Book A

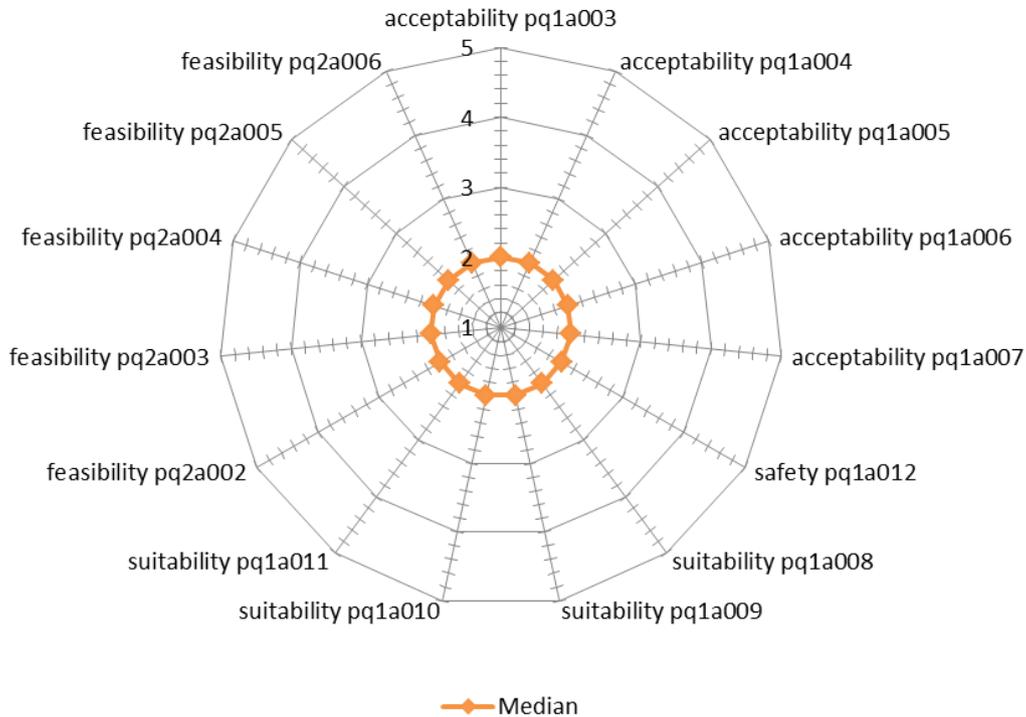


Figure 9.3.2: Radar chart of acceptability, suitability & feasibility of Book A

In general, the above findings indicate that the respondents agreed the contents of different sections of Book A are acceptable and suitable (both Median=2) to be used in clinical practice. They also agreed that it is feasible and safe to use Book A (both Median=2).

However, one therapist disagreed that section 3 of Book A is acceptable for the identification of full available technology to support stroke survivors. Additionally, one therapist disagreed that it is appropriate to use section 2 of Book A to determine self-managed stroke exercises for functional rehabilitation.

9.3.1.3 Book B: My stroke exercise manual

The questions were narrowed down to explore their attitudes towards the contents of the *Book B: My stroke exercise manual*. The findings are reported below. The codes were used to represent the statement in the radar chart displayed below.

A total of 19 statements were used to evaluate the acceptability, safety, suitability and feasibility of each section of *Book B: My stroke exercise manual*. Quantitative findings for the evaluation of Book B are reported in table 9.3.3a to c below.

Table 9.3.3a: Acceptability & safety of Book B

Statement	acceptability					safety
	Section 1 (Summary from my therapist) is acceptable for helping stroke survivors to determine their actions for their goals for activity and participation (pq1b013)	It is acceptable to use section 2 (What rehabilitation exercises do I need to do) to prescribe individualised stroke rehabilitation exercises (pq1b014)	Section 3 (Sources of help for me to manage my exercises) is acceptable for assisting stroke survivors to manage their own exercises (pq1b015)	Section 4 (Learning from stroke survivors like me) is acceptable for facilitating stroke survivors to manage their own exercises (pq1b016)	The contents of "My monthly progress record" are acceptable for helping stroke survivors to monitor their own progress (pq1b017)	It is safe to use Book B to help stroke survivors to manage their own exercises in the community (pq1b025)
SP001	2	2	2	2	2	2
SP002	2	2	2	2	2	2
SP003	2	2	2	2	2	2
SP004	1	2	2	2	1	1
SP005	2	2	2	2	2	2
SP006	2	2	4	2	2	2
SP007	2	1	2	2	2	2
Median	2 (Agree)	2 (Agree)	2 (Agree)	2 (Agree)	2 (Agree)	2 (Agree)
Total number of respondents of the median score (out of 7*)	7	7	6	7	7	7

Table 9.3.3b: Suitability of Book B

suitability Statement	I don't feel section 1 (Summary from my therapist) is suitable for helping stroke survivors to plan their actions for their goals for activity and participation (pq1b018)	Section 2 (What rehabilitation exercises do I need to do) is appropriate for helping stroke survivors to manage their own exercises based on their conditions in the community (pq1b019)	I don't feel section 3 (Sources of help for me to manage my exercises) is suitable for helping stroke survivors to use the identified assistance according to local context (pq1b020)	Section 4 (Learning from stroke survivors like me) is suitable for facilitating stroke survivors to manage their own exercises with the use of available technology in the community (pq1b021)	I don't think "tips for user" provides appropriate information to help stroke survivors to manage this programme (pq1b022)	I don't think proper information are provided in "Useful resources and networks" to support stroke survivors for their physical rehabilitation (pq1b023)	It is suitable to use "My monthly progress record" to help stroke survivors to regulate their own exercises in the community (pq1b024)
SP001	2	2	2	2	2	2	2
SP002	2	2	2	2	2	2	2
SP003	2	2	2	2	2	2	2
SP004	1	2	2	2	1	1	2
SP005	2	2	2	2	2	2	2
SP006	2	2	4	2	2	4	2
SP007	2	2	2	2	2	1	1
Median	2 (Disagree)	2 (Agree)	2 (Disagree)	2 (Agree)	2 (Disagree)	2 (Disagree)	2 (Agree)
Total number of respondents of the median score (out of 7*)	7	7	6	7	7	6	7

Table 9.3.3c: Feasibility of Book B

feasibility						
Statement	It is not possible to use section 1 (Summary from my therapist) to help stroke survivors to plan their actions for their goals for physical rehabilitation for activity and participation (pq2a007)	It is feasible for stroke survivors to use section 2 (What rehabilitation exercises do I need to do) to manage their own exercises with the support of available technology in the community (pq2a008)	Section 3 (Sources of help for me to manage my exercises) is workable for helping stroke survivors to practise their own exercises (pq2a009)	It is feasible to adopt section 4 (Learning from stroke survivors like me) to facilitate stroke survivors to manage their own exercises with the use of available technology in the community (pq2a010)	It is feasible to use "My monthly progress record" to enable stroke survivors to regulate their own programme (pq2a011)	The information in "Useful resources and networks" is practical for helping stroke survivors to manage their own exercises in the community (pq2a012)
SP001	2	2	2	2	2	2
SP002	4	2	2	2	2	2
SP003	2	1	2	2	2	4
SP004	1	2	2	2	2	1
SP005	2	2	2	2	2	2
SP006	2	2	2	2	2	2
SP007	2	2	2	2	2	2
Median	2 (Disagree)	2 (Agree)	2 (Agree)	2 (Agree)	2 (Agree)	2 (Agree)
Total number of respondents of the median score (out of 7*)	6	7	7	7	7	6

Acceptability, suitability & feasibility of Book B

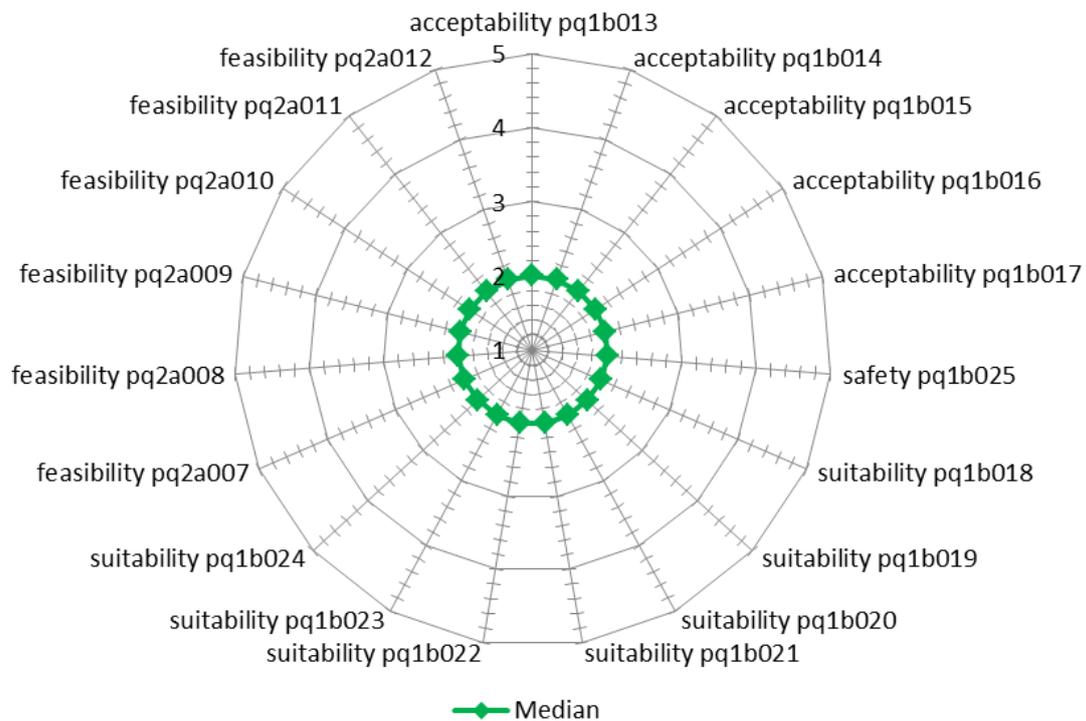


Figure 9.3.3: Radar chart of acceptability, suitability & feasibility of Book B

The above findings demonstrate that the respondents generally agreed the contents of different sections of Book B are acceptable and suitable (both Median=2) to be used in clinical practice. They agreed that it is feasible to use Book B (Median=2). They also agreed that it is safe for stroke survivors to use Book B (Median=2).

However, one therapist disagreed that section 3 of Book B is acceptable for assisting stroke survivors to manage their own exercises. With regards to suitability, one therapist disagreed that the section 3 of Book B is suitable for helping stroke survivors to use the identified assistance and another one disagreed that the information in “useful resources and networks” is suitable for supporting stroke survivors for their physical rehabilitation. Furthermore, one therapist disagreed that section 1 of Book B is feasible to help stroke survivors to plan their actions for their goals for physical rehabilitation for activity and participation and another one disagreed that the information in “useful resources and networks” is practical for helping stroke survivors to manage their own exercises.

9.3.2 Qualitative section

The written texts in response to the open-ended questions were coded and categorised using thematic analysis. These provide additional feedback on respondents’ opinions towards the acceptability, suitability and feasibility of the programme.

9.3.2.1 Acceptability

Four themes were identified with regards to the acceptability of the contents of the programme for physical functional stroke rehabilitation. The following table 9.3.2.1 summarises the feedback:

Table 9.3.2.1: Additional feedback on acceptability of the programme

Themes	Number of respondents	Quotes
Reliance on the support of professional instruction for delivery	3	"This will strongly depend on the skill of the clinician defining the exercise" (SP001)
Reliance on stroke survivor's ability to learn	1	"This will strongly depend on learning ability of the stroke survivor" (SP001)
Need of further refinement for contents	1	"With some adaptations would be acceptable (for Book A)" (SP003)
Need of adding other contents for stroke rehabilitation	1	"Relevant, may possibly need outcome for mood and follow up" (SP005)

In view of the acceptability, the above findings indicate clinicians thought that support from professionals will be required to deliver the programme. Stroke survivor's ability to learn was reported as a concern. Further refinement of the contents and providing additional contents for stroke rehabilitation were also suggested in the survey.

9.3.2.2 Suitability

Four themes were identified in relation to the suitability of using the programme according to the current stroke pathway. The following table 9.3.2.2 summarises their feedback:

Table 9.3.2.2: Additional feedback on suitability of the programme

Themes	Number of respondents	Quotes
Useful contents for small minority group	2	"Would be useful for a small minority of stroke survivors" (SP005)
Need to consider specific needs from other stroke related impairments	1	"It is accessible, however, the choice of patient would need to be specific due to reduced cognition and reduced insights" (SP004)
Need further simplification for the contents	2	" Monthly progress record is cluttered and difficulty to use" (SP003)
Provide guidance to assist stroke survivors	2	"Patients need lots of guidance" (SP002)

For suitability, the contents were considered to be useful for a small minority of stroke survivors. Specific needs resulting from other impairments associated with stroke were suggested to be considered for better suitability of the programme. Additionally, further simplification of the contents and the provision of guidance to assist stroke survivors to use the programme were also recommended to promote the suitability of the programme.

9.3.2.3 Feasibility

Five themes were identified from the written texts concerning the feasibility of using the programme. The following table 9.3.2.3 summarises the feedback:

Table 9.3.2.3: Additional feedback on feasibility of the programme

Themes	Number of respondents	Quotes
Reliance on the support of professional instruction for delivery	1	"Will strongly depend on skills of clinicians to set out appropriate exercise" (SP001)
Require professional training	2	"Appropriate training for staff" (SP003)
Need to assist stroke survivors to use the programme	2	"Very few patients will manage own rehab, will need lots of assistance" (SP002)
Further simplification of the contents	1	"Lengthy and wordy, stroke survivors often have reduced attention" (SP005)
Time management for prescription	3	"Time to complete with patient, therapy time is often limited" (SP005)

With regards to the feasibility of using the programme, it has been suggested that the support of professional instruction and the provision of training by professionals will be required for the feasibility of delivering the programme. The provision of assistance to stroke survivors to use the programme and further simplification of the contents were also recommended to enhance the feasibility of using the programme. Additionally, time management for prescription was suggested to be the potential influence on the feasibility of the programme.

9.3.3 Integration of findings: Mixed methods matrix

The findings of the 4 domains: acceptability, suitability, feasibility and safety, were further analysed using a mixed methods matrix. Table 9.3.7 illustrates the combined results from integrating the key quantitative and qualitative findings in this survey.

Table: 9.3.3: Mixed methods matrix of findings of acceptability, safety, suitability & feasibility of the programme⁵⁵

	QN findings	QL findings
	Central tendency of agreement	Themes
Acceptability	Overall: Mean=6.6 (out of 10) Median=2 (agree) Book A: Median=2 Book B: Median=2	<ul style="list-style-type: none"> - Reliance on the support of professional instruction for delivery (N=3) - Reliance on stroke survivor's ability to learn (N=1) - Need of further refinement for contents (N=1) - Need of adding other contents for stroke rehabilitation (N=1)
Suitability	Overall: Mean=7 (out of 10) Median=2 Book A: Median=2 Book B: Median=2	<ul style="list-style-type: none"> - Useful contents for small minority (N=2) - Need to consider specific needs from other stroke related impairments (N=1) - Need further simplification for the contents (N=2) - Provide guidance to assist stroke survivors (N=2)
Feasibility	Overall: Mean=6.3 (out of 10) Median=2 Book A: Median=2 Book B: Median=2	<ul style="list-style-type: none"> - Reliance on the support of professional instruction for delivery (N=1) - Require professional training (N=2) - Need to assist stroke survivors to use the programme (N=2) - Further simplification of the contents (N=1) - Time management for prescription (N=3)
Safety	Book A: Median=2 Book B: Median=2	

⁵⁵ QN= quantitative , QL= qualitative

The above matrix summarises the overall understanding about the respondents' attitudes towards the four aspects of the programme from both quantitative and qualitative findings. The findings reflect that the respondents generally agreed the contents of the programme are acceptable, suitable, feasible and safe to use for practice. They also provided a range of advice to enhance the acceptability, safety, suitability and feasibility of the programme.

9.4 Discussion

Evaluation of the applicability of interventions has been emphasised as a component for evidence-based practice for stroke (Langhorne et al., 2009b). Hence, this evaluation sought to understand whether the programme developed in phase 1 of this research is appropriate and applicable for clinical practice as judged by professional physiotherapists and occupational therapists.

The following research questions were answered in this study:

- *“What do clinicians think about the acceptability of the programme for physical functional stroke rehabilitation in the community?”*
- *“What do clinicians think about the suitability of using the programme according to the current health service system and policy for stroke rehabilitation?”*
- *“What do clinicians think about the feasibility of using the programme in practice?”*
- *“Do clinicians consider the programme is safe to be used in clinical setting?”*

The acceptability, suitability, safety and feasibility of each section of the manual were evaluated by a group of therapists who were independent to the previous development stage to determine whether the programme is applicable and appropriated for use. Professional attitudes and willingness to change is important for the support of self-management to people with chronic conditions (Kennedy et al., 2007). Thus, this study explored professionals' attitudes in changing their practice to include the programme as a new alternative.

The use of stroke self-management programmes was evaluated and reported in studies (Jones, 2013, Lennon et al., 2013). Evidence has been reported for the possibility of using technology to provide stroke rehabilitation (Mawson et al., 2013). In particular, the importance of evaluating written stroke materials from the perspective of health professionals before using them with stroke survivors has been highlighted (Hoffmann and Ladner, 2012, Hoffmann et al., 2007). However, little is known about clinicians' attitudes and opinions towards the acceptability, suitability, safety and feasibility of using available ICTs to support stroke survivors to self-manage their own exercises.

The findings of this evaluation indicated that therapists agreed that that it is acceptable, suitable, feasible and safe to use the materials in this programme for community physical stroke rehabilitation, although they have suggested some aspects for further improvement.

It has been highlighted that more research is needed to understand stroke professionals' readiness to interact to fully support self-management (Jones et al., 2013b). The findings of this survey help to understand whether a newly developed self-managed stroke intervention is ready to be delivered by professionals in a community setting.

Participant demographics

The length of time working with stroke rehabilitation of the respondents was diverse, which is ranging from 1 to 30 years. It reflects that the programme was evaluated by people with a wide range of professional experiences in stroke rehabilitation. Therefore, the findings of this evaluation may reflect that the programme can be understood and accepted by clinicians regardless to their length of practice.

The majority of the respondents were PTs. More OTs will be needed in future evaluation to understand the acceptability and readiness of the programme to be delivered by both professions to support stroke self-management. Further studies may be required to explore the potential influence from the professional grade of the clinicians in relation to the professional judgement of a self-managed stroke exercise manual and the delivery of such intervention, since most of the respondents were at

Band 6. Studies with wider ranking of therapists will help to obtain more opinions from therapists of different pay grades to understand how well the programme can be fit into practice.

Acceptability

The acceptability of an intervention can influence its uptake and usage, subsequently affecting the impact on the target population (Keller et al., 2000). It is important to recognise influencing factors on the acceptability of a self-managed intervention supported with technology to ensure it is a good-quality method of service delivery (Palmer et al., 2013).

Professional evaluation of the acceptability and safety of using the programme with healthcare professionals is required, since their attitudes towards the acceptability and safety of using available technology to deliver health care service have been considered important (Car and Sheikh, 2004). Hence, therapists' judgement about the acceptability of the programme can help to reflect the general needs of stroke survivors. If a service programme is to be adopted into clinical practice, it is essential that it can be accepted by the clinicians. Clinicians' attitudes and acceptance towards using the programme as a new alternative intervention may directly influence their willingness to utilise it in their practice.

Evidence indicates that it is acceptable to deliver stroke self-management programmes to stroke survivors (Jones, 2013). The use of technology device to provide stroke rehabilitation has also been reported acceptable (Mawson et al., 2013). Similarly, this study provides evidence showing professional acceptance regarding the use of the programme. Findings of this survey indicate that clinicians generally accept the programme can be used to provide physical stroke rehabilitation service. This reflects willingness of some to deliver the programme.

However, disagreements and uncertainties were still found from some respondents in relation to the acceptability of some parts of the programme, including the needs assessment section and the use of section 3 for the selection of available technology in Book A. Although, the acceptability of the sections of Book B was generally promising, there was a concern about the acceptability of the section 3 "Sources of

help for me to manage my exercises". Moreover, the mean of the overall score of the acceptability is modest (6.6 out of 10). Further studies will be needed to further analyse clinicians' concerns for the acceptability of such a programme.

Qualitative findings about the acceptability issues may provide some insights to understand the potential reason for the above concerns. Although the materials in both Books were being accepted by therapists; there are parts of the programme that should be improved to promote the acceptability of the materials for clinical application. The therapists were concerned the delivery of the programme may be too dependent on professional instruction. Thus, it will be worth considering a way to minimise dependency on professionals when providing the programme in further research.

They were also concerned that the use of the materials may depend on the learning ability of the individual stroke survivor. This insight is consistent with the reason for involving educational theories in this research. Further research is needed to understand the effectiveness and impact on stroke survivor's learning ability by employing learning theories for this client group. This may help to determine an efficient way to help stroke survivors learn how to self-manage. This may increase the acceptability of the programme.

In addition to the contents for functional rehabilitation, the inclusion of other stroke related content and outcome measures were suggested for the programme by the clinicians to promote the acceptability of the programme for clinical use. Hence, further work will be needed to understand the extra components that may be added to this programme to enhance its acceptability for physical stroke rehabilitation.

This study can only provide information in relation to professional's acceptance towards delivering the programme from a provider's perspective. End-users' acceptance towards any new technology is important if a system is to be adopted to deliver healthcare (Jackson et al., 2009). Further evaluation with stroke survivors and their carers will be required to determine their acceptance of using the programme. The programme will need to be evaluated using clinical trials to inform how well it can be received by users to meet their needs before implementing it.

Safety

Findings indicate that therapists generally agreed that it will be safe to use the programme. They had no additional comment on the safety of the programme. This may be due to the reliance on professional knowledge and instruction for the delivery of the programme.

Therefore, although the findings of this evaluation demonstrated that reliance on professionals is a concern affecting the acceptability and feasibility of the programme, it may still be important to have professionals' involvement for the prescription and delivery of a self-managed stroke exercise manual supported with ICTs for the reasons of safety in practice.

The safety of any intervention must be the first priority before using it in clinical practice. It is necessary to understand the safety issues about using the exercises prescribed in the programme and the selected ICTs to manage the exercises in future clinical studies.

Suitability

The importance of evaluating the suitability of written stroke materials by healthcare professionals before using them with stroke survivors and their carers has been emphasised (Hoffmann and Ladner, 2012, Hoffmann et al., 2007). Jones (2013) highlighted that a reason that more participants in a generic self-management programme withdraw was due to unsuitability of the programme. Although the programme of this research was based on stroke survivors and therapists, it was essential to determine whether it is suitable to be used according to local contexts. This may help to determine how well it can be "fit" into the current stroke pathway to address the needs of physical stroke rehabilitation in the community according to local standards, health systems, policy and resources.

The understanding about the suitability of a clinical intervention may help to facilitate the smooth translation of knowledge and concepts generated from this research into practice. Programme suitability should involve the understanding about the extent to which a person is ready to engage in a change process of the programme (Casey et

al., 2007). The use of professional knowledge and experiences may help to determine how well the programme can fit into the current system for stroke rehabilitation. This is crucial to determine whether it can and should be incorporated into current practice.

However, disagreements and uncertainties were still found in relation to the appropriateness of delivering the programme within the current stroke pathway. Some respondents were not sure if the programme can be used to fit the timing of the provision of community stroke rehabilitation. Concerns and uncertainties were still raised by some respondents in relation to the suitability of the section 2 “Select stroke specific physical rehabilitation exercises” and the section 3 “What technology is available” in Book A. Disagreements related to the suitability of using some sections in Book B were also found. One respondent disagreed that the sections of “Sources of help for me to manage my exercises” and “useful resources and networks” were suitable to be used.

It remains important to refer to the qualitative data about the suitability of the programme for further improvement. The therapists were concerned that the programme may only be useful for a small minority group of stroke survivors. The need to consider other stroke related impairments was also highlighted in this study. Hence, further research will be needed to identify a way to use the programme with other existing stroke self-management interventions to address the multiple needs of stroke survivors for rehabilitation. This may help to increase the proportion of stroke population for which the programme is suitable.

Further simplification of the contents has also been suggested to promote the suitability of the programme. However, it is important to reach a balance between simplifying the materials and keeping the information required for the needs and conditions of different stroke survivors in clinical situation. Further evaluation is needed to determine which part of the programme could be simplified further. Clinical and process evaluation will need to determine the best way to simplify the programme and retain the elements of it to address the needs of physical stroke rehabilitation.

The provision of guidance to assist stroke survivors to use the programme has been recommended to enhance its suitability. Thus, more instructions will be required in future versions to guide stroke survivors to manage the programme.

However, this study could only inform the decision about using the programme from provider's perspective. In view of the suitability of written materials for stroke survivors, it is important to ensure that relevant information is delivered in the most optimal format to tailor the information to the users, since they are the target audience (Eames et al., 2003). What might be the factors affecting the suitability of the programme to be managed by stroke survivors?

Many factors might determine an individual's suitability to use technology to receive health services. A person's ability to understand information and his/her attitudes may determine his/her ability to benefit from online therapy (Suler, 2001). Thus, further evaluation with the involvement of stroke survivors will be needed to determine how well the programme can meet stroke survivor's needs.

Feasibility

It has been reported that it is feasible to deliver stroke self-management programmes to stroke survivors in the community (Jones, 2013, Lennon et al., 2013, McKenna et al., 2013). Moreover, studies reported that it is feasible to apply ICTs to home-based physical stroke rehabilitation (Lennon et al., 2013, Mawson et al., 2013, Parker et al., 2013, Chumbler et al., 2012, Taylor et al., 2012, Zheng et al., 2006). Therefore, it indicates that it is possible to combine self-management concepts with the use of ICTs to deliver functional stroke rehabilitation services. It remains necessary to understand the feasibility of using the programme developed in this research which contains components and concepts in addition to the interventions reported in related literature.

Findings of this survey show that clinicians generally agreed that it will be feasible to deliver this self-managed programme including the use of ICTs in practice. However, compared to the overall scores for the suitability and acceptability; it appears that the extent of agreement about the feasibility of the programme were relatively lower.

Although overall findings demonstrated that clinicians generally considered the programme is feasible to be used, some disagreements were still being reported by some respondents towards the practicability of using some sections of the manual. Some therapists did not think that it will be feasible for patients to use section 1 “Summary from my therapist” and the section of “useful resources and networks”.

From qualitative findings, there are parts of the programme that should be improved to make that more feasible. The potential reliance on the support of professional instruction to deliver the programme is a concern from the professional perspective. It is important to identify the way to enable stroke survivors to use the programme with minimal reliance on therapists to empower patients to self-manage. Some respondents suggested additional methods are needed to facilitate stroke survivors to use the programme to enhance the feasibility of using it, in addition to the types of assistance identified in phase 1 of this research.

The provision of professional training to therapists was suggested by some respondents to make the programme. This reflects that the provision of written information may be insufficient to assist therapists to deliver the programme. This may be because the contents and concepts are relatively new.

Time management for prescription and further simplification of the contents were of concern to some respondents. This indicates that further work may be needed to adjust the programme to facilitate its smooth and quick prescription for the applicability of it.

The overall score of feasibility is modest (6.3 out of 10). It remains unclear why the clinicians rate the feasibility of the programme lower than that of acceptability and suitability. Their relative hesitation towards the practicability of the programme may be due to the lack of available clinical evidence and their specific knowledge about the programme. This may also be due to the time that it might take to prescribe and support the patients to use the programme. The clinicians might also hesitate the time that they have available to deliver the programme. Hence, clinical trials should be conducted to test feasibility of the programme to provide further insights into

potential difficulties with delivering it in practice. This may be similar to the overall score of the acceptability of the programme.

Professional evaluation of a new intervention with clinical expertise

The professional judgements from clinicians were used in this evaluation. Practical knowledge from practitioners' clinical experience has been deemed as an important source of evidence for patient-centred care (Gerrish et al., 2007, Rycroft-Malone et al., 2004). The knowledge and experience of clinical experts can enable the integration of knowledge into clinical practice for making patient-centred and evidence-based clinical decisions (Cullen et al., 2008, Hardy et al., 2006, Lambert, 2006).

The use of professional judgement from related clinicians may help to bring evidence and clinical decision making together for clinical application of an intervention, since professional judgement⁵⁶ can influence the use of health services (Black and Gruen, 2005). From my clinical experiences, the use of clinical judgements can help to integrate a variety of sources of knowledge and concepts to make effective patient-centered and evidence-based decisions so as to determine whether a new intervention can be used to address the needs with the considerations of different clinical circumstances for case management in practice.

In addition to patients' perspective, I consider it is important to involve clinicians' judgement to critically appraise the contents of a new intervention designed to be used in a clinical setting. This can help in decisions as to whether the programme is appropriate and can be used. This may facilitate the translation of new knowledge of this research into practice.

It is necessary to make decisions about the scope of the evaluation, since the agreement of the purpose of an evaluation can guide choices of design and approach (Green, 2006). Therefore, professional evaluation of the programme was

⁵⁶ Professional (or clinical judgement) can help to determine whether the individual's need for health is also a need for health care (Black and Gruen, 2005)

conducted in this research in which clinicians' judgement was used to decide whether the programme is appropriate and possible to be used.

However, questions remain concerning the delivery of the programme in the community. There is no single evaluation method can serve all purpose to evaluate an intervention. The choice and design of an evaluation should be based on the purpose and focus of the individual evaluation. Therefore, additional evaluations will be needed to understand other aspects about using the programme, such as process, outcome and economic evaluations. This may provide useful information to facilitate the adaption and application of the programme for practice.

9.5 Limitations

Although representative respondents were recruited for this survey, the evaluation was limited by the small sample size due to the limited availability of related therapists in the local area. This may limit the extent to which the findings of this evaluation can be applied to other areas. Hence, larger scale evaluations covering more districts will be required to collect more data from other areas in future evaluation of the programme. This may help to promote the generalizability of the findings to a wider group of therapists in the UK to facilitate the adaption of the programme in different regions managed under the same health service system.

9.6 Implications

This study reflects clinicians' willingness and perception towards using the programme in practice. The majority of the respondents indicated that the programme is considered to be deliverable from a practitioner's perspective. The findings of this evaluation suggest that the programme is ready to be tested clinically to evaluate its clinical impact on community stroke rehabilitation since it is important to understand the delivery processes and the potential impact of the programme before it can be fully adapted and implemented into routine practice. This evaluation implies that the inclusion of the components identified in this research can help to develop an appropriate and usable programme for the self-management of stroke exercise supported with available ICTs according to provider's judgement.

The preliminary findings of this evaluation also reflect that most of the clinicians consider it is acceptable, suitable, feasible and safe to apply the concepts of the gear model to help stroke survivors to manage their own exercises with the use of ICTs.

The relatively small sample size reflects the fact of having insufficient manpower to provide physical stroke rehabilitation services in the community. This indicates the importance of enabling stroke survivors to continue to self-manage their own exercises with available ICTs to reduce their reliance on professionals for ongoing rehabilitation. Thus, the constraint from small numbers of respondents in this survey reflects the key value and urgency to accelerate the practice of self-management to address the unmet needs of physical stroke rehabilitation in the community.

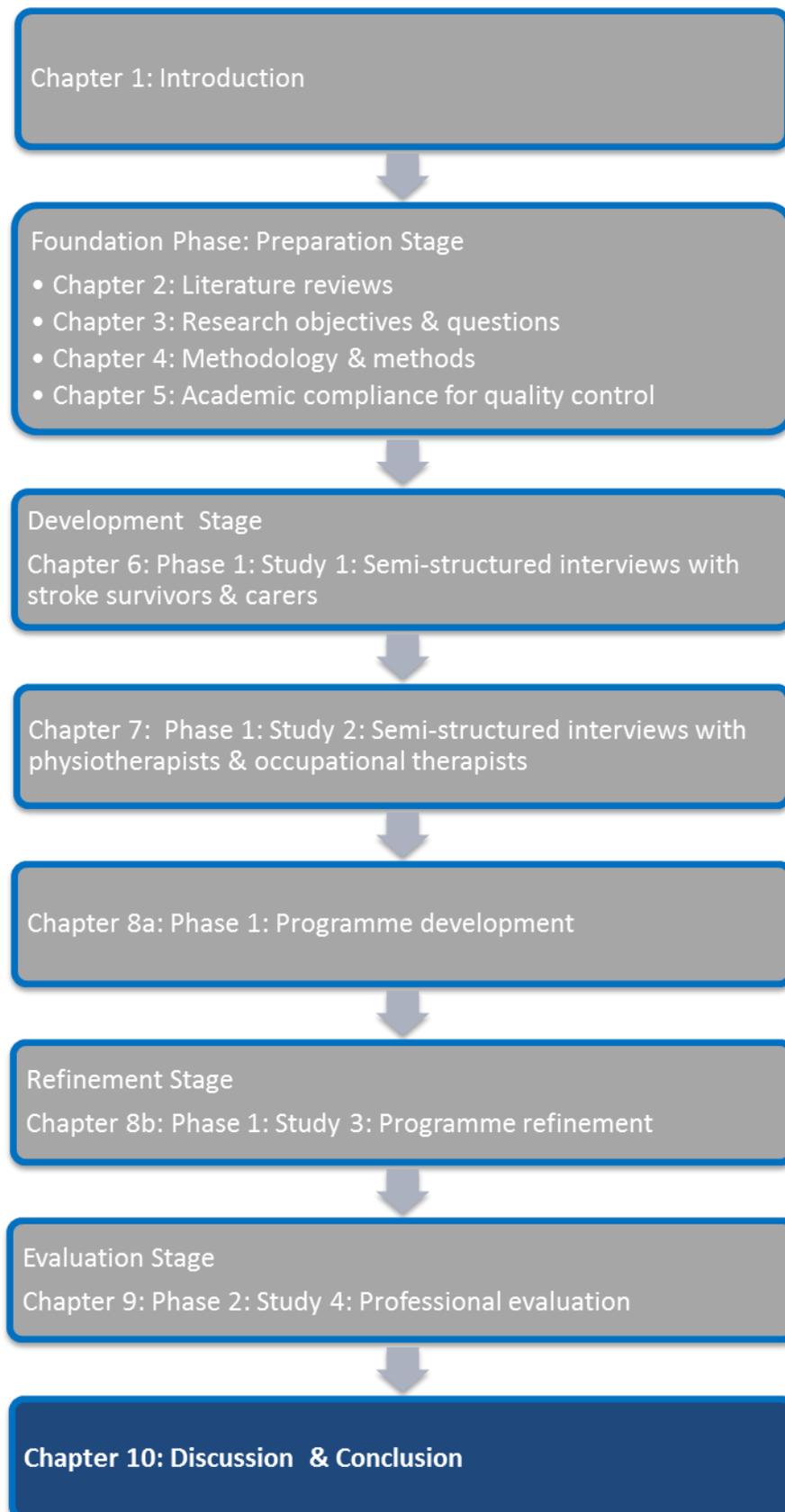
This evaluation may provide useful information for the deployment of stroke rehabilitation services to commissioners, health policy makers and clinicians in community setting.

9.7 Summary

This evaluation explored whether the programme is appropriate and applicable to meet the needs of physical functional stroke rehabilitation in the community. This was to understand whether the programme is deliverable in a clinical setting. Clinicians' involvement may facilitate the translation of new knowledge generated in this research into practice. Each part of the manual of the programme was evaluated by clinicians by a survey.

The findings of this evaluation suggest that the programme is considered to be generally and clinically acceptable, suitable, feasible and safe from a professional perspective. This study provides empirical evidence supporting the use of the programme to meet the service need of managing stroke exercises for physical functional stroke rehabilitation in the community. This informs that the programme is ready to be used in clinical trials. This evaluation provides a starting point to support the use of the programme. Clinical evaluation is required to understand its potential impact on community physical stroke rehabilitation before recommending it to be embedded within routine practice.

Section 5: Discussion and Conclusion



Chapter 10: Discussion and Conclusion:

Discussion, limitations, implications, future research and conclusion

Chapter summary

This chapter discusses the development and evaluation of the programme in this research. A conceptual framework is built to inform the delivery of the programme in practice. Limitations of this research and the programme are scrutinised. Additionally, this chapter considers the implications from this research, the limitations of this study, and highlights the areas requiring further investigations. Reflections of the underpinning philosophy of this research are also discussed.

10.1 Overall discussion

Physical functional recovery often continues over a long period of time after stroke. Self-management programmes for stroke survivors are emerging and have been recommended for helping stroke survivors to manage their chronic condition and rehabilitation in the literature. However, research was needed to determine ways to support stroke survivors to take control over the management of their physical rehabilitation exercise with the use of information and communication technologies (ICTs) for their ongoing physical rehabilitation. This is to minimise the reliance on face-to-face rehabilitation services to stroke survivors by enabling them to continue to manage their own exercise with the support of ICTs in the longer term.

Hence, this research aimed to develop a personalised, functional oriented and self-managed exercise manual supported with the use of available ICTs. This is to provide an alternative approach for stroke survivors to continue to manage their physical rehabilitation according to their needs, abilities and available resources.

10.1.1 A framework for clinical practice

The programme is considered to be usable and appropriate according to the findings in the refinement and evaluation studies. It remains important to illustrate the relationships between the practical components and selected theories for the delivery the programme in practice.

Establishing a conceptual framework of how to use the programme could assist clinicians to integrate the knowledge generated through this research into their practice. Therefore, a framework was built in this chapter for the above purpose.

Both theoretical and practical considerations are included in the framework. The structure of this framework was built on the themes obtained from the interviews with stroke survivors and therapists, and the theories selected for this research. The use of this framework can help to link abstract concepts of the theories with practical components within a visual configuration to inform a way to use the programme in a clinical setting. The architecture of the programme is presented in figure 10.1.

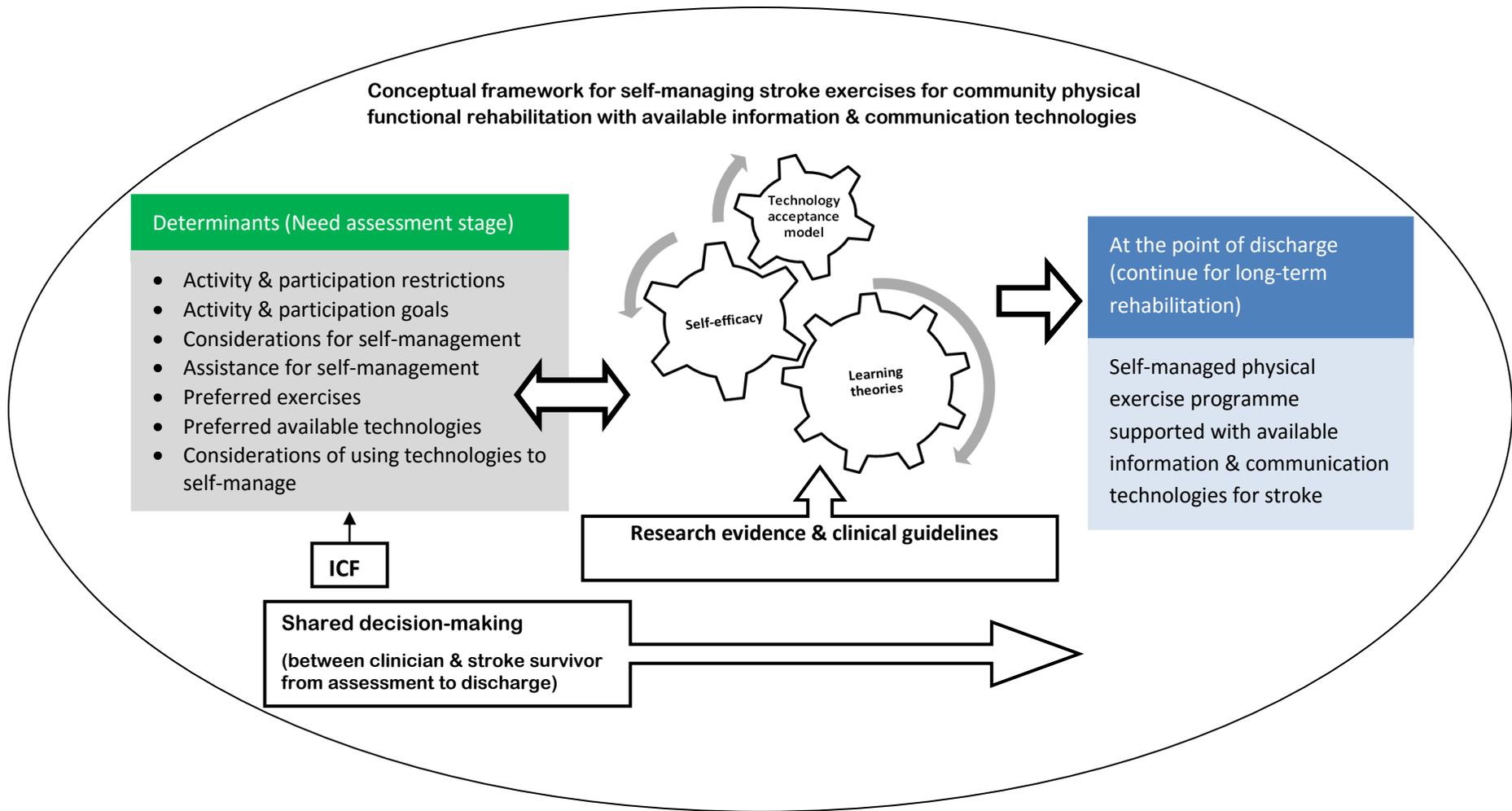


Figure 10.1 Conceptual framework for self-managing stroke exercises for community physical functional rehabilitation with available information & communication technologies

Constructs of the framework

The theoretical foundation, constructs and structure of the framework are summarised below: needs assessment stage, the gear model, evidence and guidelines, shared decision making, and long-term rehabilitation. It is intended that the overall process is started from the needs assessment stage in which the therapist visits the stroke survivor in the community before discharging him/her from community stroke rehabilitation services. The therapist should start from the determinants listed in the assessment stage to prescribe the programme.

The gear model is designed to be the core foundation to drive the thinking process during the prescription of the programme. A shared decision-making approach is recommended in which the therapist and stroke survivor make decisions together from the needs assessment stage till discharge.

The relationships between the constructs are represented with arrows. The entire system progresses from left to right, from the assessment to discharge stages. The arrow between determinants and the gear model indicate that they are intended to be used together to plan and deliver the programme. This is supposed to be an iterative process between the stroke survivor and therapist.

The arrow from the "ICF" box to the determinants indicates the use of ICF to frame and plan the contents for functional rehabilitation. The arrow pointing from the box of research evidence and clinical guidelines represents the integration of evidence and guidelines about stroke self-management, physical stroke rehabilitation and stroke exercises, with the determinants and the gear model to provide the programme.

The arrow pointing from the gear model to the box called "at the point of discharge" identifies the output from the prescription process at the point of the discharge from formal therapist support which is a personalised, functional oriented and self-managed physical exercise manual supported with available ICTs for the stroke survivor.

10.1.2 Foundation phase: Preparation stage

Literature related to the topic of this research was reviewed to identify the key issues and service and research gaps in the field of stroke self-management, physical exercises for functional stroke rehabilitation and the use of technology for physical stroke rehabilitation. This was used to prepare and plan this research.

10.1.3 Phase 1: Programme development and refinement

Both stroke survivors and therapists were involved in this phase. A personalised, functional oriented and self-managed physical exercise manual supported with available ICTs for stroke survivors was developed in this phase after exploring the opinions of stroke survivors and professionals. The programme was formed with knowledge from related literature, the components elicited from interviews with stroke survivors and therapists as well as a new theoretical foundation generated from a group of theories: the “Gear Model”.

The importance of being aware of identifying new ways to deliver stroke self-management interventions has been highlighted for stroke rehabilitation (Jones et al., 2013b). One-size of intervention does not fit all stroke survivors for their physical functional rehabilitation. Hence, a new alternative intervention was developed to suggest a way to empower stroke survivors to manage their own exercises using available ICTs for which a new conceptual approach was developed in this research.

Integration of theories

With regards to the findings from interviews with stroke survivors and therapists and the literature reviews conducted in this research, it is inadequate to only rely on a single theory to address the needs of developing the programme of this research. Hence, the gear model was established with the combination of self-efficacy theory, learning theories (andragogy, self-regulated learning and motor learning theory) and technology acceptance model (TAM) to provide an integrated foundation to support the programme in which self-efficacy theory is the key supporting mechanism for the programme. Combining theories allowed me to utilise the features of different theories to explore new ways to support stroke survivors to self-manage.

With regards to andragogy, it assumes that adult learners have motivation that drives them to learn what they think can help them to manage difficulties in their lives (Knowles et al., 2012). However, facilitation of motivation has been suggested to help stroke survivors to manage their own exercises according to the participants in the interviews of this research. Therefore, a theoretical concept was still needed to help to motivate stroke survivors to learn in addition to the use of andragogy. Hence, self-efficacy theory was adopted in conjunction with andragogy.

In addition to using andragogy concepts to help stroke survivors to acquire knowledge and skills for the self-management of their exercises, it is equally important to enable the individuals to take the responsibility to manage their own learning process for self-management purpose. The value of introducing self-regulated learning (SRL) in this programme is to develop stroke survivors' competence to learn how to actively participate and control the self-management of their own exercises. The SRL concepts were used to facilitate the individuals to monitor, regulate and control their own learning (Zimmerman, 2002, Puustinen and Pulkkinen, 2001). This is in line with the vision in this research about enabling stroke survivors to take up their own physical rehabilitation by learning how to self-manage. As therapists reported the application of SRL concept is acceptable, suitable and feasible for stroke survivors to learn how to self-manage exercises in the evaluation of this research, future studies may need to identify how to enhance and maintain stroke survivors' self-regulation during the delivery of the programme in practice including what strategy may help to optimise the process of self-observation, self-judgement and self-reaction in the future.

Since neither the six core assumptions of andragogy nor the concepts of SRL include concepts leading to enhance the motor relearning process of the stroke survivors for physical functional rehabilitation in the programme, the concepts of motor learning theory were introduced in this research.

Further studies will be required to verify the relationship between the educational learning theories and to examine the effects of combining them to enable stroke survivors to learn how to self-manage their own exercises.

In view of the application of technologies, the adoption of TAM in this research is a novel concept for the field of stroke self-management intervention. Based on the user-centred design principle, I would argue that users (stroke survivors in this research) should be involved in deciding what available ICTs they would like and can use to self-manage their own exercises according to their own resources and perception of their own needs. This research sought to find out how to help individual stroke survivors to identify and use appropriate ICTs. The focus was on investigating the usage of technologies. Hence, the use of perceived usefulness and perceived easy-of-use concepts can serve for the above purpose in the programme. This has also been supported by the positive responses of the stroke survivors and clinicians in the refinement and evaluation studies of this research.

However, very little has been done to understand the effect of using the constructs of TAM to support stroke survivors to determine and use ICTs to support them for the self-management of exercise for physical stroke rehabilitation. Although TAM has been suggested to be useful for helping to understand and explain use behaviour in information system implementation (Legris et al., 2003), further research is required to confirm the theoretical importance of TAM in view of using ICTs for the self-management of stroke exercises to understand its effect for physical stroke rehabilitation. How the individual stroke survivors' attitudes and behavioural intention be affected for the actual use of ICTs with the adoption of perceived usefulness and easy-of-use concepts for the self-management of physical rehabilitation?

The findings from interviews with stroke survivors and therapists were combined before being triangulated with the key elements of the theories within the gear model. This was to combine the new concepts from the theories and the practical components generated from the findings of the interviews to form a new and practical programme with both considerations.

However, any theory may become outdated or be changed in the future with the growth of evidence or information and changes in the field over time. Since the programme was developed and evaluated according to current clinical standards and services needs in the UK, refinement of the programme will be needed over time. Stroke survivors' problems and needs also change over time (Satink et al., 2014).

Telerehabilitation and the technology associated with it are fast changing. The concept about using technologies for stroke rehabilitation is still in its early development stages. Hence, I highlight the need to refer to up to date research evidence, policy and clinical guidelines in the delivery of the programme. It has to be flexible for any change when there is new information emerges in the field.

Shared decision-making approach

Shared decision-making⁵⁷ is a process in which a healthcare option is made jointly by professional and patient together to choose tests, treatments, management, or support packages based on clinical evidence and patients' informed preferences the best available evidence (Légaré et al., 2012, Elwyn et al., 2010, Silva, 2011, King et al., 2013). Facilitating people to engage in decision-making for health and social care services has been suggested to support people to self-manage their own conditions (Silva, 2011).

Inviting the individual to participate in the decision-making and problem-solving is the key to integrating shared decision-making in rehabilitation (Jones, 2011). The King's Fund has also recommended clinicians and patients should work together using a shared decision-making process to agree goals, identify support needs, develop and implement action plans, and monitor progress to deliver better services for people with long-term conditions (Coulter et al., 2013). Stroke survivors may be more motivated to take control over the management of their own rehabilitation programme if they feel that it belongs to them as they can make decisions for the content of it whilst enhancing self-motivation. Therefore, a shared decision-making approach was adopted to underpin the prescription and delivery of this programme to promote stroke survivors' participation in making decisions for their own rehabilitation programme.

The balance of power may lie on the health professional's side if a self-management programme is provided in a clinical setting (Jones, 2011, Wilson et al., 2007). This may happen in the delivery of this programme since it was designed to be provided

⁵⁷ The key principle of shared-decision making is to ensure patients are informed about the choices and that the intervention or care package which they select supports them to achieve their goals (King et al., 2013, Coulter and Collins, 2011)

within the community stroke rehabilitation setting. Different viewpoints were found between stroke survivors and therapists in this research about the preferred way of helping stroke survivors to self-manage rehabilitation exercises using technology. This has suggested that stroke survivors may have different viewpoints and expectations about self-managing exercises with the support of ICTs from that of their therapists. This may happen during the prescription of the programme in clinical setting. Stroke survivors may have higher expectations of what they can achieve than what clinicians consider and prescribe to them. However, over expectation may affect the stroke survivors' adherence to exercise prescription and cause disappointment and attrition.

Realistic expectations may improve self-efficacy which may promote exercise adherence (Jones et al., 2005). Clinicians have an ethical duty to inform patients about options and elicit their preferences to ensure each patient can make a decision about treatment or support that is right for them (Coulter and Collins, 2011). Thus, therapists play an important role in ensuring stroke survivors decide realistic goals as they deliver a self-managed intervention in practice. From the interviews with stroke survivors in this research, it is important to provide information and knowledge about risk and safety to support them to self-manage their own exercises. Hence, clinicians should support stroke survivors to make realistic decisions after helping them to balance the potential risks and benefits of available options.

To achieve shared decision-making for the delivery of a self-managed intervention, I consider it is necessary to assess what the user needs and likes, offer specific possible options that he/she can consider and choose between, and provide a tool and information to facilitate discussion and decision-making between the clinician and patient based on user's needs, abilities, related knowledge (including benefits and risks) and available resources. It is also important that both the clinician and the patient review decisions made to check for any misinterpretation and to confirm decisions. Hence, the manual of this research was developed to facilitate interactions between the clinician and the patient to make shared decisions.

Programme refinement

An iterative approach was adopted to refine the programme. The multiple factors and components identified from the participant interviews were used to develop the programme before it was reviewed by the same participants. The processes were, therefore, grounded in stroke survivors' and therapists' perspectives.

Integrating quantitative and qualitative findings using a mixed methods matrix allowed me to understand the stroke survivors' and therapists' comments and attitudes towards the programme as well as synthesising practical information to modify each part of the programme simultaneously. However, some of the comments were rather broad and unspecific, such as "simplify the contents" and "simplify the structure". This raised questions about how best to simplify the structure and content whilst keeping important components in the programme.

In phase 2 of the research, it was necessary to evaluate the refined programme with opinions from an independent group of targeted providers of the programme to ensure the programme could be used to achieve the study aim.

10.1.4 Phase 2: Professional evaluation

Since the programme was designed to be delivered by therapists in a clinical setting, it was logical to invite those who are the intended providers of the programme to evaluate it. The findings of the independent professional evaluation reveal that the programme is generally acceptable, suitable, feasible and safe to be used from a professional perspective. This provided preliminary evidence supporting the application of the programme.

Although the professional evaluation designed in this study helps to determine the programme is appropriate and applicable, other evaluations; such as process, outcome, impact and economic evaluations (Green, 2006, Ovretveit, 2003) will be required to understand issues to do with implementing the programme and evaluating its efficacy, clinical and cost effectiveness.

For instance, full process evaluation has been suggested for investigating the feasibility and acceptability of stroke self-management programmes with stroke survivors, their carers and professionals (Jones et al., 2013b). This may also be

needed in future clinical trials to evaluate this programme, and to understand how the programme operates and influences the users, their carers and providers with regards to functional stroke rehabilitation. This may help to identify potential barriers and facilitators to delivering the programme.

10.2 Limitations

The limitations of this research and potential solutions are discussed below.

Methodological constraints

Only one researcher collected and analysed data, and designed the programme, therefore, an element of researcher bias cannot be ruled out in this research. I acknowledge that the reliance on a single researcher may lead to potential bias during the course of this research, although different strategies have been used to minimise the bias, such as checking the data and the programme with experienced researchers and participants. The above limitation may be improved with the use of investigator triangulation⁵⁸ (Hussein, 2009, Flick, 2004) for data analysis of the qualitative sections of this research, including cross-coding with additional researchers; this might have helped to generate additional data from the interviews. This could have provided larger amounts of information to formulate the programme with a wider range of viewpoints and more data. However, it was not implemented due to limited available resources and time constraints.

Further research should provide a clear practical framework and stepwise method with a solid philosophical base to conduct mixed methods studies. This may assist the process of combining quantitative and qualitative elements for further analysis and interpretation to glean useful information using both quantitative and qualitative components. It is important to establish explicit and practical quality criteria to guide the process to design, conduct and analyse mixed methods studies in future health services research.

The feature of purposive sampling and exclusion of those with cognitive and language difficulties may have limited the data yielded from participants recruited

⁵⁸ Investigator triangulation refers to the use of multiple researchers in the same study (Hussein, 2009, Flick, 2004)

based on specific selection criteria. Sample sizes were relatively small in the four studies. These factors may limit the generalizability of the findings to fit the needs of all stroke survivors. However, self-management interventions should be appropriately modified with consideration to specific cognitive impairments related to stroke (Jones, 2006). People with language barriers are already less likely to receive health education, and it is more difficult to receive self-management support (Taylor and Jones, 2014). Therefore, stroke survivors with cognitive, memory, visual and/or language barriers should be considered in further development of the programme.

The length of the questionnaires used for refinement and evaluation studies might be too long to the participants to complete. This may affect their motivation to complete the questionnaires, especially the one used in phase 2 which was time consuming. Thus, a relatively longer period of time was given to the respondents to complete the questionnaires. I needed to send reminders via the managers of the therapists recruited for phase 2 to prompt them to complete and return the questionnaires. Although detailed and useful information were collected in the surveys, it would have been helpful to improve the problem from using long questionnaire to encourage the respondents to complete the questionnaires and facilitate data collection processes. Other approach may be needed for future surveys. For instance, the questionnaire may be broken into two smaller questionnaires. Additionally, launching a quarterly “pulse survey” which simply focuses on one to two key themes per survey per quarter may be another possible approach.

Further investigation is needed to develop special editions of the programme to cater for the special needs of the stroke survivors with different disabilities and health conditions. This may help more stroke survivors to self-manage their own exercises using available ICTs.

Geographical constraints

The programme contents may be limited by potential geographical factors since the participants of this research were recruited from Sheffield and Rotherham. It is uncertain the extent to which their points of views, preferences and suggestions have been influenced by their perception and understanding of local services and resources within South Yorkshire. Service commissioning and provision for

community stroke rehabilitation may be different in different NHS trusts. The nature of community rehabilitation services varies greatly within the UK (Enderby and Wade, 2001), whilst physical environments may affect participation in physical activity (Bauman et al., 1999). The access to health and social care resources and networks is a concern of stroke survivors' to self-manage exercises according to the interviews with them in this research. Resources and services for stroke may be different in different areas of the UK. Hence, limiting data collection to only one area limits generalizability to patients in other areas.

Research is required to assess potential geographical influence on the programme in other parts of the UK to understand whether the contents are applicable outside of South Yorkshire.

10.3 Implications of the research study

This section discussed the overall implications from the work of this research.

10.3.1 Introduction

Therapists may need to modify their practice from traditional hands on approaches to facilitate stroke survivors to actively engage with the management their own exercise manual. The programme provides a new method and concepts for clinicians to provide self-managed stroke exercises in the community. The interviews of this research implied essential components required by stroke survivors and professionals to be included in a self-managed exercise manual supported with available ICTs. The findings of refinement and evaluation studies implies that the identified components and the theoretical concepts adopted for the programme were considered to be acceptable and applicable for physical functional stroke rehabilitation in the community according to stroke survivors and clinicians.

Self-management should not be "do-it-yourself", instead, support should be provided for the users to co-manage the intervention with peers, carers and service providers. This argument is supported by the findings about assistance needed for stroke survivors to self-manage exercises identified in the interviews of this research.

In view of applying ICTs in this programme, although the use of ICTs may not completely replace the importance of direct contact from professionals to the

patients, this suggests an alternative method to support the individuals to continue to manage their own exercises.

10.3.2 Engaging stroke survivors for co-management

Professionals' knowledge about a person's incentives and motivation to achieve personal goals could increase the chance to develop strategies and confidence to succeed (Jones, 2011). However, co-management among stroke survivors, relatives and professionals has been suggested for stroke self-management programmes (Satink et al., 2014). Whilst it remains valuable for the input of professional knowledge and clinical reasoning skills for the prescription of stroke-specific exercises for physical rehabilitation, stroke survivors' engagement is needed to practise a self-managed intervention. Whilst "availability of professional support" has been identified as a concern in the interviews with stroke survivors and "professional support and feedback" and "professional instruction and advice" were suggested by them for helping them to self-manage exercises in this research, they have also reported that "application of self-monitoring and self-regulation" as a concern for them to self-manage exercises. They have also suggested the need of including "education of knowledge and learning skills to self-manage" as an assistance. These imply that they have also considered the importance of their own input for the management of their own programme in addition to the input from professionals.

Therefore, stroke survivors and therapists should work in partnership to co-manage the programme. In addition, since the support and feedback from carers and peer have been suggested by stroke survivors as assistance, future studies may be needed to understand how they can also be involved into the co-management of the programme together with the stroke survivors and professionals.

10.3.3 Personalisation with users' physical functional conditions

The personalisation concept in a self-managed programme is in line with the value of supporting stroke survivors to manage their own rehabilitation. The concept of personalisation has been used to develop a stroke self-management programme (Jones, 2008, Jones et al., 2009) and a computer-based technology system for self-managed stroke rehabilitation (Mawson et al., 2013, Parker et al., 2013) in which

personalised extrinsic feedback is highlighted to promote the stroke survivors' motor learning behaviour and improve their functional performance.

From the findings of the interviews of this research, "personalisation of the exercises programme" has been reported by stroke survivors and therapists as a concern for stroke survivors to self-manage exercises. They have suggested that "user centred design for personal needs and conditions" should be considered for stroke survivors to use available ICTs to self-manage exercises. This implies the importance of personalisation concept in a self-managed exercise manual supported with available ICTs for the individuals to manage their own physical rehabilitation.

Stroke rehabilitation programme should be delivered in accordance with the needs and goals of each individual. Stroke symptoms are affected by the site and size of the initial stroke lesion and the extent of recovery, hence, stroke survivors' recovery is heterogeneous (Langhorne et al., 2011). Thus, the individual's physical functional difficulties and health condition should be considered in any stroke rehabilitation programme as different people have different disabilities, comorbidities and goals.

Therapist may better meet the individual's targets at her/his stage of physical rehabilitation by personalising the programme for each stroke survivor. This research provides a new way to systematically personalise a self-managed exercise manual supported with the use of ICTs according to individual stroke survivor's preference and ability. This research demonstrates a new way to individualise a self-managed stroke exercise manual using the ICF model. The ICF model helps to frame the needs assessment of the intervention to plan a personalised prescription for physical functioning. The programme allows therapists to personalise each programme based on the individual's physical barriers and goals. The options of assistance can also be determined by the users' preferences and conditions. These may enable therapists to look beyond the needs at the impairment level and consider a wider range of functional needs of individual survivor.

From the findings of the refinement and evaluation sections of this research, the concept and the method of personalising a self-managed exercise manual supported with ICTs according to the individual's physical functional conditions and goals has

been considered to be acceptable and applicable from stroke survivors' and clinicians' perspectives.

10.3.4 Technical support for using ICTs

Both stroke survivors and therapists expressed their concerns regarding technical support for using available technology to self-manage exercises in this research. Breakdowns of equipment, the lack of maintenance support and other technical problems have also been reported as barriers to applying healthcare programmes supported with ICTs by the WHO (WHO, 2010). The provision of technical support to stroke survivors will therefore be needed to enable them to utilise their preferred available ICTs to self-manage. Technical support is considered an essential element to ensure the sustainability of using technology to remotely deliver healthcare services (RCN, 2012, Scotland, 2011). The provision of sufficient training to stroke survivors and carers on the use of technology may also be useful in supporting the use of technology as found by Palmer et al (2013).

Trainings are needed to develop patients', carers' and professionals' knowledge about different technology devices to prepare them to use that to support health services (RCN, 2012). A guide or tool kit may help patients and clinicians to tackle different technical problems from different technologies and social media.

Carer support was reported by stroke survivors as the main factor in assisting them to self-manage their exercises in this research. Thus, technical support could also be provided to carers to enable them to support stroke survivors to overcome technical difficulties from using ICTs to self-manage.

10.3.5 Safety and privacy issues for using ICTs

Safety education was suggested by both stroke survivors and therapists in the interviews in this research. Therapists also indicated the consideration of safety and confidentiality issues about using ICTs to support stroke survivors to self-manage. Although the programme is considered to be safe to use, it remains important to determine how to ensure stroke survivors' safety and privacy when they self-manage their own exercises using ICTs. For instance, is it safe for them to use new exercise equipment recommended on some websites? Can they trust the methods

recommended by peers or on e-forum? How can we help them to protect their own privacy when they share or obtain exercise information with ICTs? Therefore, further consideration of how to develop policy and guidance to ensure stroke survivors' safety and privacy for using ICTs to self-manage is required.

10.4 Future research

Further work is required before translating this programme into routine practice.

10.4.1 Clinical evaluation

Patient utility and usability should be considered in the development of a telerehabilitation system for stroke survivors to practise their home exercises with the use of technology (Mountain et al., 2010). Hence, pilot and clinical trials of the programme with stroke survivors will be required to examine its usability in a clinical setting. This may help to decide how to integrate this programme into existing stroke services and what further refinements are required

Further research will be required to evaluate the potential barriers and enablers of using and delivering the programme in practice. For instance, what are barriers and enablers for stroke survivors to use or access the selected ICTs to self-manage exercises? The understanding about the related barriers and enablers may help clinicians and commissioners to deploy necessary resources to implement the programme. What factors can effectively enable stroke survivors to use the selected ICTs in practice?

The next step will be examining clinical impact of the programme on physical functional stroke rehabilitation. What is the effect and effectiveness in clinical setting? What will be the impact of the programme on physical functional stroke rehabilitation? Understanding the clinical impact of this new programme would provide more information to help patients, clinicians and commissioners to make more informed decisions, and assist policy making and implementation for self-managing exercises for community stroke rehabilitation.

The outcomes resulting from the use of the programme should be compared to other interventions and usual treatments to evaluate its benefits and limitations for physical stroke rehabilitation.

Outcome measurement is important in order that service users and providers identify whether the stated service objectives can be met. An outcome measure should reflect change associated with service delivery (Enderby, 2013). Suitable outcome measure instruments can indicate the change in a particular aspect of an intervention. Effective stroke rehabilitation improves functional outcome (Duncan et al., 2005). Therefore, functional specific outcome measures will be needed to monitor and evaluate stroke survivors' functional status for activity and participation to understand the effect of using the programme. Potential outcome measures may include the Functional Independence Measure⁵⁹ (Duncan et al., 2005, Ring et al., 1997), Nottingham Extended Activities of Daily Living Scale⁶⁰ (Wu et al., 2011, Hsueh, 2000), and Stroke Impact Scale⁶¹ (Lin et al., 2010, Duncan et al., 2003).

Since the ICF framework was adopted to frame the programme, a specific outcome measure will be required to examine the change of physical functional rehabilitation for activity and participation due to the programme, such as the Therapy Outcome Measure⁶² (Enderby et al., 2006). This may help to structure the evaluation process in line with the design of the programme to understand the change of functional oriented outcomes in relation to physical impairments, activity and participation restrictions from the programme.

Measuring self-efficacy during stroke rehabilitation can provide useful information to understand stroke recovery. Since self-efficacy is central to this programme, it will be essential to measure the change of stroke survivors' self-efficacy to evaluate the

⁵⁹ The Functional Independence Measure (FIM) was developed to measure the activities of daily living so as to measure functional independence. It assesses six areas of function: Self-care, Sphincter control, Mobility, Locomotion, Communication and Social cognition (Ring et al., 1997, Duncan et al., 2005)

⁶⁰The Nottingham Extended Activities of Daily Living (NEADL) is an instrumental ADL scale developed to assess patients' independence in activities of daily living (Wu et al., 2011, Hsueh, 2000)

⁶¹ The Stroke Impact Scale (SIS) was developed from patients' and caregivers' perspectives to evaluate how stroke has impacted on the stroke survivor's health and life including the measure of changes in strength, hand function, activities of daily (ADL)/ instrumental ADL, mobility, communication, emotion, memory and thinking, and participation, especially in mild-to-moderate strokes (Lin et al., 2010, Duncan et al., 2003)

⁶² Therapy Outcome Measure (TOM) is a validated outcome measure tool developed by using the system of the International Classification of Functioning, Disability, and Health (ICF) of the WHO. It allows therapists to describe the relative abilities and difficulties of a patient/client in the domains of impairment, activity, participation and well-being in order to monitor changes over time (Enderby et al., 2006).

clinical impact of using the programme. Specific and valid instruments should be used to measure the change of the stroke survivors' confidence in performing functions with self-managed practice. The Stroke Self-Efficacy Questionnaire⁶³ may be an appropriate option to assess the change of stroke survivors' self-efficacy and understand their functional performance with self-management. It is validated and recommended to evaluate stroke survivors' self-efficacy and stroke self-management interventions (Riazi et al., 2014, Jones et al., 2009, Jones et al., 2008b). It will also be useful for measuring stroke survivors' self-efficacy for their rehabilitation in physical functioning in the future clinical evaluation of the programme of this research and/or other intervention containing self-efficacy concept. This may help to understand how a self-managed exercise manual can empower stroke survivors to take control over their own rehabilitation via enhancing their self-confidence.

Measuring the change in the quality of life of the stroke survivors may help to further understand how the individuals' feel about their own rehabilitation and health status as a result of using the programme of this research in addition to physical specific instruments. Stroke Specific Quality of Life scale⁶⁴ (Williams et al., 1999) and EuroQol EQ-5D⁶⁵ (Group, 1990, Rabin and Charro, 2001) may be suitable options to serve the above purpose as some domains of physical mobility, self-care, and usual activities are involved in the programme and the scales.

A variety of activity and participatory goals have been suggested by stroke survivors and professionals in the interviews of this research. Therefore, it will be helpful to

⁶³ Stroke Self-Efficacy Questionnaire (SSFQ) is a specific measure of self-efficacy after stroke. It includes 13-items in relation to functional and self-management performance after stroke; such as walking, getting comfortable in bed, use of both hands for eating, preparing a meal, and persevere to make progress after discharge (Riazi et al., 2014, Jones et al., 2009, Jones et al., 2008b).

⁶⁴ Stroke Specific Quality Of Life scale (SS-QOL) is a patient-centred outcome measure intended to provide an assessment of health-related quality of life specific to patients with stroke. It includes 49 items in following 12 domains: Mobility (6 items), Energy (3 items), Upper extremity function (5 items), Work/productivity (3 items), Mood (5 items), Self-care (5 items), Social roles (5 items), Family roles (3 items), Vision (3 items), Language (5 items), Thinking (3 items), Personality (3 items) (Williams et al., 1999)

⁶⁵ For ED-5D, it includes a descriptive system to measuring health on five dimensions: mobility, self-care, usual activities, pain/discomfort and anxiety/depression, with three or five responses levels depending on whether EQ-5D-3L or EQ-5D-5L is used. A visual analogue scale is also included for the quantitative measure of health status judged by the individual (Group, 1990, Rabin and Charro, 2001)

evaluate the effect of the programme to the individuals' social integration in order to understand its impact on the individuals' functional rehabilitation to perform activities and participations in their daily livings; such as measuring the change of that using Reintegration to Normal Living Index⁶⁶ (Murtezani et al., 2009, Wood-Dauphinee et al., 1988). Checking their perceptions in social participation may also help to under their reintegration into the community as a result of using the programme.

Moreover, it will be important to evaluate the impact of using the programme at both individual and community levels, since it was designed to be used in the community. For instance, the subtheme of "community, social and civic life" has been reported to be a type of rehabilitation goal by stroke survivors and therapists in the interviews in this research; including recreation and leisure, and return to work. Hence, whether the use of the programme changes the outcomes of people's social participation and work-related issues will be important to establish.

Neither the impact on the rehabilitation of an individual nor the influence to the community can be fully understood without understanding both, in view of understanding the impacts of a programme designed for community practice. Understanding the effects at both individual and community levels may help to determine how we can better integrate the programme into the local system according to local contexts. For instance, stroke survivors' changes in social and community participation and health resources utilisation should be evaluated in addition to physical status alone.

Additionally, it will be important to reflect on therapists' experiences of using this new programme in a clinical setting. This may help to explore the possible change to the clinicians in their practice due to the use of the programme and inform the integration of the programme into routine use.

A full process evaluation has been recommended within clinical trials of stroke self-management programmes (Jones et al., 2013b). This should be considered to

⁶⁶ The Reintegration to Normal Living Index (RNLI) was developed to assess, quantitatively, the degree to which individuals who have experienced traumatic or incapacitating illness achieve reintegration into normal social activities. The first 8 items represent 'daily functioning' and the remaining 3 items represent 'perception of self'. Each domain is accompanied by a visual analogue scale (VAS) (0 to 10 cm). The score out of total of 110 will be converted to out of 100 (Murtezani et al., 2009, Wood-Dauphinee et al., 1988).

determine the optimal way to deliver the self-management programme developed in this research with individuals, their carers and professionals.

Recommended prescription for service delivery

In addition, it is important to determine the intensity and frequency of self-managed practice required. It is necessary to consider fatigue thresholds and competing demands on stroke survivor and carer time when providing recommendations for frequency and length of practice (Palmer et al 2013). Although guidelines for stroke were used to design this programme, it remains important to understand the frequency and length of support required by the individual stroke survivor before he/she can self-manage exercises with available ICTs according to personal factors. Whilst support from professionals is important for self-managed interventions; how much professional support and instruction will be sufficient to enable stroke survivors to self-manage exercises?

Follow-up support is often unclear, which may create an impression of extended rehabilitation rather than supporting stroke survivors to participate and make full use of resources in the community (Jones et al., 2013). Many factors, both for the therapist and client; influence the decision of the intensity and frequency of an intervention (Enderby, 2012). Hence, research is required to determine adequate support required from therapists to enable stroke survivors to take control over managing their own exercises. This may affect the utilisation and allocation of resources to provide sufficient professional support.

Therapists' clinical reasoning skills remain important to determine the amount of therapy required to meet an individual's needs for rehabilitation when they prescribe personalised exercises in addition to the recommendations in guidelines for stroke. Research will be needed to evaluate therapists' clinical reasoning as a result of using the programme. This may help to provide practical guidance to therapists to decide how much support is adequate for their clients to achieve desirable outcomes.

Medical Research Council Framework for clinical evaluation of the programme

The Medical Research Council Framework for the Development and Evaluation of randomised controlled trials for Complex Interventions to Improve Health (MRC

framework⁶⁷) (MRC, 2000, MRC, 2009) may be a suitable approach for structuring the evaluation of the clinical effects of the programme in the future. This research has provided information in relation to the initial phases of the framework including the development, modelling and evaluation for the feasibility of the intervention. Further evaluations will be needed to complete the rest of the phases including clinical piloting, the evaluations of the effectiveness, cost-effectiveness and implementation of the programme. Barriers and enablers about implementing the programme may also be identified in clinical evaluation.

Socioeconomic and cultural factors

Stroke survivors' experience of self-management may be influenced by ethnicity and cultural background (Boger et al., 2014).

Socioeconomic factors were identified in the assistance for stroke survivors to self-manage their exercises for functional rehabilitation by the stroke survivors and therapists in this research. Stroke survivors' relationships with others may influence their ability to self-manage exercises, since the support and feedback from peers and carers were considered as influencing factors in this research. Furthermore, personal economic status was also found to be a concern regarding exercise self-management. The issues of financial support and cost utility of using ICTs were also identified as an influencing factor to self-manage exercises with ICTs in this research.

The interactions between socioeconomic and cultural factors, and the self-management of stroke exercises supported with the use of ICTs, and the impact on physical stroke rehabilitation will need to be investigated. For instance, how would stroke survivors' educational backgrounds influence their ability to learn how to self-manage their own programme? What would be helpful to support stroke survivors with different educational levels to use suitable ICTs to self-manage their physical rehabilitation? Ethnographic studies⁶⁸ may be a method of choice to discover the

⁶⁷ MRC framework involves 4 main phases: development, feasibility piloting, effectiveness and cost-effectiveness evaluation, and implementation (MRC, 2009). This can provide a systematic approach to evaluate an intervention containing several interacting components using randomised controlled trials

⁶⁸ Ethnography is the study of social interactions, behaviours, and perceptions that occur within groups, teams, organisations, and communities. It seeks to explain both explicit aspects of a culture and tacit elements that is the outside of awareness of the participants (Reeves et al., 2008, Hodgson, 2000, Savage, 2000).

interactions between socioeconomic related factors and the provision of stroke self-management interventions supported with the use of ICTs within local society.

10.4.2 Programme fidelity

Fidelity⁶⁹ has been regarded as a key factor for the systematic implementation of evidence-based interventions in the community (Breitenstein et al., 2010). Research into the fidelity of a stroke self-management programme has been recommended to monitor whether it is being delivered as intended (McKenna et al., 2013). It has been considered important for the design, implementation, and evaluation of rehabilitation interventions (Hennessey and Jr, 2003). Exploring the fidelity of implementing an intervention may provide a better understanding of how and why an intervention works, and the extent to which outcomes can be improved (Carroll et al., 2007).

Further evaluations about the fidelity of the programme will be needed to determine how to promote the fidelity of the programme in which professional training to clinicians will be a key factor.

10.4.3 Professional training

Professional training on stroke self-management may facilitate the consistency of the use of self-management interventions in practice. Knowledge about particular interventions is required before commencing implementation and for the maintenance of treatment fidelity (McCluskey et al., 2013). The understanding of professional training gaps can facilitate the smooth translation of research on self-management for stroke. Practitioners require specific skills for supporting self-management (Jones et al., 2013a). Training providers is important to satisfactorily deliver an intervention to enhance and monitor fidelity (Spillane et al., 2007).

Some therapists have suggested the provision of training to professionals to enhance the feasibility of the using the programme in the phase 2 evaluation. Therefore, although an instructor's handbook has been included in the programme to provide information to clinicians to use it, training to clinicians will still be required to

⁶⁹ Fidelity can be referred to the degree to which an intervention or programme is delivered as intended, which is critical for the translation of evidence-based interventions into practice (Breitenstein et al., 2010, Carroll et al., 2007)

educate them to provide it. This may help to ensure the fidelity of the programme in practice. For fidelity, research will be needed to determine how to effectively educate therapists with the knowledge of self-management, patient education and technical issues about using ICTs to promote their competencies for delivering the programme. This may facilitate the smooth translation of the new concepts from this research into practice. For instance, “safety and confidentiality issues for stroke survivors to use available ICTs” have been considered by therapists in this research. How can we equip clinicians with adequate knowledge and skills about using different ICTs or social media to promote their competencies to teach their patients to use that safely?

It has been suggested that knowledge of underpinning theory is integrated into self-management training to inform decision-making on when and with whom to use stroke self-management (Jones et al., 2013a, Taylor et al., 2011).

10.4.4 Economic evaluation

In view of the economic burden from stroke, further evaluation should examine the economic impact of the programme for stroke rehabilitation services in addition to the understanding of its effects. Economic evaluation⁷⁰ can influence and provide a way for healthcare decision-making. It helps to compare 2 or more healthcare intervention alternatives by examining both costs and consequences. Cost is generally considered important due to the tension between the available resources and increasing demands (van Velden et al., 2005, Evers et al., 2000). It is important to demonstrate cost-effective use of health service resources to commissioners to determine service provision by understanding the relative cost-effectiveness of alternative ways of service delivery (Palmer et al., 2012). However, evidence about cost and cost-effectiveness is needed to support clinical and policy decision of using technology to deliver rehabilitation services for people with physical disabilities (Kairy et al., 2009).

⁷⁰ Economic evaluation can be referred as the comparative analysis of alternative courses of action in terms of both their costs and consequences. Thus, it can help to identify, measure, value, and compare the costs and consequences of the alternatives being considered for health services. Four types of full economic evaluation include cost-minimization analysis, cost-effectiveness analysis, cost-benefit analysis, and cost-utility analysis (van Velden et al., 2005, Evers et al., 2000)

Financial support was recognised by stroke survivors as the identified assistance for them to self-manage exercises in the interviews of this research. Additionally, cost utility for using available technologies was suggested by stroke survivors and therapists as a consideration for stroke survivors to use available technologies to self-manage exercises. Therefore, economic evaluation of the programme of this research will help to understand whether it is a cost-effective intervention before adoption into routine practice. Is it a cheaper alternative in comparison with usual interventions and other services for continued physical stroke rehabilitation? This may provide cost related information for stroke survivors, therapists, commissioners to value the programme. This may help to decide whether the programme can be sustained in local health system.

10.5 Realism: Philosophical reflection of this research

This section describes my reflection on the philosophy of this research after reviewing my thought process in this project. This reflection helped me to critically rethink about the process of developing and evaluating a realistic rehabilitation intervention for practice so as to learn from my experience and thought pattern in this research. I am aware that the overall philosophical basis of this research can be interpreted from the angle of realism⁷¹. This philosophical assumption has underpinned my thoughts to develop a realistic programme for clinical practice.

Scientific realism is the type of realism I have used to reflect on my work. From realism, both material and social worlds are real and can have real effects (Pawson, 2013, Pawson, 2006, Pawson and Tilley, 1997). The application of realist philosophy may not only address the effects but also the internal workings and operations of the components of a programme and how the factors are connected for practice (Kazi, 2003).

⁷¹ Realism: it refers to a philosophy of science and social science sits between the positivism and constructivism. It agrees that a real world exists independently. Our knowledge of it is processed through human senses, brains, language and culture. It also acknowledges the existence of social reality and its influence on human behaviour which can help us to understand the social world. It is also deemed as a methodological orientation. A key feature of realism is the mechanism of explanation and its attempt to demonstrate the application of such explanatory approaches for the body of scientific knowledge. (Wong et al., 2013, Pawson, 2006, Pawson and Tilley, 1997)

In general, context-mechanism-outcome configuration (CMOC) is a generative causation of realist philosophy. The following formula of CMOC shows the core concept and the interaction of the elements of the philosophical science of realism (Pawson, 2013, Pawson, 2006, Pawson and Tilley, 1997).

Context (C) + Mechanism (M) = Outcome (O)

Context: the conditions that enable or limit the mechanisms, Mechanism: intervention which produces B from A, Outcome: the intended or unintended consequences of the intervention.

Realism for programme development and evaluation

Programmes can work in different ways for different people via different mechanisms and contexts. According to realist philosophy, it is important to focus on “what works for whom in what circumstances and respects, and why?” (Wong et al., 2013, Pawson, 2013, Rycroft-Malone et al., 2012, Pawson, 2006, Pawson and Tilley, 1997). The logic of CMOC may have influenced my thoughts towards the research questions, and data analyses and syntheses to find out what works in what contexts for community-dwelling stroke survivors, and why from stroke survivors’ and clinicians’ perspectives. This logic has driven me to identify and synthesis useful information to produce an acceptable programme.

Methodological pluralism and both quantitative and qualitative methods are recommended for realistic data collection and evaluation (Wong et al., 2013, Pawson, 2013, Pawson and Tilley, 1997). Thus, I adopted a mixed methods approach to design this research with the cognitive influence of realism.

Although the CMOC has been used to investigate the development of the SMART programme (Parker et al., 2014, Parker et al., 2013), different contexts and mechanisms were used in this research. The stroke rehabilitation framework described at the beginning of this chapter can be interpreted as the product of realist thinking, in which the identified themes (contexts) and selected theories (mechanisms) were combined based on the logic thinking of the CMOC.

The CMOC can be used to illustrate the logic of my thought process in this research. The following table 10.5 summarises my philosophical reflection in terms of CMOC based on realism.

Table 10.5: Summary of philosophical reflection on this research with CMOC

Construct of CMOC	Philosophical reflection on this research
Context	<ul style="list-style-type: none"> - Identified themes and subthemes that informed the contents and design of the programme that are considered to be contexts - Information of the ICF model was used to shape the contents of the programme which is regarded as a context - Research evidence and clinical guidelines are considered as contexts, since these provide information required to operate the programme
Mechanism	<p>The following mechanisms serve to drive the development of the programme in this research:</p> <ul style="list-style-type: none"> - The gear model which provides supporting concepts to drive the prescription and contents of each programme - Shared decision-making approach is considered to drive the process for stroke survivor and professional to work together to decide the contents of each programme <p>Realist approach is theory-driven and assumes that interventions are “theories incarnate”. I described the details of selected theories to illustrate the underpinning mechanisms driving the delivery of the programme.</p>
Outcome	<ul style="list-style-type: none"> - The programme is the product of this project as a result of the interactions between the components identified from the interviews with stroke survivors and therapists (contexts) and selected theories (mechanisms) - The interaction between contexts and mechanisms can affect the outcome according to realist philosophy. This concept is similar to the interaction between identified components and theories selected in this research - Selection or input of different items in the manual (context) may generate different programmes (outcome) using the same theories (mechanism) during the process to prescribe individualised programme

Going beyond the review of my thought process, realism may be a useful philosophy to provide a cognitive structure leading to the design of future research to realistically evaluate the programme for community stroke rehabilitation.

10.6 Conclusion

This research aimed to develop a personalised and self-managed exercise manual supported with available ICTs for physical functional stroke rehabilitation in the community.

Theoretical and practical considerations were involved in this research to develop and evaluate such a programme. This research contributes new options, insights, concepts and knowledge about the method of enabling stroke survivors to manage their own exercises with the support of available ICTs. It was designed using the concepts of user-centred design and the model for evidence-based clinical decisions with the value of providing patient-centred care to stroke survivors.

This research has contributed a new personalised and self-managed exercise manual supported with available ICTs for functional stroke rehabilitation. A self-managed physical rehabilitation exercise manual for stroke survivors was created, in which Book A (Clinical checklist), Book B (My stroke exercise manual) and a USB memory card are included in a package. This provides an alternative option for helping stroke survivors to manage their own exercise in practice.

This research has developed a new theoretical model to support the self-management of exercises using available ICTs for physical stroke rehabilitation in the community called: the “Gear Model”. The model combines the concepts of self-efficacy, learning theories (include andragogy, self-regulated learning theory and motor learning theory), and technology acceptance model to provide joint conceptual support to the prescription of the programme. The ICF model was adopted to frame the needs assessment for personalisation and functional rehabilitation purposes. These are to enable stroke survivors to continue to manage their own physical rehabilitation to achieve their daily activity and participatory goals. The “Gear Model” suggests an alternative mechanism for therapists to empower their stroke survivors to self-manage their own exercise with the use of available ICTs.

Both stroke survivors’ and professionals’ experiences and viewpoints were collected to determine the components with which to develop and refine the programme. These provide choices for stroke survivors and clinicians for the prescription of the programme for patient-centred care. The components of the programme were

confirmed with stroke survivors and therapists, and they considered it contains what they need to self-manage exercises and that it is likely to be usable.

To ensure the programme can be clinically relevant and appropriate for use, it was evaluated by an independent group of therapists, for which, the acceptability, suitability, feasibility and safety of using it were evaluated. The findings indicate that it was considered to be acceptable, safe and usable from a professional perspective.

A framework within which to deliver the self-management programme was proposed using the findings and theories referred to in this research. Shared decision-making was incorporated into the framework to empower stroke survivors to take control over their rehabilitation. The ICF model was also combined into the framework to illustrate the personalisation concept of the programme. The framework was designed to show the relationships in the programme and suggests a system within which to deliver it. This may help to facilitate the translation of the knowledge generated from this research into practice.

With the growth of stroke self-management interventions and the use of ICTs for the delivery of stroke rehabilitation, understanding how to enable stroke survivors to self-manage and how to apply technologies for the delivery of rehabilitation services appears to be inevitable. I hope the concepts developed in this research may be applicable for the use of other technologies for stroke services when they become available in the community in the future.

I hope that this research can contribute useful knowledge and insights in addition to current knowledge and concepts about stroke self-management particularly for the management of exercises and about using available ICTs for physical functional rehabilitation in the community. I hope the programme developed from this preliminary study can provide a useful option for helping stroke survivors to manage their rehabilitation. I also hope the initial work of this research will lead to further development of stroke-specific and patient-centred self-management services to benefit community-dwelling stroke survivors in the longer-term.

References

- ABELA, J. (2009). Adult learning theories and medical education: a review. *Malta Medical Journal*, 21, 11-18.
- ABRAS, C., MALONEY-KRICHMAR, D. & PREECE, J. (2004) User-centered design. *Bainbridge, W. Encyclopedia of Human-Computer Interaction. Thousand Oaks: Sage Publications.*
- ACSM 2013. ACSM's guidelines for exercise testing and prescription, Lippincott Williams & Wilkins.
- ADA, L., DORSCH, S. & CANNING, C. G. (2006) Strengthening interventions increase strength and improve activity after stroke: a systematic review. *Journal of Physiotherapy*, 52, 241-248.
- ADEOGUN, O., TIWARI, A. & ALCOCK, J. (2011) Models of information exchange for UK telehealth systems. *International Journal of Medical Informatics*, 80, 359-370.
- AL-KHAWAJA, I., WADE, D. T. & COLLIN, C. F. (1996) Bedside screening for aphasia: a comparison of two methods. *Journal of Neurology*, 243, 201-204.
- ALGURÉN, B. (2010) Functioning after stroke: An application of the International Classification of Functioning, Disability and Health (ICF).
- ALGURÉN, B., LUNDGREN-NILSSON, Å. & SUNNERHAGEN, K. S. (2010) Functioning of stroke survivors-A validation of the ICF core set for stroke in Sweden. *Disability & Rehabilitation*, 32, 551-559.
- ALLEN, I. E. & SEAMAN, C. A. (2007) Likert scales and data analyses. *Quality Progress*, 40, 64-65.
- ALLEN, K., HAZELETT, S., JARJOURA, D., HUA, K., WRIGHT, K., WEINHARDT, J. & KROPP, D. (2009) A randomized trial testing the superiority of a postdischarge care management model for stroke survivors. *Journal of Stroke and Cerebrovascular Diseases*, 18, 443-452.
- ALLEN, K., HAZELETT, S., JARJOURA, D., WRIGHT, K., CLOUGH, L. & WEINHARDT, J. (2004) Improving stroke outcomes: implementation of a postdischarge care management model. *Journal of Clinical Outcomes Management*, 11, 707-714.
- ANDERSON, E. S., WOJCIK, J. R., WINETT, R. A. & WILLIAMS, D. M. (2006) Social-cognitive determinants of physical activity: the influence of social support, self-efficacy, outcome expectations, and self-regulation among participants in a church-based health promotion study. *Health Psychology*, 25, 510.
- ANTONUCCI, G., APRILE, T. & PAOLUCCI, S. (2002) Rasch analysis of the Rivermead Mobility Index: a study using mobility measures of first-stroke inpatients. *Archives of Physical Medicine and Rehabilitation*, 83, 1442-1449.
- ARMITAGE, C. J. & CONNER, M. (2000) Social cognition models and health behaviour: A structured review. *Psychology and Health*, 15, 173-189.
- ASHFORD, S., EDMUNDS, J. & FRENCH, D. P. (2010) What is the best way to change self-efficacy to promote lifestyle and recreational physical activity? A systematic review with meta-analysis. *British Journal of Health Psychology*, 15, 265-288.
- ASSMANN, S. F., POCOCK, S. J., ENOS, L. E. & KASTEN, L. E. (2000) Subgroup analysis and other (mis) uses of baseline data in clinical trials. *The Lancet*, 355, 1064-1069.
- AUDEBERT, H. J. & SCHWAMM, L. (2009) Telestroke: scientific results. *Cerebrovascular Diseases*, 27, 15-20.
- AYOTTE, B. J., MARGRETT, J. A. & HICKS-PATRICK, J. (2010) Physical activity in middle-aged and young-old adults the roles of self-efficacy, barriers, outcome expectancies, self-regulatory behaviors and social support. *Journal of Health Psychology*, 15, 173-185.
- AZIZ, N. (2010) Long-term rehabilitation after stroke: where do we go from here? *Reviews in Clinical Gerontology*, 20, 239-245.
- BANDURA, A. (1977) Self-efficacy: toward a unifying theory of behavioral change. *Psychological Review*, 84, 191.
- BANDURA, A. (1986) Social foundations of thought and action: A cognitive social theory. *Pretince Hall, Englewood Cliffs, New York.*
- BANDURA, A. (1989) Human agency in social cognitive theory. *American psychologist*, 44, 1175.
- BANDURA, A. (1991) Social cognitive theory of self-regulation* 1. *Organizational behavior and human decision processes*, 50, 248-287.
- BANDURA, A. (1993) Perceived self-efficacy in cognitive development and functioning. *Educational psychologist*, 28, 117-148.
- BANDURA, A. (1997a) The nature and structure of self-efficacy. *Self-efficacy: the exercise of control. New York: WH Freeman and Company.*
- BANDURA, A. (1997b) Self-efficacy: The exercise of control. New York: Freeman.
- BANDURA, A. (1999) Social cognitive theory: An agentic perspective. *Asian journal of social Psychology*, 2, 21-41.

- BANDURA, A. (2000) Social-cognitive theory. *Encyclopedia of Psychology*, 7, 329-332.
- BANDURA, A. & ADAMS, N. E. (1977) Analysis of self-efficacy theory of behavioral change. *Cognitive therapy and research*, 1, 287-310.
- BANDURA, A. & JOURDEN, F. J. (1991) Self-regulatory mechanisms governing the impact of social comparison on complex decision making. *Journal of Personality and Social Psychology*, 60, 941.
- BARLOW, J., STURT, J. & HEARNSHAW, H. (2002a) Self-management interventions for people with chronic conditions in primary care: Examples from arthritis, asthma and diabetes. *Health Education Journal*, 61, 365-378.
- BARLOW, J., WRIGHT, C., SHEASBY, J., TURNER, A. & HAINSWORTH, J. (2002b) Self-management approaches for people with chronic conditions: a review. *Patient Education and Counseling*, 48, 177-187.
- BASHSHUR, R. L., REARDON, T. G. & SHANNON, G. W. (2000) Telemedicine: a new health care delivery system. *Annual Review of Public Health*, 21, 613-637.
- BAZELEY, P. & JACKSON, K. (2013) *Qualitative data analysis with NVivo*, Sage Publications Limited.
- BEALE, S., TRUMAN, P., SANDERSON, D. & KRUGER, J. (2010) The Initial Evaluation of the Scottish Telecare Development Program. *Journal of Technology in Human Services*, 28, 60-73.
- BERWICK, D. M. 2005. Broadening the view of evidence-based medicine. *Quality and Safety in Health Care*, 14, 315-316.
- BEST, C., VAN WIJCK, F., DINAN-YOUNG, S., DENNIS, J., SMITH, M., FRASER, H., DONAGHY, M. & MEAD, G. (2010) Best Practice Guidance for the Development of Exercise after Stroke Services in Community Settings. *The University of Edinburgh, Edinburgh*.
- BILLINGER, S. A., ARENA, R., BERNHARDT, J., ENG, J. J., FRANKLIN, B. A., JOHNSON, C. M., MACKAY-LYONS, M., MACKO, R. F., MEAD, G. E. & ROTH, E. J. 2014. Physical Activity and Exercise Recommendations for Stroke Survivors A Statement for Healthcare Professionals From the American Heart Association/American Stroke Association. *Stroke*, 45, 2532-2553.
- BLACK, N. & GRUEN, R. (2005) *Understanding health services*, McGraw-Hill International.
- BODENHEIMER, T., LORIG, K., HOLMAN, H. & GRUMBACH, K. (2002a) Patient self-management of chronic disease in primary care. *JAMA*, 288, 2469-75.
- BODENHEIMER, T., MACGREGOR, K. & SHARIFI, C. (2005) *Helping patients manage their chronic conditions*, California HealthCare Foundation.
- BODENHEIMER, T., WAGNER, E. H. & GRUMBACH, K. (2002b) Improving primary care for patients with chronic illness. *JAMA: the journal of the American Medical Association*, 288, 1909.
- BOGER, E. J., DEMAIN, S. H. & LATTER, S. M. (2014) Stroke self-management: A focus group study to identify the factors influencing self-management following stroke. *International Journal of Nursing Studies*.
- BONETTI, D. & JOHNSTON, M. (2008) Perceived control predicting the recovery of individual-specific walking behaviours following stroke: Testing psychological models and constructs. *British Journal of Health Psychology*, 13, 463-478.
- BOWLING, A. & EBRAHIM, S. (2005) *Handbook of health research methods: investigation, measurement and analysis*, Open University Press.
- BOYD, L. A., VIDONI, E. D. & WESSEL, B. D. (2010) Motor learning after stroke: is skill acquisition a prerequisite for contralesional neuroplastic change? *Neuroscience letters*, 482, 21-25.
- BOYNTON, P. M. & GREENHALGH, T. (2004) Hands-on guide to questionnaire research: Selecting, designing, and developing your questionnaire. *BMJ: British Medical Journal*, 328, 1312.
- BRAUN, V. & CLARKE, V. (2006) Using thematic analysis in psychology. *Qualitative research in psychology*, 3, 77-101.
- BRAZZELLI, M., SAUNDERS, D., GREIG, C. & MEAD, G. (2011) Physical fitness training for stroke patients (Review). *The Cochrane Library*.
- BRITTO, R. R., REZENDE, N. R., MARINHO, K. C., TORRES, J. L., PARREIRA, V. F. & TEIXEIRA-SALMELA, L. F. 2011. Inspiratory Muscular Training in Chronic Stroke Survivors: A Randomized Controlled Trial. *Archives of Physical Medicine and Rehabilitation*, 92, 184-190.
- BROWN, V. A., GROOTJANS, J., RITCHIE, J., TOWNSEND, M. & VERRINDER, G. (2007) Jackie Green and Jane South.
- BROWNSELL, S. (2009) Measuring the 'success' of telehealth interventions. *Journal of Assistive Technologies*, 3, 12-20.
- BRYMAN, A. (2012) *Social research methods*, Oxford university press.

- BUCKINGHAM, A. & SAUNDERS, P. (2004) *The survey methods workbook: From design to analysis*, Polity.
- BURTON-JONES, A. & HUBONA, G. S. (2005) Individual differences and usage behavior: revisiting a technology acceptance model assumption. *ACM SIGMIS Database*, 36, 58-77.
- BURTON, C. R. (2000) Living with stroke: a phenomenological study. *Journal of Advanced Nursing*, 32, 301-309.
- BURY, M., NEWBOULD, J., TAYLOR, D., HEALTH, N. I. F. & ., C. E. (2005) *A rapid review of the current state of knowledge regarding lay-led self-management of chronic illness: evidence review*, National Institute for Health and Clinical Excellence London.
- BUTTERY, A. K. & MARTIN, F. C. (2009). Knowledge, attitudes and intentions about participation in physical activity of older post-acute hospital inpatients. *Physiotherapy*, 95, 192-198.
- CADILHAC D, K. M., HOFFMANN S, OSBORNE R, LINDLEY R, LALOR E & BATTERSBY M (2010) Developing a self management program for stroke: results of a phase II multi centred single blind RCT. *World Stroke Congress 2010* Seoul South Korea, Blackwell Publishing Ltd.
- CADILHAC, D. A., HOFFMANN, S., KILKENNY, M., LINDLEY, R., LALOR, E., OSBORNE, R. H. & BATTERSBY, M. (2011) A Phase II Multicentered, Single-Blind, Randomized, Controlled Trial of the Stroke Self-Management Program. *Stroke*, 42, 1673-1679.
- CAR, J. & SHEIKH, A. (2004) Email consultations in health care: 2—acceptability and safe application. *Bmj*, 329, 439-442.
- CARE, I. C. I. (2011) *The Chronic Care Model*. Seattle, WA, USA, The MacColl Institute.
- CARIN-LEVY, G., KENDALL, M., YOUNG, A. & MEAD, G. (2009) The psychosocial effects of exercise and relaxation classes for persons surviving a stroke. *Canadian Journal of Occupational Therapy*, 76, 73-80.
- CARR, J. H. & SHEPHERD, R. B. (1989) A motor learning model for stroke rehabilitation. *Physiotherapy*, 75, 372-380.
- CARR, M. & JONES, J. (2003) Physiological effects of exercise on stroke survivors. *Topics in Stroke Rehabilitation*, 9, 57-64.
- CASEY, S., DAY, A., HOWELLS, K. & WARD, T. (2007) Assessing Suitability for Offender Rehabilitation Development and Validation of the Treatment Readiness Questionnaire. *Criminal justice and behavior*, 34, 1427-1440.
- CASP (2013) *Critical Appraisal Skills Programme*. Oxford, the UK, CASP UK.
- Centre for Reviews and Dissemination. (2009). *Systematic reviews: CRD's guidance for undertaking reviews in health care*, Centre for Reviews and Dissemination.
- CATHERINE POPE, N. M. (2006) *Qualitative research in health care*, BMJ Books.
- CHAN, D. Y., CHAN, C. C. & AU, D. K. (2006) Motor relearning programme for stroke patients: a randomized controlled trial. *Clinical Rehabilitation*, 20, 191-200.
- CHEN, C. C. & BODE, R. K. (2011). Factors influencing therapists' decision-making in the acceptance of new technology devices in stroke rehabilitation. *American Journal of Physical Medicine & Rehabilitation*, 90, 415-425.
- CHEN, H. M., HSIEH, C. L., LO, S. K., LIAW, L. J., CHEN, S. M. & LIN, J. H. (2007) The test-retest reliability of 2 mobility performance tests in patients with chronic stroke. *Neurorehabilitation and Neural Repair*, 21, 347.
- CHO, S.-H., LEE, J.-H. & JANG, S.-H. (2015). Efficacy of pulmonary rehabilitation using cervical range of motion exercise in stroke patients with tracheostomy tubes. *Journal of physical therapy science*, 27, 1329.
- CHUMBLER N.R., ROUDEBUSH R.L., MOREY M.C., GRIFFITHS P., QUIGLEY P., ROSE D.K., SANFORD J. & H, H. (2011) The effects of a stroke telerehabilitation in-home intervention on function and disability: Preliminary results of a randomized clinical trial. *Stroke*.
- CHUMBLER, N. R., QUIGLEY, P., LI, X., MOREY, M., ROSE, D., SANFORD, J., GRIFFITHS, P. & HOENIG, H. (2012) Effects of Telerehabilitation on Physical Function and Disability for Stroke Patients A Randomized, Controlled Trial. *Stroke*, 43, 2168-2174.
- CIKAJLO, I., RUDOLF, M., GOLJAR, N., BURGER, H. & MATJACIC, Z. (2011) Telerehabilitation using virtual reality task can improve balance in patients with stroke. *Disability & Rehabilitation*, 1-6.
- CIRSTEA, C., PTITO, A. & LEVIN, M. (2006) Feedback and cognition in arm motor skill reacquisition after stroke. *Stroke*, 37, 1237-1242.
- CLARK, M. & GOODWIN, N. (2010) Sustaining innovation in telehealth and telecare.
- CLARK, N. M., BECKER, M. H., JANZ, N. K., LORIG, K., RAKOWSKI, W. & ANDERSON, L. (1991) Self-management of chronic disease by older adults. *Journal of Aging and Health*, 3, 3.

- CLARK, N. M. & ZIMMERMAN, B. J. (1990) A social cognitive view of self-regulated learning about health. *Health Education Research*, 5, 371-379.
- COLLEN, F., WADE, D., ROBB, G. & BRADSHAW, C. (1991) The Rivermead mobility index: a further development of the Rivermead motor assessment. *Disability & Rehabilitation*, 13, 50-54.
- COULTER, A. & COLLINS, A. (2011) Making shared decision-making a reality. *London: King's Fund*.
- COULTER, A. & DUNN, N. (2002) After Bristol: putting patients at the centre Commentary: Patient centred care: timely, but is it practical? *BmJ*, 324, 648-651.
- COULTER, A., ROBERTS, S. & DIXON, A. (2013) *Delivering better services for people with long-term conditions: building the house of care*.
- CRAMER, S. C. & RILEY, J. D. (2008) Neuroplasticity and brain repair after stroke. *Current opinion in neurology*, 21, 76-82.
- CRESWELL, J. & PLANO CLARK, V. (2011) *Designing and Conducting Mixed Methods Research* Sage. *Thousand Oaks, CA*.
- CRESWELL, J. W. (2009) *Research design: Qualitative, quantitative, and mixed methods approaches*, Sage Publications, Inc.
- CRESWELL, J. W. (2012) *Qualitative inquiry and research design: Choosing among five approaches*, Sage publications.
- CRESWELL, J. W., KLASSEN, A., PLANO CLARK, V. & SMITH, K. C. (2011) Best practices for mixed methods research in the health sciences. *Bethesda (Maryland): National Institutes of Health*.
- CULLEN, L., DICENSO, A., GRIFFITHS, R., MCCORMACK, B. & MALONE, J. (2008) Sigma Theta Tau international position statement on evidence-based practice. *Worldviews on Evidence-Based Nursing*, 5, 57-59.
- DABBS, A. D. V., MYERS, B. A., MC CURRY, K. R., DUNBAR-JACOB, J., HAWKINS, R. P., BEGEY, A. & DEW, M. A. (2009) User-centered design and interactive health technologies for patients. *Computers, informatics, nursing: CIN*, 27, 175.
- DAMUSH, T. M., PLUE, L., BAKAS, T., SCHMID, A. & WILLIAMS, L. S. (2007) Barriers and facilitators to exercise among stroke survivors. *Rehabilitation nursing: the official journal of the Association of Rehabilitation Nurses*, 32, 253.
- DAMUSH, T. M., PLUE, L. & WILLIAMS, L. S. (2008) Development of a post stroke self-management program. *Annals of Behavioral Medicine*, 35, S18-S18.
- DA SILVA, P. B., ANTUNES, F. N., GRAEF, P., CECHETTI, F. & DE SOUZA PAGNUSSAT, A. (2015). Strength Training Associated with Task-Oriented Training to Enhance Upper-Limb Motor Function in Elderly Patients with Mild Impairment After Stroke: A Randomized Controlled Trial. *American Journal of Physical Medicine & Rehabilitation*, 94, 11-19.
- DAVID, T. & PATEL, L. (1995) Adult learning theory, problem based learning, and paediatrics. *Archives of disease in childhood*, 73, 357.
- DAVIS, F. D. (1985) A technology acceptance model for empirically testing new end-user information systems: Theory and results. Massachusetts Institute of Technology, Sloan School of Management.
- DAVIS, F. D. (1989) Perceived usefulness, perceived ease of use, and user acceptance of information technology. *MIS quarterly*, 319-340.
- DAVIS, F. D. (1993) User acceptance of information technology: system characteristics, user perceptions and behavioral impacts.
- DAVIS, F. D., BAGOZZI, R. P. & WARSHAW, P. R. (1989) User acceptance of computer technology: a comparison of two theoretical models. *Management science*, 982-1003.
- DEAN, C. M., RICHARDS, C. L. & MALOUIN, F. (2000). Task-related circuit training improves performance of locomotor tasks in chronic stroke: a randomized, controlled pilot trial. *Archives of physical medicine and rehabilitation*, 81, 409-417.
- DE VAUS, D. A. (2002) *Surveys in social research*, Psychology Press.
- DENZIN, N. K. (2009) *The research act: A theoretical introduction to sociological methods*, Transaction Publishers.
- DH (2001) The expert patient: a new approach to chronic disease management for the 21st century. IN HEALTH, D. O. (Ed.) London, UK, Department of Health.
- DH (2004a) Improving Chronic Disease Management. IN HEALTH, D. O. (Ed.) UK, Department of Health.
- DH (2004b) The NHS Improvement Plan : Putting people at the heart of public services. IN HEALTH, D. O. (Ed.) London, UK, Department of Health.
- DH (2005a) Building Telecare in England. IN HEALTH, D. O. (Ed.) London, UK, Department of Health.

- DH (2005b) Self care - A real choice: Self care support - A practical option. IN HEALTH, D. O. (Ed.) London, UK, Department of Health.
- DH (2005c) Supporting People with Long Term Conditions. An NHS and Social Care Model to support local innovation and integration. IN HEALTH, D. O. (Ed.) Leeds, UK, Department of Health.
- DH (2006a) Improving stroke services: a guide for commissioners. IN HEALTH, D. O. (Ed.) London, UK, Department of Health.
- DH (2006b) Self care for people with long term conditions. IN HEALTH, D. O. (Ed.) UK, Department of Health.
- DH (2006c) Supporting people with long term conditions to self care: a guide to developing local strategies and good practice. IN HEALTH, D. O. (Ed.) Leeds, UK, Department of Health.
- DH (2007a) Generic choice model for long term conditions. IN HEALTH, D. O. (Ed.) London, UK, Department of Health.
- DH (2007b) National Stroke Strategy. IN HEALTH, D. O. (Ed.) London, United Kingdom, Stroke Team, Vascular Programme, Department of Health.
- DH (2009a) Living Well With Dementia: A National Dementia Strategy - Implementation Plan. IN HEALTH, D. O. (Ed.) Leeds, UK, Department of Health.
- DH (2009b) Stroke-specific education framework. IN HEALTH, D. O. (Ed.) UK, UK Forum for Stroke Training 2010.
- DH (2009c) Transforming Adult Social Care. IN HEALTH, D. O. (Ed.), Department of Health.
- DH (2009d) Whole Systems Demonstrators: an overview of telecare and telehealth. IN HEALTH, D. O. (Ed.), Department of Health.
- DH (2009e) Your health, your way-a guide to long term conditions and self care. Information for healthcare professionals. IN HEALTH, D. O. (Ed.) Leeds, United Kingdom, Department of Health.
- DH (2010) Building the National Care Service. IN HEALTH, D. O. (Ed.) London, Department of Health.
- DH (2011) Start Active, Stay Active: a report on physical activity from the four home countries' Chief Medical Officers. IN DEPARTMENT OF HEALTH, U. (Ed.) London, UK, Department of Health, UK.
- DIMYAN, M. A. & COHEN, L. G. (2011) Neuroplasticity in the context of motor rehabilitation after stroke. *Nature Reviews Neurology*, 7, 76-85.
- DIXON-WOODS, M., AGARWAL, S., YOUNG, B., JONES, D. & SUTTON, A. (2004) *Integrative approaches to qualitative and quantitative evidence*, Citeseer.
- DESROSIERS, J., BOURBONNAIS, D., CORRIVEAU, H., GOSSELIN, S. & BRAVO, G. (2005). Effectiveness of unilateral and symmetrical bilateral task training for arm during the subacute phase after stroke: a randomized controlled trial. *Clinical rehabilitation*, 19, 581-593.
- DONG, Y. H., SHARMA, V. K., CHAN, B. P. L., VENKETASUBRAMANIAN, N., TEOH, H. L., SEET, R. C. S., TANICALA, S., CHAN, Y. H. & CHEN, C. (2010) The Montreal Cognitive Assessment (MoCA) is superior to the Mini-Mental State Examination (MMSE) for the detection of vascular cognitive impairment after acute stroke. *Journal of the neurological sciences*, 299, 15-18.
- DROMERICK, A., LANG, C., BIRKENMEIER, R., WAGNER, J., MILLER, J., VIDEEN, T., POWERS, W., WOLF, S. & EDWARDS, D. (2009). Very early constraint-induced movement during stroke rehabilitation (VECTORS) A single-center RCT. *Neurology*, 73, 195-201.
- DUNCAN, P., STUDENSKI, S., RICHARDS, L., GOLLUB, S., LAI, S. M., REKER, D., PERERA, S., YATES, J., KOCH, V. & RIGLER, S. (2003). Randomized clinical trial of therapeutic exercise in subacute stroke. *Stroke*, 34, 2173-2180.
- DUNCAN, P. W. (1994) Stroke disability. *Physical Therapy*, 74, 399.
- DUNCAN, P. W., BODE, R. K., MIN LAI, S. & PERERA, S. (2003) Rasch analysis of a new stroke-specific outcome scale: the Stroke Impact Scale. *Archives of Physical Medicine and Rehabilitation*, 84, 950-963.
- DUNCAN, P. W., MIN LAI, S. & KEIGHLEY, J. (2000) Defining post-stroke recovery: implications for design and interpretation of drug trials. *Neuropharmacology*, 39, 835-841.
- DUNCAN, P. W., ZOROWITZ, R., BATES, B., CHOI, J. Y., GLASBERG, J. J., GRAHAM, G. D., KATZ, R. C., LAMBERTY, K. & REKER, D. (2005) Management of adult stroke rehabilitation care a clinical practice guideline. *Stroke*, 36, e100-e143.
- DURFEE, W., CAREY, J., NUCKLEY, D. & DENG, J. (2009) Design and implementation of a home stroke telerehabilitation system. IEEE.
- EAMES, S., MCKENNA, K., WORRALL, L. & READ, S. (2003) The suitability of written education materials for stroke survivors and their carers. *Topics in Stroke Rehabilitation*, 10, 70-83.
- EGGLESTONE, S. R., AXELROD, L., NIND, T., TURK, R., WILKINSON, A., BURRIDGE, J., FITZPATRICK, G., MAWSON, S., ROBERTSON, Z. & HUGHES, A. M. (2009) A design

- framework for a home-based stroke rehabilitation system: Identifying the key components. *Pervasive Computing Technologies for Healthcare, 2009. PervasiveHealth 2009. 3rd International Conference on. IEEE.*
- ELO, S., KÄÄRIÄINEN, M., KANSTE, O., PÖLKKI, T., UTRIAINEN, K. & KYNGÄS, H. (2014) Qualitative Content Analysis A Focus on Trustworthiness. *SAGE Open*
- ELO, S. & KYNGÄS, H. (2008) The qualitative content analysis process. *Journal of Advanced Nursing*, 62, 107-115.
- ELWYN, G., LAITNER, S., COULTER, A., WALKER, E., WATSON, P. & THOMSON, R. (2010) Implementing shared decision making in the NHS. *Bmj*, 341.
- ENDERBY, P. (2013) Introducing the therapy outcome measure for AAC services in the context of a review of other measures. *Disability and Rehabilitation: Assistive Technology*, 1-8.
- ENDERBY, P. & CROW, E. (1996) Frenchay aphasia screening test: Validity and comparability. *Disability & Rehabilitation*, 18, 238-240.
- ENDERBY, P., JOHN, A. & PETHERAM, B. (2006) *Therapy Outcome Measures for Rehabilitation Professionals: Speech and Language Therapy, Physiotherapy, Occupational Therapy*, Wiley.
- ENDERBY, P. & WADE, D. T. (2001) Community rehabilitation in the United Kingdom. *Clinical Rehabilitation*, 15, 577-581.
- ENDERBY, P., WOOD, V. A., WADE, D. T. & HEWER, R. L. (1986a) Aphasia after stroke: A detailed study of recovery in the first 3 months. *Disability & Rehabilitation*, 8, 162-165.
- ENDERBY, P. M., WOOD, V. A., WADE, D. T. & HEWER, R. L. (1986b) The Frenchay Aphasia Screening Test: a short, simple test for aphasia appropriate for non-specialists. *Disability & Rehabilitation*, 8, 166-170.
- ENE, H., MCRAE, C. & SCHENKMAN, M. (2011). Attitudes toward exercise following participation in an exercise intervention study. *Journal of Neurologic Physical Therapy*, 35, 34-40.
- ENG, J.J. & HARRIS, J.E. (2012) *Graded Repetitive Arm Supplementary Program: A home-work based program to improve arm and hand function in people living with stroke*. Vancouver, Canada. <http://neurorehab.med.ubc.ca/grasp>. Accessed 1.7.2015
- EPPING-JORDAN, J., PRUITT, S., BENGGOA, R. & WAGNER, E. (2004) Improving the quality of health care for chronic conditions. *Quality and Safety in Health Care*, 13, 299.
- EVANS, D. (2003) Hierarchy of evidence: a framework for ranking evidence evaluating healthcare interventions. *Journal of clinical nursing*, 12, 77-84.
- EVERS, S. M., AMENT, A. J. & BLAAUW, G. (2000) Economic Evaluation in Stroke Research A Systematic Review. *Stroke*, 31, 1046-1053.
- FINK, A. (2003) *The survey handbook*, SAGE Publications, Incorporated.
- FORLANDER, D. A. & BOHANNON, R. W. (1999) Rivermead Mobility Index: a brief review of research to date. *Clinical Rehabilitation*, 13, 97.
- FRANCESCHINI, M., CARDA, S., AGOSTI, M., ANTENUCCI, R., MALGRATI, D. & CISARI, C. (2009). Walking after stroke: what does treadmill training with body weight support add to overground gait training in patients early after stroke? A single-blind, randomized, controlled trial. *Stroke*, 40, 3079-3085.
- FRANK, G., JOHNSTON, M., MORRISON, V., POLLARD, B. & MACWALTER, R. (2000) Perceived control and recovery from functional limitations: Preliminary evaluation of a workbook-based intervention for discharged stroke patients. *British Journal of Health Psychology*, 5, 413-420.
- FRENCH, B., LEATHLEY, M. J., SUTTON, C. J., MCADAM, J., THOMAS, L. H., FORSTER, A., LANGHORNE, P., PRICE, C., WALKER, A. & WATKINS, C. L. (2007). A systematic review of repetitive task training with modelling of resource use, costs and effectiveness. *Health Technology Assessment*, 12, 1-117.
- FU-LING, T., YEA-RU, Y., CHAO-CHUNG, L. & RAY-YAU, W. (2010). Balance outcomes after additional sit-to-stand training in subjects with stroke: a randomized controlled trial. *Clinical Rehabilitation*, 24, 533-542.
- GELBER, D. A., JOSEFCZYK, B., HERRMAN, D., GOOD, D. C. & VERHULST, S. J. (1995) Comparison of two therapy approaches in the rehabilitation of the pure motor hemiparetic stroke patient. *Neurorehabilitation and Neural Repair*, 9, 191-196.
- GERRISH, K., ASHWORTH, P., LACEY, A., BAILEY, J., COOKE, J., KENDALL, S. & MCNEILLY, E. (2007) Factors influencing the development of evidence-based practice: a research tool. *Journal of Advanced Nursing*, 57, 328-338.
- GEYH, S., CIEZA, A., KOLLERITS, B., GRIMBY, G. & STUCKI, G. (2007) Content comparison of health-related quality of life measures used in stroke based on the international classification of functioning, disability and health (ICF): a systematic review. *Quality of Life Research*, 16, 833-851.

- GEYH, S., CIEZA, A., SCHOUTEN, J., DICKSON, H., FROMMELT, P., OMAR, Z., KOSTANJSEK, N., RING, H. & STUCKI, G. (2004) ICF Core Sets for stroke. *Journal of Rehabilitation Medicine*, 36, 135-141.
- GILLHAM, B. (2005) *Research interviewing: The range of techniques*, Open Univ Pr.
- GORDON, C. D., WILKS, R. & MCCAWE-BINNS, A. (2013). Effect of Aerobic Exercise (Walking) Training on Functional Status and Health-related Quality of Life in Chronic Stroke Survivors A Randomized Controlled Trial. *Stroke*, 44, 1179-1181.
- GORDON, N. F., GULANICK, M., COSTA, F., FLETCHER, G., FRANKLIN, B. A., ROTH, E. J. & SHEPHARD, T. (2004) Physical activity and exercise recommendations for stroke survivors. *Stroke*, 35, 1230-1240.
- GOULD, J. D. & LEWIS, C. (1985) Designing for usability: key principles and what designers think. *Communications of the ACM*, 28, 300-311.
- GRAHAM, J. V., EUSTACE, C., BROCK, K., SWAIN, E. & IRWIN-CARRUTHERS, S. (2009) The Bobath concept in contemporary clinical practice. *Topics in Stroke Rehabilitation*, 16, 57-68.
- GREEN, J. & YOUNG, J. (2001) A test-retest reliability study of the Barthel Index, the Rivermead Mobility Index, the Nottingham Extended Activities of Daily Living Scale and the Frenchay Activities Index in stroke patients. *Disability & Rehabilitation*, 23, 670-676.
- GREEN, J. S. A. J. (2006) *Evaluation*, Berkshire, England, Open University Press.
- GREEN, M. L. & ELLIS, P. J. (1997) Impact of an evidence based medicine curriculum based on adult learning theory. *Journal of General Internal Medicine*, 12, 742-750.
- GRIFFITHS, C., FOSTER, G., RAMSAY, J., ELDRIDGE, S. & TAYLOR, S. (2007) How effective are expert patient (lay led) education programmes for chronic disease? *BMJ: British Medical Journal*, 334, 1254.
- GROUP, T. E. (1990) EuroQol-a new facility for the measurement of health-related quality of life. *Health Policy*, 16, 199-208.
- GUBA, E. G. & LINCOLN, Y. S. (1994) Competing paradigms in qualitative research. *Handbook of qualitative research*, 2, 163-194.
- GUNNAR GRIMBY, C. W., MARGARETA ENGARDT, KATHARINA STIBRANT SUNNERHAGEN (2010) Stroke. IN PROFESSIONAL ASSOCIATIONS FOR PHYSICAL ACTIVITY, S. (Ed.) *Physical Activity in the Prevention and Treatment of Disease*. 2nd ed., Swedish National Institute of Public Health, Sweden.
- GURALNIK, J. M., FERRUCCI, L., BALFOUR, J. L., VOLPATO, S. & DI IORIO, A. (2001) Progressive versus catastrophic loss of the ability to walk: implications for the prevention of mobility loss. *Journal of the American Geriatrics Society*, 49, 1463-1470.
- HAFSTEINSDÓTTIR, T. B., VERGUNST, M., LINDEMAN, E. & SCHUURMANS, M. (2011) Educational needs of patients with a stroke and their caregivers: A systematic review of the literature. *Patient Education and Counseling*, 85, 14-25.
- HAKKENNES, S. & KEATING, J. L. (2005) Constraint-induced movement therapy following stroke: a systematic review of randomised controlled trials. [Review] [45 refs]. *Australian Journal of Physiotherapy*, 51, 221-31.
- HANGER, H. C. & WILKINSON, T. J. (2001) Stroke education: can we rise to the challenge? *Age and Ageing*, 30, 113-114.
- HANKEY, G. J. (2002) *Stroke: Your questions answered*, Elsevier Health Sciences.
- HANLON, R. E. (1996) Motor learning following unilateral stroke* 1. *Archives of Physical Medicine and Rehabilitation*, 77, 811-815.
- HARDY, S., TITCHEN, A., MANLEY, K. & MCCORMACK, B. (2006) Re-defining nursing expertise in the United Kingdom. *Nursing Science Quarterly*, 19, 260-264.
- HART, J., KANNER, H., GILBOA-MAYO, R., HAROEH-PEER, O., ROZENTHUL-SOROKIN, N. & ELДАР, R. (2004). Tai Chi Chuan practice in community-dwelling persons after stroke. *International Journal of Rehabilitation Research*, 27, 303-304.
- HARWOOD, M., WEATHERALL, M., TALEMAITOGA, A., BARBER, P. A., GOMMANS, J., TAYLOR, W., MCPHERSON, K. & MCNAUGHTON, H. (2012) Taking charge after stroke: promoting self-directed rehabilitation to improve quality of life—a randomized controlled trial. *Clinical rehabilitation*, 26, 493-501.
- HAYNES, R. B., DEVEREAUX, P. J. & GUYATT, G. H. (2002) Clinical expertise in the era of evidence-based medicine and patient choice. *Evidence Based Medicine*, 7, 36-38.
- HAYNES, R. B., SACKETT, D. L., GRAY, J. M. A., COOK, D. J. & GUYATT, G. H. (1996) Transferring evidence from research into practice: 1. the role of clinical care research evidence in clinical decisions. *Evidence Based Medicine*, 1, 196-198.

- HERBER, R, JAMTVEDT G, HAGEN KB, MEAD J. (2011) *Practical evidence-based physiotherapy* (2nd ed), Elsevier.
- HES (2011) Hospital Episode Statistics Online. The NHS Information Centre
- HIPPISLEY-COX, J., PRINGLE, M. & RYAN, R. (2004) Stroke: prevalence, incidence and care in general practices 2002 to 2004. *Final Report to the National Stroke Audit Team. London: Royal College of Physicians.*
- HOFFMANN, T. & LADNER, Y. (2012) Assessing the suitability of written stroke materials: an evaluation of the interrater reliability of the suitability assessment of materials (SAM) checklist. *Topics in stroke rehabilitation*, 19, 417-422.
- HOFFMANN, T. & MCKENNA, K. (2006) Analysis of stroke patients' and carers' reading ability and the content and design of written materials: recommendations for improving written stroke information. *Patient Education and Counseling*, 60, 286-293.
- HOFFMANN, T., MCKENNA, K., HERD, C. & WEARING, S. (2007) Written education materials for stroke patients and their carers: perspectives and practices of health professionals. *Topics in stroke rehabilitation*, 14, 88-97.
- HOLROYD, K. A., CREER, T. L. & CONGER, J. J. (1986) *Self-management of chronic disease: handbook of clinical interventions and research*, Cambridge Univ Press.
- HOLMGREN, E., GOSMAN-HEDSTRÖM, G., LINDSTRÖM, B. & WESTER, P. (2010). What is the benefit of a high-intensive exercise program on health-related quality of life and depression after stroke? A randomized controlled trial. *Advances in physiotherapy*, 12, 125-133.
- HOUGH, M. (1984) Motivation of adults: Implications of adult learning theories for distance education. *Distance Education*, 5, 7-23.
- HØYER, E., JAHNSEN, R., STANGHELLE, J. K. & STRAND, L. I. (2012). Body weight supported treadmill training versus traditional training in patients dependent on walking assistance after stroke: a randomized controlled trial. *Disability & Rehabilitation*, 34, 210-219.
- HSIEH, C. L., HSUEH, I. P. & MAO, H. F. (2000) Validity and responsiveness of the Rivermead Mobility Index in stroke patients. *Scandinavian Journal of Rehabilitation Medicine*, 32, 140-142.
- HSIEH, H.-F. & SHANNON, S. E. (2005) Three approaches to qualitative content analysis. *Qualitative Health Research*, 15, 1277-1288.
- HSUEH, I., WANG, C. H., SHEU, C. F. & HSIEH, C. L. (2003) Comparison of psychometric properties of three mobility measures for patients with stroke. *Stroke*, 34, 1741-1745.
- HSUEH, S.-L. H., MEI-HSIANG CHEN, SHI-DONG JUSH, CHING-LIN HSIEH, I-PING (2000) Evaluation of stroke patients with the extended activities of daily living scale in Taiwan. *Disability & Rehabilitation*, 22, 495-500.
- HUIJBREGTS, M. P., CAMERON, J., TAYLOR, D., MCEWEN, S. E., KAGAN, A. & STREINER, D. (2010) Videoconference Delivery of a Stroke Self-Management Program: A Mixed Methods Waiting List Randomized Controlled Trial. *Stroke*, 41, E357-E357.
- HUIJBREGTS, M. P. J., MCEWEN, S. & TAYLOR, D. (2009) Exploring the feasibility and efficacy of a telehealth stroke self-management programme: a pilot study. *Physiotherapy Canada*, 61, 210-220.
- HUIJBREGTS, M. P. J., MYERS, A. M., STREINER, D. & TEASELL, R. (2008) Implementation, process, and preliminary outcome evaluation of two community programs for persons with stroke and their care partners. *Topics in Stroke Rehabilitation*, 15, 503-20.
- HUSSEIN, A. (2009) The use of Triangulation in Social Sciences Research: Can qualitative and quantitative methods be combined. *Journal of Comparative Social Work*, 1, 1-12.
- ISWP (2010) National Sentinel Stroke Audit. Organisational Audit 2010. *Royal College of Physicians, London.*
- ISWP (2012) *National clinical guideline for stroke*, Royal College of Physicians of London.
- IVANCO, T. L. & GREENOUGH, W. T. (2000) Physiological consequences of morphologically detectable synaptic plasticity: potential uses for examining recovery following damage. *Neuropharmacology*, 39, 765-776.
- IVEY, F. M., HAFER-MACKO, C. E. & MACKO, R. F. (2006) Exercise rehabilitation after stroke. *NeuroRx*, 3, 439-450.
- JACKSON, A., MAKOWER, S., CULMER, P., HOLT, R., COZENS, J., LEVESLEY, M. & BHAKTA, B. (2009) Acceptability of robot assisted active arm exercise as part of rehabilitation after stroke. *Rehabilitation Robotics, 2009. ICORR 2009. IEEE International Conference on. IEEE.*
- JACOBS, S. (2009) Expert Patients Programme. *NHS Healthcare*, 39.
- JAGLAL, S. B., HAROUN, V. A., SALBACH, N. M., HAWKER, G., VOTH, J., LOU, W., KONTOS, P., CAMERON, J. E., COCKERILL, R. & BERKET, T. (2013) Increasing access to chronic

- disease self-management programs in rural and remote communities using telehealth. *TELEMEDICINE and e-HEALTH*, 19, 467-473.
- JAMIESON, S. (2004) Likert scales: how to (ab) use them. *Medical education*, 38, 1217-1218.
- JENNETT, P., AFFLECK HALL, L., HAILEY, D., OHINMAA, A., ANDERSON, C., THOMAS, R., YOUNG, B., LORENZETTI, D. & SCOTT, R. (2003) The socio-economic impact of telehealth: a systematic review. *Journal of Telemedicine and Telecare*, 9, 311.
- JENSEN, M. P., NIELSON, W. R. & KERNS, R. D. (2003) Toward the development of a motivational model of pain self-management* 1. *The Journal of Pain*, 4, 477-492.
- JERANT, A. F., FRIEDERICHS-FITZWATER, M. M. & MOORE, M. (2005) Patients' perceived barriers to active self-management of chronic conditions. *Patient Education and Counseling*, 57, 300-307.
- JIN, H., JIANG, Y., WEI, Q., CHEN, L. & MA, G. 2013. Effects of aerobic cycling training on cardiovascular fitness and heart rate recovery in patients with chronic stroke. *NeuroRehabilitation*, 32, 327-335.
- JOHANSSON, T. & WILD, C. (2010) Telemedicine in acute stroke management: systematic review. *International journal of technology assessment in health care*, 26, 149-155.
- JOHANSSON, T. & WILD, C. (2011) Telerehabilitation in stroke care—a systematic review. *Journal of Telemedicine and Telecare*, 17, 1.
- JOHNSON, R. B. & ONWUEGBUZIE, A. J. (2004) Mixed methods research: A research paradigm whose time has come. *Educational researcher*, 33, 14-26.
- JOHNSON, R. B., ONWUEGBUZIE, A. J. & TURNER, L. A. (2007) Toward a definition of mixed methods research. *Journal of mixed methods research*, 1, 112-133.
- JOHNSTON, M., BONETTI, D., JOICE, S., POLLARD, B., MORRISON, V., FRANCIS, J. J. & MACWALTER, R. (2007) Recovery from disability after stroke as a target for a behavioural intervention: results of a randomized controlled trial. *Disability & Rehabilitation*, 29, 1117-1127.
- JOICE, S. (2012) Self-management following stroke. *Nursing standard*, 26, 39-46.
- JOICE, S., JOHNSTON, M., BONETTI, D., MORRISON, V. & MACWALTER, R. (2012) Stroke survivors' evaluations of a stroke workbook-based intervention designed to increase perceived control over recovery. *Health Education Journal*, 71, 17-29.
- JONES, F. (2004) An individual approach to stroke recovery. *Physiotherapy Research International*, 9, 147-148.
- JONES, F. (2006) Strategies to enhance chronic disease self-management: How can we apply this to stroke? *Disability & Rehabilitation*, 28, 841-847.
- JONES, F. (2008) Stepping out: a programme focusing on self-management after stroke. *International Journal of Therapy & Rehabilitation*, 15, 540-541.
- JONES, F. (2010) Confiding in those better than ourselves: stroke research and clinical practice, are we asking the right questions? *Physiotherapy Research International*, 15, 1-4.
- JONES, F. (2011) Self-management. IN STACK, M. S. A. E. (Ed.) *Physical Management for Neurological Conditions*. 3rd ed. London, UK, Churchill Livingstone, Elsevier.
- JONES, F. (2013) Self-management: is it time for a new direction in rehabilitation and post stroke care? *Panminerva medica*, 55, 79-86.
- JONES, F., HARRIS, P., WALLER, H. & COGGINS, A. (2005) Adherence to an exercise prescription scheme: The role of expectations, self-efficacy, stage of change and psychological well-being. *British journal of health psychology*, 10, 359-378.
- JONES, F., LIVINGSTONE, E. & HAWKES, L. (2013a) 'Getting the Balance between Encouragement and Taking Over'—Reflections on Using a New Stroke Self-Management Programme. *Physiotherapy Research International*, 18, 91-99.
- JONES, F., MANDY, A. & PARTRIDGE, C. (2000) Who's in control after a stroke? Do we disempower our patients? *Physiotherapy Research International*, 5, 249-253.
- JONES, F., MANDY, A. & PARTRIDGE, C. (2008a) Reasons for recovery after stroke: a perspective based on personal experience. *Disability & Rehabilitation*, 30, 507-516.
- JONES, F., MANDY, A. & PARTRIDGE, C. (2009) Changing self-efficacy in individuals following a first time stroke: Preliminary study of a novel self-management intervention. *Clinical Rehabilitation*, 23, 522-533.
- JONES, F., PARTRIDGE, C. & REID, F. (2008b) The Stroke Self-Efficacy Questionnaire: measuring individual confidence in functional performance after stroke. *Journal of Clinical Nursing*, 17, 244-252.
- JONES, F. & RIAZI, A. (2011) Self-efficacy and self-management after stroke: a systematic review. *Disability & Rehabilitation*, 33, 797-810.

- JONES, F., RIAZI, A. & NORRIS, M. (2013b) Self-management after stroke: time for some more questions? *Disability and Rehabilitation*, 35, 257-264.
- KAIRY, D., LEHOUX, P., VINCENT, C. & VISINTIN, M. (2009) A systematic review of clinical outcomes, clinical process, healthcare utilization and costs associated with telerehabilitation. *Disability & Rehabilitation*, 31, 427-447.
- KALRA, L. & RATAN, R. (2007) Recent advances in stroke rehabilitation 2006. *Stroke*, 38, 235-237.
- KARTHIKABABU, S., NAYAK, A., VIJAYAKUMAR, K., MISRI, Z. K., SURESH, B. V., GANESAN, S. & JOSHUA, A. M. (2011). Comparison of physio ball and plinth trunk exercises regimens on trunk control and functional balance in patients with acute stroke: a pilot randomized controlled trial. *Clinical Rehabilitation*, 25, 709-719.
- KAUFMAN, D. M. (2003) Applying educational theory in practice. *Bmj*, 326, 213.
- KAZDIN, A. E. (1981) Acceptability of child treatment techniques: The influence of treatment efficacy and adverse side effects. *Behavior Therapy*, 12, 493-506.
- KAZI, M. (2003) Realist evaluation for practice. *British Journal of Social Work*, 33, 803-818.
- KELLER, M. B., MCCULLOUGH, J. P., KLEIN, D. N., ARNOW, B., DUNNER, D. L., GELENBERG, A. J., MARKOWITZ, J. C., NEMEROFF, C. B., RUSSELL, J. M. & THASE, M. E. (2000) A comparison of nefazodone, the cognitive behavioral-analysis system of psychotherapy, and their combination for the treatment of chronic depression. *New England Journal of Medicine*, 342, 1462-1470.
- KELLY-HAYES, M., BEISER, A., KASE, C. S., SCARAMUCCI, A., D'AGOSTINO, R. B. & WOLF, P. A. (2003) The influence of gender and age on disability following ischemic stroke: the Framingham study. *Journal of Stroke and Cerebrovascular Diseases*, 12, 119-126.
- KENDALL, E., CATALANO, T., KUIPERS, P., POSNER, N., BUYS, N. & CHARKER, J. (2007) Recovery following stroke: The role of self-management education. *Social Science & Medicine*, 64, 735-746.
- KIM, C.-B., SHIN, J.-H. & CHOI, J.-D. (2015). The effect of chest expansion resistance exercise in chronic stroke patients: a randomized controlled trial. *Journal of physical therapy science*, 27, 451.
- KIM, K., LEE, B. & LEE, W. (2014). Effect of gross motor group exercise on functional status in chronic stroke: a randomized controlled trial. *Journal of physical therapy science*, 26, 977.
- KING, E., TAYLOR, J., WILLIAMS, R., & VANSON, T. (2013) The MAGIC programme: evaluation: An independent evaluation of the MAGIC improvement programme. London, Office for Public Management.
- KITTO, S. C., CHESTERS, J. & GRBICH, C. (2008) Quality in qualitative research. *Medical Journal of Australia*, 188, 243.
- KLECUN-DABROWSKA, E. (2003) Telehealth in the UK: A critical perspective. Academic Conferences Limited.
- KNOWLES, M. S. (1973) *The modern practice of adult education*, Association Press.
- KNOWLES, M. S., HOLTON III, E. F. & SWANSON, R. A. (2012) *The adult learner: The definitive classic in adult education and human resource development*, New York, USA, Routledge.
- KORPERSHOEK, C., VAN DER BIJL, J. & HAFSTEINSDÓTTIR, T. B. (2011) Self-efficacy and its influence on recovery of patients with stroke: a systematic review. *Journal of Advanced Nursing*, 67, 1876-1894.
- KOSKI, L., XIE, H. & FINCH, L. (2009) Measuring cognition in a geriatric outpatient clinic: Rasch analysis of the Montreal Cognitive Assessment. *Journal of geriatric psychiatry and neurology*, 22, 151-160.
- KRAKAUER, J. W. (2006) Motor learning: its relevance to stroke recovery and neurorehabilitation. *Current Opinion in Neurology*, 19, 84-90.
- KREFTING, L. (1991) Rigor in qualitative research: The assessment of trustworthiness. *The American journal of occupational therapy*, 45, 214-222.
- KRUGER, J., HAM, S. A. & SANKER, S. (2008) Physical inactivity during leisure time among older adults -- Behavioral Risk Factor Surveillance System, 2005. *Journal of Aging & Physical Activity*, 16, 280-291.
- KUGLER, C., ALTENHÖNER, T., LOCHNER, P. & FERBERT, A. (2003) Does age influence early recovery from ischemic stroke? *Journal of Neurology*, 250, 676-681.
- KUO, Y. H., CHIEN, Y. K., WANG, W. R., CHEN, C. H., CHEN, L. S. & LIU, C. K. (2011) Development of a home-based telehealthcare model for improving the effectiveness of the chronic care of stroke patients. *The Kaohsiung Journal of Medical Sciences*.
- KUPER, A., REEVES, S. & LEVINSON, W. (2008) Qualitative research: An introduction to reading and appraising qualitative research. *BMJ: British Medical Journal*, 337, 404-407.

- KWAKKEL, G., KOLLEN, B. J. & KREBS, H. I. (2008) Effects of robot-assisted therapy on upper limb recovery after stroke: a systematic review. *Neurorehabilitation and Neural Repair*, 22, 111-121.
- KWAKKEL, G., KOLLEN, B. J. & WAGENAAR, R. C. (1999) Therapy Impact on Functional Recovery in Stroke Rehabilitation: A critical review of the literature. *Physiotherapy*, 85, 377-391.
- KWAKKEL, G., VAN PEPPEN, R., WAGENAAR, R. C., DAUPHINEE, S. W., RICHARDS, C., ASHBURN, A., MILLER, K., LINCOLN, N., PARTRIDGE, C. & WELLWOOD, I. (2004) Effects of augmented exercise therapy time after stroke. A meta-analysis. *Stroke*, 01. STR. 0000143153.76460. 7dv1.
- LAI, J. C. K., WOO, J., HUI, E. & CHAN, W. (2004) Telerehabilitation--a new model for community-based stroke rehabilitation. *Journal of Telemedicine and Telecare*, 10, 199-205.
- LAMBERT, H. (2006) Accounting for EBM: notions of evidence in medicine. *Social Science & Medicine*, 62, 2633-2645.
- LAMONTE, M. P., BAHOUTH, M. N., XIAO, Y., HU, P., BAQUET, C. R. & MACKENZIE, C. F. (2008) Outcomes from a comprehensive stroke telemedicine program. *Telemedicine and e-Health*, 14, 339-344.
- ER, B. & LINDMARK, B. (2012) Functional exercise and physical fitness post stroke: The importance of exercise maintenance for motor control and physical fitness after stroke. *Stroke research and treatment*, 2012.
- LANGHAMMER, B., LINDMARK, B. & STANGHELLE, J. K. (2007) Stroke patients and long-term training: is it worthwhile? A randomized comparison of two different training strategies after rehabilitation. *Clinical Rehabilitation*, 21, 495-510.
- LANGHAMMER, B. & STANGHELLE, J. K. (2000) Bobath or motor relearning programme? A comparison of two different approaches of physiotherapy in stroke rehabilitation: a randomized controlled study. *Clinical Rehabilitation*, 14, 361-369.
- LANGHAMMER, B. & STANGHELLE, J. K. (2003) Bobath or motor relearning programme? A follow-up one and four years post stroke. *Clinical Rehabilitation*, 17, 731-734.
- LANGHAMMER, B., LINDMARK, B. & STANGHELLE, J. K. (2014). Physiotherapy and physical functioning post-stroke: Exercise habits and functioning 4 years later? Long-term follow-up after a 1-year long-term intervention period: A randomized controlled trial. *Brain injury*, 28, 1396-1405.
- LANGHORNE, P., BERNHARDT, J. & KWAKKEL, G. (2011) Stroke rehabilitation. *The Lancet*, 377, 1693-1702.
- LANGHORNE, P., COUPAR, F. & POLLOCK, A. (2009a) Motor recovery after stroke: a systematic review. *The Lancet Neurology*, 8, 741-754.
- LANGHORNE, P. & POLLOCK, A. (2002) What are the components of effective stroke unit care? *Age and Ageing*, 31, 365-371.
- LANGHORNE, P., SANDERCOCK, P. & PRASAD, K. (2009b) Evidence-based practice for stroke. *The Lancet Neurology*, 8, 308-309.
- LAUFER, Y., DICKSTEIN, R., CHEFEZ, Y. & MARCOVITZ, E. (2001). The effect of treadmill training on the ambulation of stroke survivors in the early stages of rehabilitation: a randomized study. *Journal of rehabilitation research and development*, 38, 69.
- LAVER, K., HALBERT, J., STEWART, M. & CROTTY, M. (2010) Patient readiness and ability to set recovery goals during the first 6 months after stroke. *Journal of allied health*, 39, 149E-154E.
- LAVER, K. E., SCHOENE, D., CROTTY, M., GEORGE, S., LANNIN, N. A. & SHERRINGTON, C. (2013) Telerehabilitation services for stroke. *status and date: New, published in.*
- LAVRAKAS, P. J. (2008) *Encyclopedia of Survey Research Methods: AM*, Sage.
- LEE, M.-J., KILBREATH, S. L., SINGH, M. F., ZEMAN, B., LORD, S. R., RAYMOND, J. & DAVIS, G. M. (2008). Comparison of Effect of Aerobic Cycle Training and Progressive Resistance Training on Walking Ability After Stroke: A Randomized Sham Exercise–Controlled Study. *Journal of the American Geriatrics Society*, 56, 976-985.
- LEE, N. K., KWON, J. W., SON, S. M., KANG, K. W., KIM, K. & HYUN-NAM, S. (2013). The effects of closed and open kinetic chain exercises on lower limb muscle activity and balance in stroke survivors. *NeuroRehabilitation*, 33, 177-183.
- LEE, S.-B. & KANG, K.-Y. (2013). The effects of isokinetic eccentric resistance exercise for the hip joint on functional gait of stroke patients. *Journal of physical therapy science*, 25, 1177-1179.
- LÉGARÉ, F., TURCOTTE, S., STACEY, D., RATTÉ, S., KRYWORUCHKO, J. & GRAHAM, I. D. (2012) Patients' perceptions of sharing in decisions. *The Patient-Patient-Centered Outcomes Research*, 5, 1-19.

- LEGRIS, P., INGHAM, J. & COLLERETTE, P. (2003) Why do people use information technology? A critical review of the technology acceptance model. *Information & Management*, 40, 191-204.
- LEMBERG, I., KIRCHBERGER, I., STUCKI, G. & CIEZA, A. (2010) The ICF Core Set for stroke from the perspective of physicians: a worldwide validation study using the Delphi technique. *European journal of physical and rehabilitation medicine*, 46, 377.
- LENNON, S., MCKENNA, S. & JONES, F. (2013) Self-management programmes for people post stroke: a systematic review. *Clinical Rehabilitation*, 27, 867-878
- LEUNG, S.-O. (2011) A comparison of psychometric properties and normality in 4-, 5-, 6-, and 11-point Likert scales. *Journal of Social Service Research*, 37, 412-421.
- LIEBERMANN, D. G., BUCHMAN, A. S. & FRANKS, I. M. (2006) Enhancement of motor rehabilitation through the use of information technologies. *Clinical biomechanics*, 21, 8-20.
- LIKERT, R. (1932) A technique for the measurement of attitudes. *Archives of psychology*.
- LIN, K.-C., FU, T., WU, C.-Y., HSIEH, Y.-W., CHEN, C.-L. & LEE, P.-C. (2010) Psychometric comparisons of the stroke impact scale 3.0 and stroke-specific quality of life scale. *Quality of Life Research*, 19, 435-443.
- LINCOLN, Y. S. & GUBA, E. G. (1985) *Naturalistic inquiry*, Sage Publications, Inc.
- LO, A. C., GUARINO, P. D., RICHARDS, L. G., HASELKORN, J. K., WITTENBERG, G. F., FEDERMAN, D. G., RINGER, R. J., WAGNER, T. H., KREBS, H. I. & VOLPE, B. T. (2010) Robot-assisted therapy for long-term upper-limb impairment after stroke. *New England Journal of Medicine*, 362, 1772-1783.
- LO, S. H. S., CHANG, A. M., CHAU, J. P. C. & GARDNER, G. (2014) Theory-based self-management programs for promoting recovery in community-dwelling stroke survivors: a systematic review. *The JBI Database of Systematic Reviews and Implementation Reports*, 11, 157-215.
- LONG, T. & JOHNSON, M. (2000) Rigour, reliability and validity in qualitative research. *Clinical effectiveness in nursing*, 4, 30-37.
- LORIG, K. R. & HOLMAN, H. R. (2003) Self-management education: history, definition, outcomes, and mechanisms. *Annals of behavioral medicine*, 26, 1-7.
- LORIG, K. R., RITTER, P. L., DOST, A., PLANT, K., LAURENT, D. D. & MCNEIL, I. (2008) The expert patients programme online, a 1-year study of an Internet-based self-management programme for people with long-term conditions. *Chronic illness*, 4, 247.
- LUFT, A. R., MACKO, R. F., FORRESTER, L. W., VILLAGRA, F., IVEY, F., SORKIN, J. D., WHITALL, J., MCCOMBE-WALLER, S., KATZEL, L. & GOLDBERG, A. P. 2008. Treadmill exercise activates subcortical neural networks and improves walking after stroke a randomized controlled trial. *Stroke*, 39, 3341-3350.
- LUK, J. K., CHEUNG, R. T., HO, S. & LI, L. (2006) Does age predict outcome in stroke rehabilitation? A study of 878 Chinese subjects. *Cerebrovascular Diseases*, 21, 229-234.
- LUSZCZYNSKA, A., SCHWARZER, R., LIPPKE, S. & MAZURKIEWICZ, M. (2011) Self-efficacy as a moderator of the planning-behaviour relationship in interventions designed to promote physical activity. *Psychology and Health*, 26, 151-166.
- LUTZ, B. J., CHUMBLER, N. R., LYLES, T., HOFFMAN, N. & KOBBS, R. (2009) Testing a home-telehealth programme for US veterans recovering from stroke and their family caregivers. *Disability & Rehabilitation*, 31, 402-409.
- MA, M. Y., WU, F. G. & CHANG, R. H. (2007) A new design approach of user-centered design on a personal assistive bathing device for hemiplegia. *Disability and Rehabilitation*, 29, 1077-1089.
- MACKO, R. F., IVEY, F. M., FORRESTER, L. W., HANLEY, D., SORKIN, J. D., KATZEL, L. I., SILVER, K. H. & GOLDBERG, A. P. (2005). Treadmill exercise rehabilitation improves ambulatory function and cardiovascular fitness in patients with chronic stroke a randomized, controlled trial. *Stroke*, 36, 2206-2211.
- MACWALTER, R. S. & SHIRLEY, C. P. (2003) *Managing strokes and TIAs in practice*, Royal Society of Medicine.
- MAES, S. & KAROLY, P. (2005) Self-Regulation Assessment and Intervention in Physical Health and Illness: A Review. *Applied Psychology*, 54, 267-299.
- MALPAS, J. (1997) *Realism (Movements in Modern Art)*. London: Tate Gallery Publishing Ltd.
- MARSDEN, D., QUINN, R., POND, N., GOLLEDGE, R., NEILSON, C., WHITE, J., MCELDUFF, P. & POLLACK, M. (2010) A multidisciplinary group programme in rural settings for community-dwelling chronic stroke survivors and their carers: a pilot randomized controlled trial. *Clinical Rehabilitation*, 24, 328-41.
- MAWSON, S., NASR, N., PARKER, J., ZHENG, H., DAVIES, R. & MOUNTAIN, G. (2013) Developing a personalised self-management system for post stroke rehabilitation; utilising a user-centred design methodology. *Disability and Rehabilitation: Assistive Technology*, 1-8.

- MAWSON, S. J. & MOUNTAIN, G. M. (2011) The SMART rehabilitation system for stroke self-management: issues and challenges for evidence-based health technology research. *Journal of Physical Therapy Education*, 25, 48-53.
- MAYS, N. & POPE, C. (2000) Assessing quality in qualitative research. *Bmj*, 320, 50-52.
- MAYO, N. E., MACKAY-LYONS, M. J., SCOTT, S. C., MORIELLO, C. & BROPHY, J. (2013). A randomized trial of two home-based exercise programmes to improve functional walking post-stroke. *Clinical rehabilitation*, 27, 659-671.
- MCCLELLAN, R. & ADA, L. 2004. A six-week, resource-efficient mobility program after discharge from rehabilitation improves standing in people affected by stroke: Placebo-controlled, randomised trial. *Australian Journal of Physiotherapy*, 50, 163-167.
- MCCLUSKEY, A., VRATISISTAS-CURTO, A. & SCHURR, K. (2013) Barriers and enablers to implementing multiple stroke guideline recommendations: a qualitative study. *BMC health services research*, 13, 1-13.
- MCKENNA, S., JONES, F., GLENFIELD, P. & LENNON, S. (2013) Bridges self-management program for people with stroke in the community: A feasibility randomized controlled trial. *International Journal of Stroke*.
- MCKEVITT, C., FUDGE, N., REDFERN, R., SHELDENKAR, A., CRICHTON, S. & WOLFE, C. (2010) The UK Stroke Survivor Needs Survey. London, UK, The Stroke Association
- MCMURDO, M. E. (2000) A healthy old age: realistic or futile goal? *BMJ: British Medical Journal*, 321, 1149.
- MEAD, G. E., GREIG, C. A., CUNNINGHAM, I., LEWIS, S. J., DINAN, S., SAUNDERS, D. H., FITZSIMONS, C. & YOUNG, A. (2007). Stroke: a randomized trial of exercise or relaxation. *Journal of the American Geriatrics Society*, 55, 892-899.
- MEAD, N. & BOWER, P. (2000) Patient-centredness: a conceptual framework and review of the empirical literature. *Social science & medicine*, 51, 1087-1110.
- MEAD, N. & BOWER, P. (2002) Patient-centred consultations and outcomes in primary care: a review of the literature. *Patient education and counseling*, 48, 51-61.
- MEEK, C., POLLOCK, A., POTTER, J. & LANGHORNE, P. (2003) A systematic review of exercise trials post stroke. *Clinical Rehabilitation*, 17, 6.
- MERRIAM, S. B. (2009) *Qualitative research: A guide to design and implementation*, John Wiley & Sons.
- MILTNER, W. H. R., BAUDER, H., SOMMER, M., DETTMERS, C. & TAUB, E. (1999) Effects of constraint-induced movement therapy on patients with chronic motor deficits after stroke: a replication. *Stroke*, 30, 586.
- MINEMAWARI, Y. & KATO, T. (1999) [The radar chart method and its analysis as a comprehensive geriatric assessment system for elderly disabled patients]. *Nihon Ronen Igakkai zasshi. Japanese journal of geriatrics*, 36, 206-212.
- MOLLOY, G. J., JOHNSTON, M., JOHNSTON, D. W., POLLARD, B., MORRISON, V., BONETTI, D., JOICE, S. & MACWALTER, R. (2008) Spousal caregiver confidence and recovery from ambulatory activity limitations in stroke survivors. *Health Psychology*, 27, 286.
- MONAGHAN, J., CHANNELL, K., MCDOWELL, D. & SHARMA, A. (2005) Improving patient and carer communication, multidisciplinary team working and goal-setting in stroke rehabilitation. *Clinical Rehabilitation*, 19, 194-199.
- MORELAND, J. D., GOLDSMITH, C. H., HUIJBREGTS, M. P., ANDERSON, R. E., PRENTICE, D. M., BRUNTON, K. B., O'BRIEN, M. A. & TORRESIN, W. D. (2003). Progressive resistance strengthening exercises after stroke: a single-blind randomized controlled trial 1, 4. *Archives of physical medicine and rehabilitation*, 84, 1433-1440.
- MORRIS, J. H., OLIVER, T., KROLL, T., JOICE, S. & WILLIAMS, B. (2014) From physical and functional to continuity with pre-stroke self and participation in valued activities: A qualitative exploration of stroke survivors', carers' and physiotherapists' perceptions of physical activity after stroke. *Disability & Rehabilitation*, 1-14.
- MORRIS, M. G. & VENKATESH, V. (2000) Age differences in technology adoption decisions: Implications for a changing work force. *Personnel psychology*, 53, 375-403.
- MORRIS, S. L., DODD, K. J. & MORRIS, M. E. (2004) Outcomes of progressive resistance strength training following stroke: a systematic review. *Clinical Rehabilitation*, 18, 27.
- MORSE, J. M., BARRETT, M., MAYAN, M., OLSON, K. & SPIERS, J. (2008) Verification strategies for establishing reliability and validity in qualitative research. *International Journal of Qualitative Methods*, 1, 13-22.
- MOUNTAIN, G., WILSON, S., ECCLESTON, C., MAWSON, S., HAMMERTON, J., WARE, T., ZHENG, H., DAVIES, R., BLACK, N. & HARRIS, N. (2010) Developing and testing a

- telerehabilitation system for people following stroke: issues of usability. *Journal of Engineering Design*, 21, 223-236.
- MRC (2000) A framework for development and evaluation of RCTs for complex interventions to improve health. *London, Medical Research Council.*
- MRC (2009) Developing and evaluating complex interventions: new guidance. *Medical Research Council.*
- MSRWG (2010). VA/DOD Clinical practice guideline for the management of stroke rehabilitation. *Journal of rehabilitation research and development*, 47, 1.
- MURTEZANI, A., HUNDOZI, H., GASHI, S., OSMANI, T., KRASNIQI, V. & RAMA, B. (2009) Factors associated with reintegration to normal living after stroke. *Women*, 18, 40.9.
- NADEAU, S. E., WU, S. S., DOBKIN, B. H., AZEN, S. P., ROSE, D. K., TILSON, J. K., CEN, S. Y. & DUNCAN, P. W. (2013). Effects of task-specific and impairment-based training compared with usual care on functional walking ability after inpatient stroke rehabilitation LEAPS Trial. *Neurorehabilitation and neural repair*, 27, 370-380.
- NAO (2010a) Department of Health: Progress in improving stroke care. London, United Kingdom, National Audit Office.
- NAO (2010b) Progress in improving stroke care: Report on findings from our modelling of stroke care provision. IN OFFICE, N. A. (Ed.), National Audit Office.
- NASR, N., TORSI, S., MAWSON, S., WRIGHT, P., MOUNTAIN, G. & IEEE (2009) *Self management of stroke supported by assistive technology.*
- NASR, N., TORSI, S. & WRIGHT, P. (2010) Supporting the self-management of stroke by applying a user-centred design approach. *Clin Rehabil*, 24, 276-87.
- NASREDDINE, Z. S., PHILLIPS, N. A., BÉDIRIAN, V., CHARBONNEAU, S., WHITEHEAD, V., COLLIN, I., CUMMINGS, J. L. & CHERTKOW, H. (2005) The Montreal Cognitive Assessment, MoCA: a brief screening tool for mild cognitive impairment. *Journal of the American Geriatrics Society*, 53, 695-699.
- NEUBERT, S., SABARIEGO, C., STIER-JARMER, M. & CIEZA, A. (2011) Development of an ICF-based patient education program. *Patient Education and Counseling*, 84, e13-e17.
- NEWBOULD, J., TAYLOR, D. & BURY, M. (2006) Lay-led self-management in chronic illness: a review of the evidence. *Chronic illness*, 2, 249.
- NHS (2010) Expert Patient Programme. National Health Service.
- NICE (2012a) Stroke - NICE Pathways. London: NICE.
- NICE (2012b) Stroke quality standard. London: NICE.
- NICE (2013) *Stroke rehabilitation: long-term rehabilitation after stroke*, London, the United Kingdom, National Institute for Health and Care Excellence.
- NILSSON, L., CARLSSON, J., DANIELSSON, A., FUGL-MEYER, A., HELLSTRÖM, K., KRISTENSEN, L., SJÖLUND, B., SUNNERHAGEN, K. S. & GRIMBY, G. (2001). Walking training of patients with hemiparesis at an early stage after stroke: a comparison of walking training on a treadmill with body weight support and walking training on the ground. *Clinical Rehabilitation*, 15, 515-527.
- O'CATHAIN, A., MURPHY, E. & NICHOLL, J. (2008) The quality of mixed methods studies in health services research. *Journal of Health Services Research & Policy*, 13, 92-98.
- O'CATHAIN, A., MURPHY, E. & NICHOLL, J. (2010) Three techniques for integrating data in mixed methods studies. *Bmj*, 341.
- OHMAN, A. (2005) Qualitative methodology for rehabilitation research. *Journal of rehabilitation medicine*, 37, 273-280.
- ONS (2009) General Lifestyle Survey - 2009 Appendices. UK.
- ONS (2011) Older People's Day 2011. IN STATISTICS, O. F. N. (Ed.) UK, Office for National Statistics.
- ONWUEGBUZIE, A. J., JOHNSON, R. B. & COLLINS, K. M. (2009) Call for mixed analysis: A philosophical framework for combining qualitative and quantitative approaches. *International Journal of Multiple Research Approaches*, 3, 114-139.
- ORRELL, A. J., EVES, F. F. & MASTERS, R. S. (2006) Motor learning of a dynamic balancing task after stroke: implicit implications for stroke rehabilitation. *Physical Therapy*, 86, 369-380.
- OVRETVEIT, J. (2003) *Evaluating health interventions: an introduction to evaluation of health treatments, services, policies and organizational interventions*, Berkshire, England, Open University Press.
- PAGE, S. J., SISTO, S., LEVINE, P., JOHNSTON, M. V. & HUGHES, M. (2002). Modified constraint induced therapy: a randomized feasibility and efficacy study. *Journal of rehabilitation research and development*, 38, 583.

- PAINTER, J. E., BORBA, C. P. C., HYNES, M., MAYS, D. & GLANZ, K. (2008) The use of theory in health behavior research from 2000 to 2005: a systematic review. *Annals of Behavioral Medicine*, 35, 358-362.
- PALMER, R., ENDERBY, P., COOPER, C., LATIMER, N., JULIOUS, S., PATERSON, G., DIMAIRO, M., DIXON, S., MORTLEY, J. & HILTON, R. (2012) Computer Therapy Compared With Usual Care for People With Long-Standing Aphasia Poststroke A Pilot Randomized Controlled Trial. *Stroke*, 43, 1904-1911.
- PALMER, R., ENDERBY, P. & PATERSON, G. (2013) Using computers to enable self-management of aphasia therapy exercises for word finding: the patient and carer perspective. *International journal of language & communication disorders*.
- PANG, M. Y. C., ENG, J. J., DAWSON, A. S. & GYLFADÓTTIR, S. (2006) The use of aerobic exercise training in improving aerobic capacity in individuals with stroke: a meta-analysis. *Clinical Rehabilitation*, 20, 97.
- PANG, M. Y. C., ENG, J. J., DAWSON, A. S., MCKAY, H. A. & HARRIS, J. E. (2005) A Community-Based Fitness and Mobility Exercise Program for Older Adults with Chronic Stroke: A Randomized, Controlled Trial. *Journal of the American Geriatrics Society*, 53, 1667-1674.
- PARKER, J., MAWSON, S., MOUNTAIN, G., NASR, N., DAVIES, R. & ZHENG, H. (2013) The provision of feedback through computer-based technology to promote self-managed post-stroke rehabilitation in the home. *Disability and Rehabilitation: Assistive Technology*, 1-10.
- PARKER, J., MAWSON, S., MOUNTAIN, G., NASR, N. & ZHENG, H. (2014) Stroke patients' utilisation of extrinsic feedback from computer-based technology in the home: a multiple case study realistic evaluation. *BMC Medical Informatics and Decision Making*, 14, 46.
- PARRY, R. (2004) Communication during goal-setting in physiotherapy treatment sessions. *Clinical Rehabilitation*, 18, 668-682.
- PARTY, I. S. W. (2012) *National clinical guideline for stroke*, Royal College of Physicians of London.
- PAWSON, R. (2006) *Evidence-based policy: A realist perspective*, Sage.
- PAWSON, R. (2013) *The science of evaluation: a realist manifesto*, Sage.
- PAWSON, R. & TILLEY, N. (1997) *Realistic evaluation*, Sage.
- PETER S, V. P., PRACHI B, ASHA K, JOSE L, RAMON LF, ALASTAIR G, MIKE R AND STEVEN A (2010) Stroke Statistics 2009. British Heart Foundation and Stroke Association.
- PEURALA, S. H., AIRAKSINEN, O., HUUSKONEN, P., JÄKÄLÄ, P., JUHAKOSKI, M., SANDELL, K., TARKKA, I. M. & SIVENIUS, J. (2009). Effects of intensive therapy using gait trainer or floor walking exercises early after stroke. *Journal of Rehabilitation Medicine*, 41, 166-173.
- PEURALA, S. H., TARKKA, I. M., PITKÄNEN, K. & SIVENIUS, J. (2005). The effectiveness of body weight-supported gait training and floor walking in patients with chronic stroke. *Archives of physical medicine and rehabilitation*, 86, 1557-1564.
- PHILP, I., LOWLES, R., ARMSTRONG, G. & WHITEHEAD, C. (2002) Repeatability of standardized tests of functional impairment and well-being in older people in a rehabilitation setting. *Disability & Rehabilitation*, 24, 243-249.
- PINTER, M. M. & BRAININ, M. (2012) Rehabilitation after stroke in older people. *Maturitas*, 71, 104-108.
- PINTRICH, P. R. (2000) The role of goal orientation in self-regulated learning.
- PIRON, L., TONIN, P., TRIVELLO, E., BATTISTIN, L. & DAM, M. (2004) Motor tele-rehabilitation in post-stroke patients. *Informatics for Health and Social Care*, 29, 119-125.
- PIRON, L., TUROLLO, A., AGOSTINI, M., ZUCCONI, C., CORTESE, F., ZAMPOLINI, M., ZANNINI, M., DAM, M., VENTURA, L. & BATTAUZ, M. (2009) Exercises for paretic upper limb after stroke: a combined virtual-reality and telemedicine approach. *Journal of Rehabilitation Medicine*, 41, 1016-1020.
- POHL, M., MEHRHOLZ, J., RITSCHER, C. & RÜCKRIEM, S. 2002. Speed-dependent treadmill training in ambulatory hemiparetic stroke patients A randomized controlled trial. *Stroke*, 33, 553-558.
- PORTER, C. E. & DONTU, N. (2006) Using the technology acceptance model to explain how attitudes determine Internet usage: The role of perceived access barriers and demographics. *Journal of Business Research*, 59, 999-1007.
- PORTNEY, L. G. & WATKINS, M. P. (2009) *Foundations of clinical research: applications to practice 3rd edition*, New Jersey, USA, Pearson/Prentice Hall.
- POTEMPA, K., LOPEZ, M., BRAUN, L. T., SZIDON, J. P., FOGG, L. & TINCKNELL, T. (1995) Physiological outcomes of aerobic exercise training in hemiparetic stroke patients. *Stroke*, 26, 101-105.

- POWELL, H. & GIBSON PETER, G. (2002) Options for self-management education for adults with asthma. *Cochrane Database of Systematic Reviews*. Chichester, UK, John Wiley & Sons, Ltd.
- PRANGE, G. B., JANNINK, M. J. A., GROOTHUIS-OUDSHOORN, C. G. M., HERMENS, H. J. & IJZERMAN, M. J. (2006) Systematic review of the effect of robot-aided therapy on recovery of the hemiparetic arm after stroke. *Journal of Rehabilitation Research and Development*, 43, 171.
- PUUSTINEN, M. & PULKKINEN, L. (2001) Models of self-regulated learning: A review. *Scandinavian Journal of Educational Research*, 45, 269-286.
- RABIN, R. & CHARRO, F. (2001) EQ-SD: a measure of health status from the EuroQol Group. *Annals of medicine*, 33, 337-343.
- RATTRAY, J. & JONES, M. C. (2007) Essential elements of questionnaire design and development. *Journal of Clinical Nursing*, 16, 234-243.
- RCN (2012) *Using telehealth to monitor patients remotely: an RCN guide on using technology to complement nursing practice*, London, the United Kingdom, Royal College of Nursing.
- REEVES, D., KENNEDY, A., FULLWOOD, C., BOWER, P., GARDNER, C., GATELY, C., LEE, V., RICHARDSON, G. & ROGERS, A. (2008) Predicting who will benefit from an Expert Patients Programme self-management course. *British Journal of General Practice*, 58, 198-203.
- REINKENSMEYER, D. J., PANG, C. T., NESSLER, J. A. & PAINTER, C. C. (2002) Web-based telerehabilitation for the upper extremity after stroke. *Neural Systems and Rehabilitation Engineering, IEEE Transactions on*, 10, 102-108.
- RESNICK, B., MICHAEL, K., SHAUGHNESSY, M., KOPUNEK, S., NAHM, E. S. & MACKO, R. E. (2008) Motivators for treadmill exercise after stroke. *Topics in Stroke Rehabilitation*, 15, 494-502.
- RIAZI, A., ASPDEN, T. & JONES, F. (2014) Stroke self-efficacy questionnaire: a Rasch-refined measure of confidence post stroke. *Journal of Rehabilitation Medicine*, 46, 406-412.
- RICHARDSON, G., KENNEDY, A., REEVES, D., BOWER, P., LEE, V., MIDDLETON, E., GARDNER, C., GATELY, C. & ROGERS, A. (2008) Cost effectiveness of the Expert Patients Programme (EPP) for patients with chronic conditions. *Journal of Epidemiology & Community Health*, 62, 361-7.
- RIMMER, J. H., WANG, E. & SMITH, D. (2008) Barriers associated with exercise and community access for individuals with stroke. *Journal of Rehabilitation Research and Development*, 45, 315.
- RING, H., FEDER, M., SCHWARTZ, J. & SAMUELS, G. (1997) Functional measures of first-stroke rehabilitation inpatients: usefulness of the Functional Independence Measure total score with a clinical rationale. *Archives of physical medicine and rehabilitation*, 78, 630-635.
- RITCHIE, J. & LEWIS, J. (2003) *Qualitative research practice: A guide for social science students and researchers*, Sage Publications Ltd.
- ROBINSON, J. & ELKAN, R. (2000) *Health needs assessment*, Churchill Livingstone.
- ROLFE, G. (2006) Validity, trustworthiness and rigour: quality and the idea of qualitative research. *Journal of Advanced Nursing*, 53, 304-310.
- ROSEWILLIAM, S., ROSKELL, C. A. & PANDYAN, A. (2011) A systematic review and synthesis of the quantitative and qualitative evidence behind patient-centred goal setting in stroke rehabilitation. *Clinical Rehabilitation*, 25, 501-514.
- ROSSIER, P. & WADE, D. T. (2001) Validity and reliability comparison of 4 mobility measures in patients presenting with neurologic impairment. *Archives of Physical Medicine and Rehabilitation*, 82, 9-13.
- RUBIN, M. N., WELLIK, K. E., CHANNER, D. D. & DEMAERSCHALK, B. M. (2013) Systematic review of telestroke for post-stroke care and rehabilitation. *Current atherosclerosis reports*, 15, 1-7.
- RYCROFT-MALONE, J. & BUCKNALL, T. (2011) *Models and frameworks for implementing evidence-based practice: Linking evidence to action*, John Wiley & Sons.
- RYCROFT-MALONE, J., MCCORMACK, B., HUTCHINSON, A. M., DECORBY, K., BUCKNALL, T. K., KENT, B., SCHULTZ, A., SNELGROVE-CLARKE, E., STETLER, C. B. & TITLER, M. (2012) Realist synthesis: illustrating the method for implementation research. *Implementation Science*, 7, 33.
- RYCROFT-MALONE, J. (2006). The politics of the evidencebased practice movements Legacies and current challenges. *Journal of Research in Nursing*, 11, 95-108.
- RYCROFT-MALONE, J., SEERS, K., TITCHEN, A., HARVEY, G., KITSON, A. & MCCORMACK, B. (2004) What counts as evidence in evidence-based practice? *Journal of Advanced Nursing*, 47, 81-90.

- SAARY, M. J. (2008) Radar plots: a useful way for presenting multivariate health care data. *Journal of clinical epidemiology*, 61, 311-317.
- SABARIEGO, C., BARRERA, A. E., NEUBERT, S., STIER-JARMER, M., BOSTAN, C. & CIEZA, A. (2013) Evaluation of an ICF-based patient education programme for stroke patients: A randomized, single-blinded, controlled, multicentre trial of the effects on self-efficacy, life satisfaction and functioning. *British journal of health psychology*, 18, 707-728.
- SAKA, Ö., MCGUIRE, A. & WOLFE, C. (2009) Cost of stroke in the United Kingdom. *Age and ageing*, 38, 27-32.
- SALBACH, N. M., MAYO, N. E., ROBICHAUD-EKSTRAND, S., HANLEY, J. A., RICHARDS, C. L. & WOOD-DAUPHINEE, S. (2006) Balance self-efficacy and its relevance to physical function and perceived health status after stroke. *Archives of physical medicine and rehabilitation*, 87, 364-370.
- SALTER, K., JUTAI, J., FOLEY, N., HELLINGS, C. & TEASELL, R. (2006) Identification of aphasia post stroke: A review of screening assessment tools. *Brain Injury*, 20, 559-568.
- SANDELOWSKI, M., VOILS, C. I. & KNAFL, G. (2009) On quantizing. *Journal of mixed methods research*, 3, 208-222.
- SANDERSON, C. J. & GRUEN, R. (2006) *Analytical models for decision-making*, McGraw-Hill International.
- SAPOSNIK, G., BLACK, S. E., HAKIM, A., FANG, J., TU, J. V. & KAPRAL, M. K. (2009) Age disparities in stroke quality of care and delivery of health services. *Stroke*, 40, 3328-3335.
- SATINK, T., CUP, E. H., DE SWART, B. J. & NIJHUIS-VAN DER SANDEN, M. W. (2014) How is self-management perceived by community living people after a stroke? A focus group study. *Disability & Rehabilitation*, 1-8.
- SAUNDERS, D.H. & MEAD, G. IN MEAD, G. & WIJCK F. V. (2013) *Exercise and Fitness Training after Stroke*. Churchill livingstone, Elsevier. pp.96-99, 191-195
- SAUNDERS, D., SANDERSON, M., BRAZZELLI, M., GREIG, C. & MEAD, G. (2013). Physical fitness training for stroke patients (Review), *the Cochrane Library*, Cochrane Collaboration.
- SCHAECHTER, J. D., KRAFT, E., HILLIARD, T. S., DIJKHUIZEN, R. M., BENNER, T., FINKLESTEIN, S. P., ROSEN, B. R. & CRAMER, S. C. (2002) Motor recovery and cortical reorganization after constraint-induced movement therapy in stroke patients: a preliminary study. *Neurorehabilitation and Neural Repair*, 16, 326.
- SCHAPER, L. K. & PERVAN, G. P. (2007) ICT and OTs: A model of information and communication technology acceptance and utilisation by occupational therapists. *International Journal of Medical Informatics*, 76, S212-S221.
- SCHMELER, M. R., SCHEIN, R. M., MCCUE, M. & BETZ, K. (2009) Telerehabilitation clinical and vocational applications for assistive technology: research, opportunities, and challenges. *International Journal of Telerehabilitation*, 1, 59-72.
- SCHMIDT, R. A. (1991) Motor learning principles for physical therapy. *Contemporary Management of Motor Control Problems: Proceedings of the II-STEP Conference*. Alexandria, Va: Foundation for Physical Therapy.
- SCHMIDT, R. A. (2008) *Motor learning and performance: a situation-based learning approach*, Human Kinetics.
- SCHREIER, M. (2012) *Qualitative content analysis in practice*, SAGE Publications Limited.
- SCHUNK, D. H. (1989) Social cognitive theory and self-regulated learning. *Self-regulated learning and academic achievement*. Springer.
- SCHUNK, D. H. (1990) Goal setting and self-efficacy during self-regulated learning. *Educational psychologist*, 25, 71-86.
- SCHUNK, D. H. & ZIMMERMAN, B. J. (2012) *Motivation and self-regulated learning: Theory, research, and applications*, Routledge.
- SCHWAMM, L. H., HOLLOWAY, R. G., AMARENCO, P., AUDEBERT, H. J., BAKAS, T., CHUMBLER, N. R., HANDSCHU, R., JAUCH, E. C., KNIGHT, W. A. & LEVINE, S. R. (2009) A review of the evidence for the use of telemedicine within stroke systems of care. *Stroke*, 40, 2616-2634.
- SCOTLAND, A. (2011) A review of telehealth in Scotland. Edinburgh, the United Kingdom, Auditor General for Scotland.
- SHAUGHNESSY, M. & RESNICK, B. M. (2009) Using theory to develop an exercise intervention for patients post stroke. *Topics in stroke rehabilitation*, 16, 140-146.
- SHAUGHNESSY, M., RESNICK, B. M. & MACKO, R. F. (2006) Testing a Model of Post-Stroke Exercise Behavior. *Rehabilitation nursing*, 31, 15-21.
- SHENTON, A. K. (2004) Strategies for ensuring trustworthiness in qualitative research projects. *Education for information*, 22, 63-76.

- SHEPHERD, R. B. (2001) Exercise and training to optimize functional motor performance in stroke: Driving neural reorganization? *Neural Plasticity*, 8, 121-130.
- SHERWOOD, N. E. & JEFFERY, R. W. (2000). The behavioral determinants of exercise: implications for physical activity interventions. *Annual review of nutrition*, 20, 21-44.
- SIGN (2010) *Management of patients with Stroke: Rehabilitation, Prevention and Management of Complications and Discharge Planning: a national clinical guideline*, Edinburgh, the United Kingdom, Scottish Intercollegiate Guidelines Network, Healthcare Improvement Scotland.
- SILVA, D. D. (2011) Evidence: Helping people help themselves. *A review of the evidence considering whether it is worthwhile to support self-management* London, UK, The Evidence Centre.
- SILVA, D. D. (2014) Helping measure person-centred care IN CENTRE, T. E. (Ed.) London, the UK, Health Foundation.
- SILVERMAN, D. (2009) *Doing qualitative research*, Sage Publications Ltd.
- SILVERMAN, D. (2010) *Doing qualitative research: A practical handbook*, London, SAGE Publications Limited.
- SILVESTRE, A.-L., SUE, V. M. & ALLEN, J. Y. (2009) If you build it, will they come? The Kaiser Permanente model of online health care. *Health Affairs*, 28, 334-344.
- SINGH, D., HAM, C., INNOVATION, N. I. F., IMPROVEMENT & CENTRE, U. O. B. H. S. M. (2006) *Improving care for people with long-term conditions: a review of UK and international frameworks*, University of Birmingham. Health services management centre.
- SINGH, J. (2013) Critical appraisal skills programme. *Journal of Pharmacology and Pharmacotherapeutics*, 4, 76.
- SKIDMORE, E. R. (2003) Functional Assessment After Stroke: Examining Outcome Models Using the International Classification of Functioning, Disability and Health. University of Pittsburgh.
- SMITH, M. K. (2004) Malcolm Knowles, informal adult education, self-direction and andragogy. In Fed, the Encyclopedia of informal education.
- SMITH, T., GILDEH, N. & HOLMES, C. (2007) The Montreal Cognitive Assessment: validity and utility in a memory clinic setting. *Canadian Journal of Psychiatry*, 52, 329.
- SNELL, R. S. (2009) *Clinical neuroanatomy*, Lippincott Williams & Wilkins.
- SORINOLA, I., POWIS, I. & WHITE, C. 2014. Does additional exercise improve trunk function recovery in stroke patients? A meta-analysis. *NeuroRehabilitation*, 35, 205-213.
- SPARKES, V. (2000) Physiotherapy for Stroke Rehabilitation: A need for evidence-based handling techniques: Literature review. *Physiotherapy*, 86, 348-356.
- SPILLANE, V., BYRNE, M. C., BYRNE, M., LEATHEM, C. S., O'MALLEY, M. & CUPPLES, M. E. (2007) Monitoring treatment fidelity in a randomized controlled trial of a complex intervention. *Journal of advanced nursing*, 60, 343-352.
- STARROST, K., GEYH, S., TRAUTWEIN, A., GRUNOW, J., CEBALLOS-BAUMANN, A., PROSIEGEL, M., STUCKI, G. & CIEZA, A. (2008) Interrater reliability of the extended ICF core set for stroke applied by physical therapists. *Physical Therapy*, 88, 841-851.
- STINEMAN, M. G., XIE, D., PAN, Q., KURICHI, J. E., SALIBA, D. & STREIM, J. (2011) Activity of Daily Living Staging, Chronic Health Conditions, and Perceived Lack of Home Accessibility Features for Elderly People Living in the Community. *Journal of the American Geriatrics Society*.
- STOLLER, O., DE BRUIN, E. D., KNOLS, R. H. & HUNT, K. J. 2012. Effects of cardiovascular exercise early after stroke: systematic review and meta-analysis. *BMC neurology*, 12, 1.
- STRADLING D.A (2009) Telestroke: State of the Science and Steps for Implementation. *Critical Care Nursing Clinics of North America*, 21, 541-548.
- STUART, M., BENVENUTI, F., MACKO, R., TAVIANI, A., SEGENNI, L., MAYER, F., SORKIN, J. D., STANHOPE, S. J., MACELLARI, V. & WEINRICH, M. (2009) Community-based adaptive physical activity program for chronic stroke: feasibility, safety, and efficacy of the Empoli model. *Neurorehabilitation and neural repair*.
- STUCKI, G. & MELVIN, J. (2007) The International Classification of Functioning, Disability and Health: a unifying model for the conceptual description of physical and rehabilitation medicine. *Journal of Rehabilitation Medicine*, 39, 286-292.
- SUBRAMANIAN, S. K., MASSIE, C. L., MALCOLM, M. P. & LEVIN, M. F. (2010) Does provision of extrinsic feedback result in improved motor learning in the upper limb poststroke? A systematic review of the evidence. *Neurorehabilitation and Neural Repair*, 24, 113-124.
- SULER, J. (2001) Assessing a person's suitability for online therapy: The ISMHO clinical case study group. *Cyberpsychology & behavior*, 4, 675-679.
- SWEENEY, T., SHEAHAN, N., RICE, I., MALONE, J., WALSH, J. & COAKLEY, D. (1993) Communication disorders in a hospital elderly population. *Clinical Rehabilitation*, 7, 113-117.

- TARKKA, I. M., PITKÄNEN, K. & SIVENIUS, J. (2005) Paretic hand rehabilitation with constraint-induced movement therapy after stroke. *American Journal of Physical Medicine & Rehabilitation*, 84, 501.
- TASHAKKORI, A. & TEDDLIE, C. (2010) *Sage handbook of mixed methods in social & behavioral research (2nd edition)*, Sage.
- TAYLOR, D., STONE, S., HUIJBREGTS, M. & TAYLOR, D. (2012) Remote participants' experiences with a group-based stroke self-management program using videoconference technology. *Rural Remote Health*, 12, 1-15.
- TAYLOR, D. M., CAMERON, J. I., WALSH, L., MCEWEN, S., KAGAN, A., STREINER, D. L. & HUIJBREGTS, M. P. J. (2009) Exploring the feasibility of videoconference delivery of a self-management program to rural participants with stroke. *Telemedicine and e-Health*, 15, 646-654.
- TAYLOR, E. & JONES, F. (2014) Lost in translation: exploring therapists' experiences of providing stroke rehabilitation across a language barrier. *Disability & Rehabilitation*, 1-9.
- TAYLOR, G. H., TODMAN, J. & BROOMFIELD, N. M. (2011) Post-stroke emotional adjustment: A modified social cognitive transition model. *Neuropsychological rehabilitation*, 21, 808-824.
- TAYLOR, S. & TODD, P. A. (1995) Understanding information technology usage: A test of competing models. *Information systems research*, 6, 144-176.
- TEDDLIE, C. & TASHAKKORI, A. (2009) *Foundations of mixed methods research: Integrating quantitative and qualitative approaches in the social and behavioral sciences*, Sage Publications Inc.
- TEIXEIRA-SALMELA, L. F., NADEAU, S., MCBRIDE, I. & OLNEY, S. J. (2001) Effects of muscle strengthening and physical conditioning training on temporal, kinematic and kinetic variables during gait in chronic stroke survivors. *Journal of Rehabilitation Medicine*, 33, 53-60.
- TEIXEIRA-SALMELA, L. F., OLNEY, S. J., NADEAU, S. & BROUWER, B. (1999) Muscle strengthening and physical conditioning to reduce impairment and disability in chronic stroke survivors* 1,* 2. *Archives of Physical Medicine and Rehabilitation*, 80, 1211-1218.
- TEMPEST, S. & MCINTYRE, A. (2006) Using the ICF to clarify team roles and demonstrate clinical reasoning in stroke rehabilitation. *Disability & Rehabilitation*, 28, 663-667.
- THIELMAN, G. T., DEAN, C. M. & GENTILE, A. (2004) Rehabilitation of reaching after stroke: Task-related training versus progressive resistive exercise^{1,*} 1. *Archives of Physical Medicine and Rehabilitation*, 85, 1613-1618.
- THURMOND, V. A. (2001) The point of triangulation. *Journal of Nursing Scholarship*, 33, 253-258.
- TIMMERMANS, A. A., SPOOREN, A. I., KINGMA, H. & SELEN, H. A. (2010) Influence of task-oriented training content on skilled arm-hand performance in stroke: a systematic review. *Neurorehabilitation and Neural Repair*, 24, 858-870.
- TRIALISTS'COLLABORATION, S. U. (1997) How do stroke units improve patient outcomes? A collaborative systematic review of the randomized trials. *Stroke*, 28, 2139-2144.
- TRUELSEN, T., PIECHOWSKI JÓ WIAK, B., BONITA, R., MATHERS, C., BOGOUSLAVSKY, J. & BOYSEN, G. (2006) Stroke incidence and prevalence in Europe: a review of available data. *European journal of neurology*, 13, 581-598.
- TSENG, C. N., CHEN, C. C. H., WU, S. C. & LIN, L. C. (2007) Effects of a range-of-motion exercise programme. *Journal of Advanced Nursing*, 57, 181-191.
- UN (2009) World Population Prospect: The 2008 Revision. IN DEPARTMENT OF ECONOMIC AND SOCIAL AFFAIRS, P. D. (Ed.) New York, United Nations
- USHER, E. L. & PAJARES, F. (2008) Self-Efficacy for Self-Regulated Learning A Validation Study. *Educational and Psychological Measurement*, 68, 443-463.
- ÜSTÜN, T. B., CHATTERJI, S., BICKENBACH, J., KOSTANJSEK, N. & SCHNEIDER, M. (2003) The International Classification of Functioning, Disability and Health: a new tool for understanding disability and health. *Disability & Rehabilitation*, 25, 565-571.
- VADIEE, M. (2012) The UK "Expert Patient Program" and self-care in chronic disease management: an analysis. *European Geriatric Medicine*, 3, 201-205.
- VALLANCE, J. K., TAYLOR, L. M. & LAVALLEE, C. (2008) Suitability and readability assessment of educational print resources related to physical activity: implications and recommendations for practice. *Patient education and counseling*, 72, 342-349.
- VAN DE PORT, I. G. L., WOOD-DAUPHINEE, S., LINDEMAN, E. & KWAKKEL, G. (2007) Effects of exercise training programs on walking competency after stroke: a systematic review. *American Journal of Physical Medicine & Rehabilitation*, 86, 935.
- VAN DER LEE, J. H. (2001). Constraint-induced therapy for stroke: more of the same or something completely different? *Current opinion in neurology*, 14, 741-744.

- VAN VELDEN, M. E., SEVERENS, J. L. & NOVAK, A. (2005) Economic evaluations of healthcare programmes and decision making. *Pharmacoeconomics*, 23, 1075-1082.
- VAN VLIET, P. M. & WULF, G. (2006) Extrinsic feedback for motor learning after stroke: What is the evidence? *Disability & Rehabilitation*, 28, 831-840.
- VEGA, G., VEGA, M., ALAJARÍN, L. I., PORTERO, B., RUÍZ, T., RUIZ, V., MARÍN, C., LÁZARO, C., GÓMEZ, M. & CONDE, F. (2014) Profile of the Patient Who Refuses to Participate in the Expert Patients Program. *Qualitative health research*, 24, 846-859.
- VENKATESH, V. (2000) Determinants of perceived ease of use: Integrating control, intrinsic motivation, and emotion into the technology acceptance model. *Information systems research*, 11, 342-365.
- VENKATESH, V. & DAVIS, F. D. (2000) A theoretical extension of the technology acceptance model: Four longitudinal field studies. *Management science*, 186-204.
- VOLPATO, S., ONDER, G., CAVALIERI, M., GUERRA, G., SIOULIS, F., MARALDI, C., ZULIANI, G. & FELLIN, R. (2007) Characteristics of nondisabled older patients developing new disability associated with medical illnesses and hospitalization. *Journal of General Internal Medicine*, 22, 668-674.
- VON KORFF, M., GLASGOW, R. E. & SHARPE, M. (2002) Organising care for chronic illness. *Bmj*, 325, 92-94.
- WADE, D. (1999) Goal planning in stroke rehabilitation: how? *Topics in Stroke Rehabilitation*, 6, 16-36.
- WADE, D. T. (2009) Goal setting in rehabilitation: an overview of what, why and how. *Clinical Rehabilitation*, 23, 291-295.
- WADE, D. T. & DE JONG, B. A. (2000) Recent advances: Recent advances in rehabilitation. *BMJ: British Medical Journal*, 320, 1385.
- WAGNER, E. H. (1998) Chronic disease management: what will it take to improve care for chronic illness? *Effective clinical practice: ECP*, 1, 2.
- WALES, L. G. D. U. (2009) A guide to questionnaire design. IN WALES, L. G. D. U. (Ed.) Cardiff, Local Government Data Unit Wales.
- WALKER, K. 2003. Why evidence-based practice now?: a polemic¹. *Nursing Inquiry*, 10, 145-155.
- WALKER, M. F., SUNNERHAGEN, K. S. & FISHER, R. J. 2013. Evidence-based community stroke rehabilitation. *Stroke*, 44, 293-297.
- WALLER, S. M. C. & WHITALL, J. (2005) Hand dominance and side of stroke affect rehabilitation in chronic stroke. *Clinical Rehabilitation*, 19, 544.
- WANG, R., LAGAKOS, S. W., WARE, J. H., HUNTER, D. J. & DRAZEN, J. M. (2007) Statistics in medicine—reporting of subgroup analyses in clinical trials. *New England Journal of Medicine*, 357, 2189-2194.
- WANG, Y. S., WU, M. C. & WANG, H. Y. (2009) Investigating the determinants and age and gender differences in the acceptance of mobile learning. *British Journal of Educational Technology*, 40, 92-118.
- WEINSTEIN, N. D. (1993) Testing four competing theories of health-protective behavior. *Health Psychology*, 12, 324.
- WEST, D. (2010) Telehealth could save NHS £2bn. *Health Service Journal*.
- WEVERS, L., VAN DE PORT, I., VERMUE, M., MEAD, G. & KWAKKEL, G. (2009) Effects of Task-Oriented Circuit Class Training on Walking Competency After Stroke. *Stroke*, 40, 2450-2459.
- WHITE, J., JANSSEN, H., JORDAN, L. & POLLACK, M. (2015). Tablet technology during stroke recovery: a survivor's perspective. *Disability and rehabilitation*, 37, 1186-1192.
- WHO (2002) *Towards a common language for functioning, disability and health: ICF*, World Health Organisation.
- WHO (2010) *Telemedicine: opportunities and developments in Member States: report on the second global survey on eHealth*, Geneva, Switzerland, World Health Organization.
- WHO (2011a) Global burden of stroke. Geneva, Switzerland, World Health Organization.
- WHO (2011b) International Classification of Functioning, Disability and Health (ICF). Geneva, Switzerland, World Health Organization
- WHO (2011c) Stroke, Cerebrovascular accident. Geneva, Switzerland, World Health Organization.
- WHO (2012) Definition of an older or elderly person. *Health statistics and health information systems* <http://www.who.int/healthinfo/survey/ageingdefnolder/en/index.html> (accessed 21 June 2012). World Health Organisation.
- WHO (2013) *How to use the ICF: A practical manual for using the International Classification of Functioning, Disability and Health (ICF)*, Geneva, Switzerland, World Health Organization.
- WHO (2014) Patient safety. IN WHO (Ed.), World Health Organization.

- WILLIAMS, L. S., WEINBERGER, M., HARRIS, L. E., CLARK, D. O. & BILLER, J. (1999) Development of a stroke-specific quality of life scale. *Stroke*, 30, 1362-1369.
- WILSON, P. M., KENDALL, S. & BROOKS, F. (2007) The Expert Patients Programme: a paradox of patient empowerment and medical dominance. *Health & Social Care in the Community*, 15, 426-438.
- WITTICH, W., PHILLIPS, N., NASREDDINE, Z. S. & CHERTKOW, H. (2010) Sensitivity and Specificity of the Montreal Cognitive Assessment Modified for Individuals Who Are Visually Impaired. *Journal of Visual Impairment & Blindness*, 104, 9.
- WOLF, M. M. (1978) SOCIAL VALIDITY: THE CASE FOR SUBJECTIVE MEASUREMENT or HOW APPLIED BEHAVIOR ANALYSIS IS FINDING ITS HEART¹. *Journal of applied behavior analysis*, 11, 203-214.
- WOLFE, C. D., CRICHTON, S. L., HEUSCHMANN, P. U., MCKEVITT, C. J., TOSCHKE, A. M., GRIEVE, A. P. & RUDD, A. G. (2011) Estimates of outcomes up to ten years after stroke: analysis from the prospective South London Stroke Register. *PLoS Medicine / Public Library of Science*, 8.
- WONG, G., GREENHALGH, T., WESTHORP, G., BUCKINGHAM, J. & PAWSON, R. (2013) RAMESES publication standards: realist syntheses. *BMC medicine*, 11, 21.
- WOOD-DAUPHINEE, S., OPZOOMER, M., WILLIAMS, J., MARCHAND, B. & SPITZER, W. (1988) Assessment of global function: The Reintegration to Normal Living Index. *Archives of physical medicine and rehabilitation*, 69, 583-590.
- WU, C.-Y., CHUANG, L.-L., LIN, K.-C., LEE, S.-D. & HONG, W.-H. (2011) Responsiveness, minimal detectable change, and minimal clinically important difference of the Nottingham Extended Activities of Daily Living Scale in patients with improved performance after stroke rehabilitation. *Archives of physical medicine and rehabilitation*, 92, 1281-1287.
- YOUNG, J. & FORSTER, A. (2007) Review of stroke rehabilitation. *British Medical Journal*, 334, 86-90.
- ZHENG, H., DAVIES, R., STONE, T., WILSON, S., HAMMERTON, J., MAWSON, S. J., WARE, P., BLACK, N. D., HARRIS, N. & ECCLESTON, C. (2007) SMART rehabilitation: implementation of ICT platform to support home-based stroke rehabilitation. *Universal Access in Human Computer Interaction. Coping with Diversity*. Springer.
- ZHENG, H., DAVIES, R., ZHOU, H., HAMMERTON, J., MAWSON, S. J., WARE, P., BLACK, N. D., ECCLESTON, C., HU, H. & STONE, T. (2006) SMART project: application of emerging information and communication technology to home-based rehabilitation for stroke patients. *International Journal on Disability and Human Development*, 5, 271-276.
- ZIMMERMAN, B. J. (1990) Self-regulated learning and academic achievement: An overview. *Educational psychologist*, 25, 3-17.
- ZIMMERMAN, B. J. (2000) Self-Efficacy: An Essential Motive to Learn* 1. *Contemporary Educational Psychology*, 25, 82-91.
- ZIMMERMAN, B. J. (2002) Becoming a self-regulated learner: An overview. *Theory into practice*, 64-70.

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Appendix 1: Ethics approval letters:

a. Approval letter from the University of Sheffield in 2012



Cheryl Oliver
Ethics Committee Administrator

Regent Court
30 Regent Street
Sheffield S1 4DA
Telephone: +44 (0) 114 2220871
Fax: +44 (0) 114 272 4095 (non confidential)
Email: c.a.oliver@sheffield.ac.uk

Our ref: 0524/CAO

18 January 2012

Ying Man Law
SchARR

Dear Ying

The development of a remotely supported self-managed exercise intervention using available information and communication technologies (ICT's) for functional physical recovery post-stroke

Thank you for submitting the above research project for approval by the SchARR Research Ethics Committee. On behalf of the University Chair of Ethics who reviewed your project, I am pleased to inform you that on 18 January 2012 the project was approved on ethics grounds, on the basis that you will adhere to the documents that you submitted for ethics review.

The research must be conducted within the requirements of the hosting/employing organisation or the organisation where the research is being undertaken.

If during the course of the project you need to deviate significantly from the documents you submitted for review, please inform me since written approval will be required. Please also inform me should you decide to terminate the project prematurely.

Yours sincerely

A handwritten signature in cursive script, appearing to read "C. Oliver".

Cheryl Oliver
Ethics Committee Administrator

Appendix 1: Ethics approval letters:

b. Approval letter from the University of Sheffield in 2013



Kirsty Woodhead
Ethics Committee Administrator

Regent Court
30 Regent Street
Sheffield S1 4DA
Telephone: +44 (0) 114 222 5453
Fax: +44 (0) 114 272 4095 (non confidential)
Email: k.woodhead@sheffield.ac.uk

Our ref: 0524/CAO

4 June 2013

Mr Ying Man Law
SchARR

Dear Mr Law

The development of a remotely supported self-managed exercise intervention using available information and communication technologies (ICTs) for functional physical recovery post-stroke.

Thank you for submitting the above amended research project for approval by the SchARR Research Ethics Committee. On behalf of the University, I am pleased to inform you that the project with changes was approved.

If during the course of the project you need to deviate significantly from the documents you submitted for review, please inform me since written approval will be required.

Yours sincerely

Kirsty Woodhead
Ethics Committee Administrator

Appendix 2: NHS governance permission letters

a. NHS permission from Sheffield Teaching Hospitals trust in 2012 (page 1/2)



3rd October 2012

Sheffield Teaching Hospitals 

NHS Foundation Trust

Ying Man Law
Health Services Research Section
School of Health & Related Research (ScHARR)
University of Sheffield
Room 1.02, The Innovation Centre,
217 Portobello,
Sheffield,
S1 4DP

Dear Angus

Project Authorisation NHS Permission for Research to commence

STH ref:	STH16588	
NIHR CSP ref:	N/A	
REC ref:	0524/CAO	
MHRA ref:	CTA no.: N/A	EudraCT no.: N/A
Study title:	The development of a remotely supported self- managed exercise intervention using available information and communication technologies for functional physical recovery post-stroke	
Chief Investigator:	Ying Man Law, University of Sheffield	
Principal Investigator:	Yong Man Law, University of Sheffield	
Sponsor:	University of Sheffield	
Funder:	Unfunded	
URMS ref:	N/A	

The Research Department has received the required documentation as listed below:

- | | |
|--|--|
| 1. Sponsorship Agreement | Not applicable |
| Clinical Trial Agreement | Not applicable |
| Material Transfer Agreement | Not applicable |
| Funding Award Letter | Not applicable |
| 2. Monitoring Arrangements | Not applicable |
| 3. STH registration document | UREC application form
Y M Law undated |
| 4. Evidence of favourable scientific review | University of Sheffield
18 Jan 12 |
| 5. Protocol – final version | No version or date |
| 6. Participant Information sheet | No version or date |
| 7. Consent form | No version or date |
| 8. Letter of indemnity arrangements | Not applicable |
| Insurance Certificate | |
| 9. ARSAC certificate / IRMER assessment | Not applicable |

Ref: STH16588/AL



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Chairman: Tony Pedder, Chief Executive: Andrew Cash OBE

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hospitals

a. NHS permission from Sheffield Teaching Hospitals trust in 2012 (page 2/2)

10. Ethical review- Letter of approval from NHS REC/ UREC	University of Sheffield REC 18 Jan 12
11. Site Specific Assessment	Not applicable
12. Clinical Trial Authorisation from MHRA	Not applicable
13. Evidence of hosting approvals	STH Finance Form
- STH Principal Investigator	R Palmer 30 Aug 12
- Clinical Director	R Brown 03 Oct 12
- Research Finance	D Patel 25 sep 12
14. Honorary Contract/Letter of Access	Not applicable
15. Associated documents	
Cover letter	No version or date
Topic Guide	No version or date

This project has been reviewed by the Research Department. NHS permission for the above research to commence has been granted on the basis described in the application form, protocol and supporting documentation on the understanding that the study is conducted in accordance with the Research Governance Framework, GCP and Sheffield Teaching Hospitals policies and procedures (see attached appendix).

Additional conditions:

STH Sponsored CTIMP

You must notify your Research Co-ordinator [insert name], as soon as the first participant is [randomised/consented/screened] into the study so that appropriate monitoring arrangements can be made.

Yours sincerely



SP

Professor S Heller
Director of R&D, Sheffield Teaching Hospitals NHS Foundation Trust
Telephone +44 (0) 114 2265934
Fax +44 (0) 114 2265937

Appendix 2: NHS governance permission letters

b. NHS permission from Sheffield Teaching Hospitals trust in 2013 (page 1/2)

STH16588/SM/JDM

Sheffield Teaching Hospitals 
NHS Foundation Trust

10th June 2013

Ying Man Law
Health Services Research Section
School of Health & Related Research (SchARR)
University of Sheffield Room 1.02,
The Innovation Centre,
217 Portobello,
Sheffield, S1 4DP

Dear Mr Yin Man Law

Substantial Amendment Letter of Continued NHS permission

STH ref:	STH16588	
NIHR CSP ref:	N/A	
REC ref:	0524/CAO	
MHRA ref:	CTA no.: N/A	EudraCT no.: N/A
Study title:	The development of a remotely supported self- managed exercise intervention using available information and communication technologies for functional physical recovery post-stroke	
Principal Investigator:	Ying Man Law, University of Sheffield	
Sponsor:	University of Sheffield	
Funder:	Unfunded	
Amendment ref:	22 May 2013	

Thank you for submitting the following documents:

Document	Version/date
ScHARR REC approval of amendment	04 Jun 13
Notice of amendment	22 May 13
Research Proposal	V2, 30 Apr 13
Cover letter – first professional refinement	V2, 30 Apr 13
Cover letter – second professional refinement	V1, 30 Apr 13
Information sheet – Healthcare Professional	V2, 30 Apr 13
Information sheet – second professional refinement	V1, 30 Apr 13
Consent form – questionnaire with healthcare professionals	V2, 30 Apr 13
Questionnaire – first refinement of the manual, professional	V1, 28 May 13
Questionnaire – second professional refinement of the manual	V1, 28 May 13
ScHARR REC application form	V2, 30 Apr 13

b. NHS permission from Sheffield Teaching Hospitals trust in 2013 (page 2/2)

STH16588/SM/JDM

These have been reviewed by the Research Department who have no objection to the amendment and can confirm continued NHS permission for the study at STH.

Yours sincerely



Professor S Heller
Director of R&D, Sheffield Teaching Hospitals NHS Foundation Trust
Telephone +44 (0) 114 22 65934
Fax +44 (0) 114 22 65937

Cc Rebecca Palmer, UoS
Sarah Moll, STH

Appendix 3: Letters to participants

a. For phase 1



COVER LETTER

Dear Sir/Madam

Full Title of Study: The development of a remotely supported self-managed exercise intervention using available information and communication technologies (ICTs) for functional physical recovery post-stroke

Stroke is a major cause of chronic impairment and disability. It is the single largest cause of adult disability in England. Stroke has major impact on individual lives and health, and some physical consequences may affect the daily activities of stroke survivors in long term.

The purpose of this study is to develop a self-managed exercise intervention supported remotely using available information and communication technologies, for functional physical recovery post-stroke.

This research is for an educational qualification of a research student. The research student, Mr. Law, will be writing up this study as part of his PhD study. He and his supervisors are part of the School of Health and Related Research of the University of Sheffield.

The experience, ideas and opinions of stroke survivors and their caregivers for physical recovery for daily activities, after the stroke survivors have been discharged from the stroke rehabilitation services, will be collected in this project to develop a self-managed physical exercise program supported remotely using available ICTs for the stroke survivors in the future.

Stroke survivors with at least one physical disability affecting their daily activities and were discharged from specialist stroke rehabilitation services within 5 years, and their caregivers may be eligible to take part in this study.

Please refer to the enclosed information sheet for further relevant details of this study.

Further information is available from Mr Ying Man Law (postgraduate research student) at Room 1.02 of the Innovation Centre, Sheffield, the United Kingdom by email at ym.law@sheffield.ac.uk or by telephone (0) 114 222 26381 or (0)7423590298.

Thank you very much for your kind attention.

Yours faithfully,

Ying Man Law (Mr)
Postgraduate Research Student
Health Services Research
School of Health and Related Research
The University of Sheffield
ym.law@sheffield.ac.uk

Rebecca Palmer (Dr)
Principle Investigator & Lead Supervisor
Research Fellow
Health Services Research
School of Health and Related Research
The University of Sheffield
r.l.palmer@sheffield.ac.uk

Encl. Information sheet of this study

Appendix 3: Letters to participants

b. For phase 2



COVER LETTER *(second professional refinement version)*

Dear Sir/Madam

Full Title of Study: The development of a remotely supported self-managed exercise intervention using available information and communication technologies (ICTs) for functional physical recovery post-stroke

Hello. First of all, thank you very much for your interest in taking part in this study. A remotely self-managed physical exercise program has newly been developed for stroke survivors. The manual for using that program is enclosed with this letter for you to read.

The purpose of this survey is to evaluate the acceptability, feasibility and suitability of using this newly developed manual from professional perspective. Your professional judgement will help to determine the further research and clinical practice of this manual.

An information sheet and consent form are enclosed with this letter for you. Moreover, a questionnaire is designed to collect your deep professional comments and opinions. These are enclosed with this letter for your information. Please be reminded to sign and return the consent form to me via email once you have received it.

You are welcome to contact me for any enquiry regarding to this survey, the questionnaire and this project via phone or email at your convenience.

Further information is available from Mr Ying Man Law (PhD student) at Room 1.02 of the Innovation Centre, Sheffield, the United Kingdom by email at ym.law@sheffield.ac.uk or by telephone (0) 114 222 26381 or (0)7423590298.

Thank you very much for your kind attention.

Yours sincerely,

Ying Man Law (Mr)
PhD student
Health Services Research
School of Health and Related Research
The University of Sheffield
ym.law@sheffield.ac.uk

Rebecca Palmer (Dr)
Principle Investigator & Lead Supervisor
Senior Clinical Lecturer
Health Services Research
School of Health and Related Research
The University of Sheffield
r.l.palmer@sheffield.ac.uk

Encl. Information sheet
Consent form
Questionnaire

Appendix 4: Information sheets to participants (page 1/3)



Information Sheet (Stroke survivors & caregivers version)

1. Research project title:

The development of a remotely supported self-managed exercise intervention using available information and communication technologies (ICTs) for functional physical recovery post-stroke

2. Invitation paragraph

You are being invited to take part in a health service research project. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

3. What is the project's purpose?

The purpose of this study is to develop a self-managed exercise intervention supported remotely using available information and communication technologies, for functional physical recovery post-stroke.

Information and communication technologies (ICTs), in this study, are referred to technologies that provide access to information through telecommunications, with the focus on communication technologies and other communication mediums to receive and provide information and communication delivered remotely over a distance. The available ICTs, for example, Internet, computer networks, telephone calls, emails, text messaging and videoconferencing are referred in this study.

4. Why have I been chosen?

You are being invited to take part in this study, as you are a stroke survivor with at least one physical disability affecting your daily activities and have been discharged from specialist stroke rehabilitation services within 5 years / a caregiver of that kind of stroke survivor.

5. Do I have to take part?

Your participation is entirely voluntary. It is up to you to take part in this study or not. It will not affect any healthcare provision that you should have, if you prefer not to take part in this study. If you decide to take part, you will be given this information sheet to keep and a consent form to sign and keep. You can still withdraw at any time without loss of healthcare provision that you are entitled. You do not have to give a reason for your withdrawal.

6. What will happen to me if I take part?

This study will last for 12 months. You will be invited to participate in 1 semi-structured interview and 1 focus group. The semi-structured interview will last up to 1 hour. The focus group session will last up to 1.5 hours.

Your written informed consent will be obtained before you take part in this study.

You will be asked with questions about your needs and experience of physical functional recovery after you or the stroke survivor has been discharged from the National Health Service (NHS) specialist stroke rehabilitation services. You will be invited to share your ideas

(page 2/3)

and opinions to design a self-managed exercise program supported remotely using available ICTs.

For stroke survivor, you will be asked with a few questions to ensure you are suitable to take part in this study, before you sign the written consent form and take part in this study. This will be done after you have verbally agreed to take the quick check.

7. What do I have to do?

For stroke survivors, you will be invited share your healthcare needs and experience for your physical recovery for daily activities, after you have been discharged from stroke rehabilitation services.

For caregivers, you will be invited share the experience and needs that you know and experience when you take care of the stroke survivor for their physical recovery.

For both stroke survivors and caregivers, you will be invited to join a group discussion session after interview, to share your ideas and opinions to develop and refine a self-managed physical exercise program supported remotely using available ICTs, according to the questions asked by the researcher.

8. What are the possible disadvantages and risks of taking part?

For stroke survivors, due to the nature of stroke consequences, it is possible you may become fatigued, frustrated, emotional or even distressed during interviews or focus groups. The investigator will be vigilant for this and you will be offered chances to rest during the session or to discontinue the session if necessary. You can be offered a second session to complete tasks if it is appropriate.

9. What are the possible benefits of taking part?

Whilst there is no immediate benefit to the participants, it is hoped that this work will help to design a remotely delivered self-managed exercise intervention using available ICTs for the physical recovery of stroke survivors in the future.

10. What happens if the research study stops earlier than expected?

You will be informed if the research is stopped earlier than expected. All the collected data will be deleted when the study ends.

11. What if something goes wrong?

If you wish to make a complaint about this research please contact the principle investigator and lead supervisor of this study, Dr. Rebecca Palmer.

12. Will my taking part in this project be kept confidential?

All collected information will be kept strictly confidential. The collected information and interview transcriptions will be anonymised and stored confidentially and securely within the project premises at room 1.02, the Innovation Centre, Sheffield, the United Kingdom in a locked room and drawers. The collected information will only be accessible to the student investigator and the project supervisors.

13. What will happen to the results of the research project?

The collected information will be used to develop and refine a physical exercise. The results of this research may be published, if possible. You will not be able to be identified in any report or publication from this study.

(page 3/3)

14. Who is organising and funding the research?

This research is sponsored by the National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care, South Yorkshire (CLAHRC SY) through the School of Health and Related Research of the University of Sheffield.

Reasonable travel expenses to participate in focus groups will be reimbursed to you, while travel expenses for interviews, which will be held in any where you prefer, will not be reimbursed.

15. Who has ethically reviewed the project?

This project has been ethically reviewed and approved by the Research Ethics Committee of the School of Health and Related Research of the University of Sheffield.

16. Contact for further information

1. Post: Postgraduate research student

Name: Mr. Ying Man Law

Department: School of Health and Related Research, the University of Sheffield

Address: Room 1.02, the Innovation Centre, 217 Portobello, Sheffield, S1 4DP, UK

Email: ym.law@sheffield.ac.uk

Telephone: (0) 114 222 26381 or (0)7423590298

2. Post: Principle Investigator & Lead Supervisor

Name: Dr. Rebecca Palmer

Department: School of Health and Related Research, the University of Sheffield

Address: Room 1.07, the Innovation Centre, 217 Portobello, Sheffield, S1 4DP, UK

Email: r.i.palmer@sheffield.ac.uk

Telephone: (0) 114 222 20863

17. Will I be recorded, and how will the recorded media be used?

Your interviews will be recorded with your permission. The audio and/or video recordings made during this research will be used for the purposes of analysis. No other use will be made of them without your permission, and no one outside the project will be allowed access to the original recordings. The recordings will be stored confidentially and securely, and only be accessible to the student investigator and the project supervisors.

All audio and video data will be kept confidentially. Memory stick and lap top containing the audio and/or video materials are password protected. No one outside the research team will have access to them. Audio and video tapes will be destroyed after transcription.

18. What are the possible disadvantages and risks of taking part?

It is not anticipated that you will be disadvantaged by taking part in this research.

19. What if new information becomes available?

You will be informed for any new relevant information; if there is additional information relevant to this study becomes available during the study. Then, you can decide to withdraw or continue. If you decide to continue in the study, you will be asked to sign an updated consent form before you continue to participate in this study.

A copy of this information sheet and a signed consent form will be given to you to keep.

Thank you very much for your kind attention and important support to this project.

Appendix 6: Permission letters for reprinting copyrighted materials

a. Permission from WHO (page 1/3)

ID: 129552 Form to request permission to reproduce or reprint WHO copyrighted material

CAMPANARIO, Dolores <campanariod@who.int> 13 Jan 2014

Dear Mr Law Ying Man,

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On behalf of the World Health Organization, we are pleased to authorize your request to reproduce the WHO item detailed in the form below.

How to use the ICF: A practical manual for using the International

Classification of Functioning, Disability and Health (ICF).

Box 1: page 7

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(page 2/3)

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WHO will not charge a fee for the above permission, however we would be grateful if you could send one copy of the final product for our records, showing where/how WHO material appears and how it is referenced on your product addressed to:

Ms Dolores Campanario

World Health Organization Press

WHO Press **WHP** (*Permissions Management*)

20 Avenue Appia, **Office 4152**

CH-1211 Genève 27, Switzerland

campanariod@who.int

We thank you for your interest in WHO Information products and we wish you all the best with your project.

Kind regards.

Ms Dolores Campanario

World Health Organization Press - (*Permissions Management, Licensing and Reprint Rights*)

Department of Knowledge Management and Sharing

20 Avenue Appia, Office: 4152, CH-1211 Genève 27, Switzerland

Tel: [+41 22 791 24 83](tel:+41227912483) - Fax: [+41 22 791 4857](tel:+41227914857) - E-mail: campanariod@who.int

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Suggested examples for references:

(page 3/3)

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"Reproduced, with the permission of the publisher, from *the World Health Report: Health Systems Financing: The Path to Universal Coverage*. Geneva, World Health Organization, 2010 (Fig. 5.1, Page 92 http://whqlibdoc.who.int/whr/2010/9789241564021_eng.pdf, accessed 04 April 2013)"

If authorship is attributed to individual authors or a group:

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Appendix 6: Permission letters for reprinting copyrighted materials

b. Permission from *Effective Clinical Practice* (granted on Jan 14, 2014)



WAACP1418386

October 9, 2014

The University of Sheffield
Room 1.02,
The Innovation Centre,
217 Portobello,
Sheffield, S1 4DP

Dear Mr. Law;

Thank you for your request to print (thesis) the following from *Effective Clinical Practice*:

Figure 1: Wagner EH, Chronic Disease Management: What Will It Take to Improve Care for Chronic Illness? *Effective Clinical Practice*, 1998, Vol1

Permission is granted to print the preceding material with the understanding that you will give appropriate credit to *Effective Clinical Practice* as the original source of the material. Any translated version must carry a disclaimer stating that the American College of Physicians is not responsible for the accuracy of the translation. This permission grants non-exclusive, worldwide rights for this edition in print (thesis) for not for profit only. ACP does not grant permission to reproduce entire articles or chapters on the Internet unless explicit permission is given. This letter represents the agreement between ACP and The University of Sheffield for request WAACP1418386 and supersedes all prior terms from the requestor. The *Annals of Internal Medicine* wants to encourage users to go to the original article on the website for scientific integrity, in the event there are retractions and corrections.

Thank you for your interest in *Annals of Internal Medicine*. If you have any further questions or would like to discuss the matter further, please contact me at 856-489-8555 or fax 856-489-4449.

Sincerely,

Gina Brown
Permissions Coordinator

Appendix 6: Permission letters for reprinting copyrighted materials

c. Permission from *Management Sciences*

Candita Gerzevitz <candita.gerzevitz@informs.org>

6 Feb 2014

Dear Ying Man Law,

Permission is granted to use the Management Science content cited below in your dissertation at no charge. Please use the following credit line:

“Reprinted by permission, (author), (title of article), (title of journal), volume (#), number (#), (month, year). Copyright (year), the Institute for Operations Research and the Management Sciences, 5521 Research Park Drive, Suite 200, Catonsville, Maryland 21228 USA.”

Please contact me directly if more information is needed.

Sincerely,

Candi Gerzevitz

Candita Gerzevitz

Senior Production Editor

and Manager, Rights and Permissions

INFORMS

5521 Research Park Drive, Suite 200, Catonsville, MD 21228

candita.gerzevitz@informs.org

401-826-8158

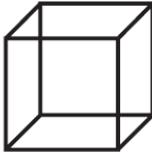
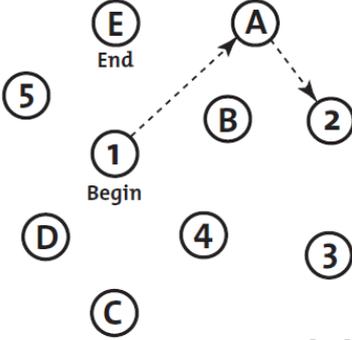
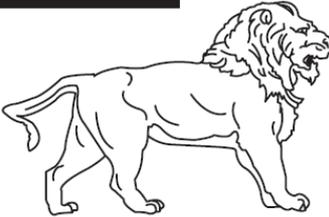
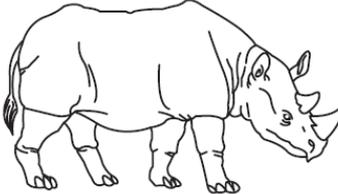
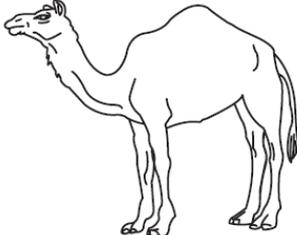
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Appendix 7: Montreal Cognitive Assessment (MoCA)

MONTREAL COGNITIVE ASSESSMENT (MOCA)

NAME :
Education :
Sex :

Date of birth :
DATE :

VISUOSPATIAL / EXECUTIVE				Copy cube []	Draw CLOCK (Ten past eleven) (3 points) [] [] [] Contour Numbers Hands	POINTS ___/5		
				[]				
NAMING				[]		[]		
				[]		___/3		
MEMORY	Read list of words, subject must repeat them. Do 2 trials. Do a recall after 5 minutes.	[]	FACE	VELVET	CHURCH	DAISY	RED	No points []
		1st trial						
		2nd trial						
ATTENTION	Read list of digits (1 digit/ sec). Subject has to repeat them in the forward order [] 2 1 8 5 4 Subject has to repeat them in the backward order [] 7 4 2							___/2
Read list of letters. The subject must tap with his hand at each letter A. No points if ≥ 2 errors								___/1
		[]	FBACMNAAJKLBAFAKDEAAAJAMOFAB					
Serial 7 subtraction starting at 100		[] 93	[] 86	[] 79	[] 72	[] 65		___/3
		4 or 5 correct subtractions: 3 pts , 2 or 3 correct: 2 pts , 1 correct: 1 pt , 0 correct: 0 pt						
LANGUAGE	Repeat : I only know that John is the one to help today. [] The cat always hid under the couch when dogs were in the room. []							___/2
Fluency / Name maximum number of words in one minute that begin with the letter F								___/1
								[] _____ (N ≥ 11 words)
ABSTRACTION	Similarity between e.g. banana - orange = fruit [] train - bicycle [] watch - ruler							___/2
DELAYED RECALL	Has to recall words WITH NO CUE	FACE	VELVET	CHURCH	DAISY	RED	Points for UNCUED recall only	___/5
		[]	[]	[]	[]	[]		
Optional	Category cue							
		Multiple choice cue						
ORIENTATION	[] Date [] Month [] Year [] Day [] Place [] City							___/6
© Z.Nasreddine MD Version November 7, 2004		Normal ≥ 26 / 30		TOTAL				___/30
www.mocatest.org				Add 1 point if ≤ 12 yr edu				

Appendix 8: Rivermead Mobility Index (RMI)

The Rivermead Mobility Index

Name: _____

Day							
Month							
Year							
Topic and Question:							
Turning over in bed: Do you turn over from your back to your side without help?							
Lying to sitting: From lying in bed, do you get up to sit on the edge of the bed on your own?							
Sitting balance: Do you sit on the edge of the bed without holding on for 10 seconds?							
Sitting to standing: Do you stand up from any chair in less than 15 seconds and stand there for 15 seconds, using hands and/or an aid if necessary?							
Standing unsupported: (Ask to stand) Observe standing for 10 seconds without any aid							
Transfer: Do you manage to move from bed to chair and back without any help?							
Walking inside: (with an aid if necessary): Do you walk 10 meters, with an aid if necessary, but with no standby help?							
Stairs: Do you manage a flight of stairs without help?							
Walking outside: (even ground): Do you walk around outside, on pavements, without help?							
Walking inside: (with no aid): Do you walk 10 meters inside, with no caliper, splint, or other aid (including furniture or walls) without help?							
Picking up off floor: Do you manage to walk five meters, pick something up from the floor, and then walk back without help?							
Walking outside: (uneven ground): Do you walk over uneven ground (grass, gravel, snow, ice etc) without help?							
Bathing: Do you get into/out of a bath or shower and to wash yourself unsupervised and without help?							
Up and down four steps: Do you manage to go up and down four steps with no rail, but using an aid if necessary?							
Running: Do you run 10 meters without limping in four seconds (fast walk, not limping, is acceptable)?							
Total							

Downloaded from www.rehabmeasures.org

The Rivermead Mobility Index is provided courtesy of Dr. Derick Wade and the Oxford Centre for Enablement.

Appendix 9: Book A of “Self-managed physical rehabilitation exercise programme”
(Total: 15 pages in Book A)

Book A: Clinical checklist



A guide to prescribe a self-managed physical rehabilitation exercise programme to an individual stroke survivor
(It is to be used by the stroke survivor and clinician together, then kept by the community rehabilitation team as a clinical record)

Name of stroke survivor:



1

Stroke survivor's profile

Age: _____ Next of kin/carer: _____ Date of prescription: _____

Phone number (and /or carer's number): _____

Email address and / or other contact methods

Home address: _____

Type of stroke (please select one answer if information is available): Infarction or haemorrhage

(Details) _____



2

Section 1: Needs assessment

Please identify personal physical rehabilitation needs and goals for the individual stroke survivor. Please complete the following sections with available information and cross out sections that are not applicable to the individual.

Section 1a: Basic personal characteristics and health conditions:

- Personal information e.g. emotion, motivation, family support, social interaction with others, living environment, overall physical conditions and discharge planning information
- Physical difficulties e.g. reduced joint mobility, arm and / or leg weakness, and pain etc.
- Restricted activity and participation e.g. cooking, dressing, walking, gardening, and shopping etc.

Section 1b: Goal-setting for activity and participation:

- Goal-setting for activity and participation, including daily tasks and / or any activity that the stroke survivor would like to do or improve e.g. cooking, dressing, walking, gardening, and shopping etc.



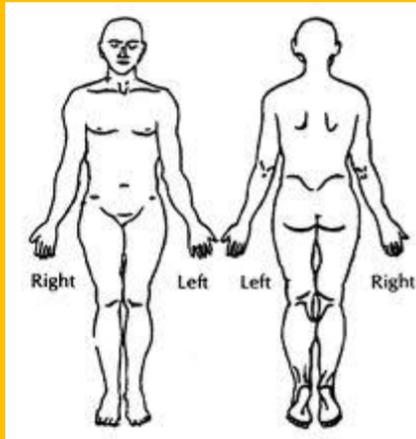
Section 1a: Basic personal characteristics and health conditions:

Personal information (Please use the results to complete the prescription in Book B Section 1 and 2)

Items	Sub-items	Details (Please complete this section with available information and discussion with the stroke survivor)
Personal factors	Psychological factor (e.g. anxiety, depression, low mood or confidence)	
	Psychosocial factor (e.g. family support, social interaction with friends and relatives)	
Environmental factor (e.g. stairs, steps or any barrier in living environment)		
Other physical health conditions (e.g. hearing or visual problem, long term back pain or shoulder pain before stroke)		
Discharge planning (Any discharge plan from doctor and / or therapist)		

Physical difficulties

Please  on the following diagram to indicate the physical barrier(s) of the stroke survivor.



Dominant hand before stroke	Right / Left (Please circle to select)
Affected body part	Comments / Details
Arm and hand	
Leg and foot	
Both arm and hand plus leg and foot	
Trunk	

5

Affected physical function	 if this is affected	Comments / Details
Active movement		
Reaction and balance control		
Joint mobility		
Muscle strength		
Energy and physical tolerance		
Sensory functions and pain		
Other (please specify)		



6

Restricted activity and participation

Please ask the stroke survivor what they find difficult to do in their everyday life due to their physical difficulties

Types of restriction	Details
	

Section 1b: Goal-setting for activity & participation

Please to decide the personal goals for physical rehabilitation. You may need to consider the findings in section 1a whilst deciding which goals will promote improved activity and participation for the individual. Use this table to guide discussion with the stroke survivor. Please use the results of this section to determine the details in Book B Section 1 and 2.

Types of physical activity / participation	Choices	<input checked="" type="checkbox"/> if it is a goal	Details
Mobility	Maintain a body position		
	Change body positions		
	Walking		
	Stair climbing		
	Hand and arm use		
	Lifting and carrying objects		
	Using transportation		
	Driving		
	Other (please specify)		
Self-care	Caring for body parts and making self comfortable		

	Dressing / Undressing		
	Eating / Drinking		
	Washing / Drying oneself		
	Toileting		
	Other (please specify)		
Domestic life	Doing housework		
	Preparing meals / drinks		
	Other (please specify)		
Community, social & civic life	Recreation and leisure		
	Shopping		
	Gardening		
	Return to work		
	Other (please specify)		
Learning & applying knowledge	Writing		
	Other (please specify)		

9

Section 2: Select stroke specific physical rehabilitation exercises

Please  to choose suitable and preferred physical rehabilitation exercises/activities to help achieve the identified goals. Please use the results of this section to prescribe personalised stroke exercises/activities in Book B Section 2.

Types of physical rehabilitation exercises / activities	 to select	Notes or Information about the details
Mobilizing		
Stretching		
Strengthening		
Balance		
Coordination		

10

Walking		
Cardiorespiratory (e.g. cycling & swimming)		
Sensory exercise (e.g. touching different shapes & / or textures of objects)		
Combined physical movements / activities (e.g. Bed exercises, grabbing and lifting a cup or sitting to standing)		
Other (please specify e.g. Tai Chi and/or Yoga)		



11

Section 3: What technology is available?

Please  to determine available and usable technology. Please choose the technology that the stroke survivor can and would like to use, based on his /her understanding, ability, preference and usable resource. Please use the results of this section to complete Book B Section 2.

Types of technology	Choices	 to select	Assistance needed?	Please describe how the selected technology can be used to support the stroke survivor to manage the exercises and / activities
Audio-visual	CD			
	DVD			
	Video recording			
Computer	Desktop / laptop computer			
	Touch screen computer			
Internet	Email			
	Online information			
	Online social group and discussion forum			

12

	Link to online video information			
	Electronic / online record			
	Videoconferencing			
	Computer game			
	Apps for touch screen computer or smartphone			
Telephone	Landline telephone call			
	Mobile phone call			
	Mobile phone text message			
Other technology (please specify)				



13

Section 4: Assistance to self-manage physical rehabilitation exercises

Please  to select suitable and feasible assistance to support the stroke survivor to manage this programme. Please use the results of this section to complete the details in Book B Section 3.

Choices of self-management assistance	 to select	Details	How?
Access to healthcare and / social care resources and networks			
Self-management information and skills			
Improve motivation			
External encouragement and support for confidence			
Professional instruction and advice			
Learning how to self-manage			
Peer support (from other stroke survivors)			

14

Carer support (including family members)			
Other kind of assistance (please specify)			



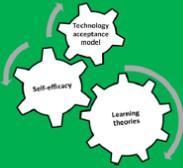
This is the end of Book A

Please complete Book B to provide the prescription for the stroke survivor



Appendix 9: Book B of “Self-managed physical rehabilitation exercise programme”

(Total: 28 pages in Book B)



Book B: My stroke exercise manual

Empowering stroke survivors to manage their own physical rehabilitation exercises!
A personalised handbook for a stroke survivor to manage physical rehabilitation exercises

This handbook belongs to:

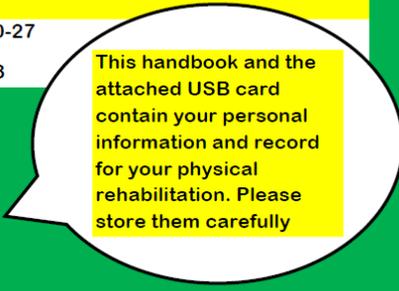
Date of prescription:



1

Contents

	Page
About this programme	3-4
Section 1: Summary from my therapist	5
Section 2: What rehabilitation exercises do I need to do?	6-10
Section 3: Sources of help for me to manage my exercises	11-12
Section 4: Learning from other stroke survivors like me	13
How well am I doing? --- My monthly progress record	14-16
Tips for user	17-19
Useful resources and networks	20-27
Glossary	28



2

About this programme

What is this?

“My stroke exercise manual” is an individualised manual of a self-managed physical rehabilitation exercise programme for stroke survivors. It is designed for you and your therapists to plan a personalised and self-managed physical rehabilitation exercise programme with the support of available information and communication technologies (ICTs).



3

What's inside?

The exercises and information in this book are designed for you. It includes information about this programme, summaries of information from your therapist, goal-setting and action planning, a personalised exercise prescription, and useful resources and contacts about physical rehabilitation. Your therapist will fill in relevant details with you following a discussion of what you need.

Section 4 is a case study part in this programme. Your therapist will choose or provide a case story from a stroke survivor who has similar needs and goals to you.

A monthly self-monitored progress record is included for you to monitor and regulate your progress to take control of your programme. The record may also help you to communicate any difficulties or changes required to health care professionals. You can complete the record either by written copy, or on a computer using the electronic copy within the USB memory stick supplied with this book.

USB memory stick

A 1GB USB memory stick is provided with this book. It contains an electronic copy of your exercise prescription and other useful information. You can save personal information, your progress record, photos, pictures about your exercises and activities. You can keep information about self-management and how technology can help you for your exercises and activities. You can also save video recordings, web links, written materials, individual advice and contacts about local health and social care resources and supporting networks on the stick.



4

Section 1: Summary from my therapist

(This part is to be completed by/with your therapist)

Items	Details
Personal information & characteristics	
Affected body part	
Affected physical function	
Affected activity and social participation	
Summary of discharge planning	

5

My goal (s)

With help from your therapist, please stick the goal(s) that you discussed in the chart using the adhesive stickers provided. You may stick extra choices on an additional paper, if you have selected more goals than the boxes provided. Then, you need to set up an action plan for each goal. Your therapist will help you to break down your plan into steps to achieve your goal (s).

Goal (s)	• Steps for action plan	
Goal	• Steps:	
Goal	• Steps:	
Goal	• Steps:	



6

How am I going to achieve my goal (s)?

Please detail the steps of your action plan. Your therapist may provide particular suggestion, skill and advice for you to manage your action plan. You can adjust this plan according to your progress and needs.

Action plan details	Personalised advice
<p>e.g. I need to strengthen my right arm for cooking. I need to be able to prepare sandwiches for my lunch before I can prepare food for a party with my friends</p> 	<p>e.g. You may start by doing light tasks; such as washing vegetables and cutlery</p> 

7

Section 2: What rehabilitation exercises do I need to do?

Physical rehabilitation exercise programmes have been shown to have positive effects on physical outcomes after stroke. Stroke survivors are advised to practise aerobic, muscle strength and task-orientated exercises in exercise programme for physical rehabilitation, unless there are special reasons.
(Please detail the personalised exercise prescription and related safety advice below.)

Section 2

Frequency (F)	Intensity (I)	Type (T)	Time (T)	Notes
e.g. 7 days per week	Without tiredness	Walking	30 minutes per day with at least 10 minutes for each session	

8

Technology that can help me do my exercises

My technology	How would you like to use the technology?	Do you need any assistance to use the technology? (Please detail, if "yes")
e.g. Mobile phone, video recording, computer, email	e.g. I will use my smart phone to take video records about my walking to monitor my own progress and share my progress with my friends in stroke club to get feedback through emails.	e.g. I need someone to help me to upload my video recordings on my computer and send emails. Jane (wife) has agreed to help with this.

Safety advice (You may need to contact your doctor, if you are experiencing worrying symptoms)
 e.g. You need to stop doing your exercises when you feel any pain or breathlessness



9

How will my exercises help me?

Your therapist will write down the possible benefits of doing exercises for your physical rehabilitation for daily activity and social participation. (e.g. increase muscle strength for walking, increase flexibility with stretching for getting in and out of a car)

Exercise / activity	Potential benefits
e.g. walking	It increases your right leg strength and mobility to go out for shopping



10

Section 3: Sources of help for me to manage my exercises

Please stick the types of assistance that you have discussed with your therapist on the following boxes using the adhesive stickers provided.



Details about the assistance required

e.g. I would like to receive feedback from other stroke survivors about the performance of my walking, in order to improve my motivation and confidence to continue my walking exercise.



Section 4: Learning from stroke survivors like me

Please refer to the selected successful story from another stroke survivor who had similar needs and conditions to you. This is to help you to learn from other stroke survivor's successful experiences about the self-management of physical exercises/activities. You may develop your way to use the selected technology for you to manage your exercises/activities after learning from the selected case.

What are the key issues that you can learn from this case to manage your exercises and activities?

Note: Any personalised advice, information and skills from your therapists or reflection from this case?

Section 4



How well am I doing? --- My monthly progress record (please photocopy this record for future use)

Please complete this record by yourself. You may ask someone to assist you, if you have difficulty in writing. There are 6 copies attached with this Book B for you to use in the first 6 months.

Date of review: _____

How many months have you been on this programme? Please 1st / 2nd / 3rd / 4th / 5th / 6th; other: _____

My overall performance: (Please ONE box or write to answer each question below, after comparing to your performance in the previous month)

How well am I doing?	Please give a score between 0 to 10 to reflect your overall progress. 0= no progress at all, 10=the best improvement The higher score, the better you feel				Score: _____
Frequency of doing my exercise	Daily	Every other day	1 per week	None	Other (please specify)
Am I progressing towards my goal (s) for activity and participation?	Yes	No	Please use the next pages to measure, summarise and describe your progress		
Do I have any discomfort / physical health problem with my exercise / activity?	Yes	No	Main discomfort		
Do I have any problem about using the technology?	Yes	No	Main problem		
My confidence in managing my exercises / activities	_____ % (Full confidence: 100%)				

How well am I doing?

<p>How has your physical conditions changed?</p> <p>Please describe the change of your <u>physical condition</u>.</p>	<p>e.g. pain, strength, flexibility, balance or fatigue</p>
<p>Please summarise the changes and achievement in your physical movement, activity and participation.</p> <p>This is to focus on the <u>results of your success</u>.</p>	<p>e.g. I can walk better. Or I can prepare a bowl of salad for a party</p>
<p>Please describe the details of the above changes and achievement.</p> <p>This is to record and review <u>the change</u> in the movement quality for activity and participation.</p>	<p>e.g. I can use a stick to walk continuously for 10 minutes without losing balance or any discomfort. Or I can wash and slice vegetables, and toss a salad with better strength, coordination and less tiredness</p>

How well am I doing?

Do I need to adjust my action plan? (please  ONE answer) **Yes**__ (please answer the next question) **No**__

What should I do to make further progress? (please break into steps to take action)

Do I need any change in using technology for managing my exercises and activities?
(please  ONE answer) **Yes**__ (please answer the next question) **No**__

What should I do to better use my technology? (please break into steps)

How well am I doing?



Tips for user

Tips for user

1. Try to discuss the contents of your programme with your therapists, including understanding of potential barriers and possible solutions, whilst you are still in touch with them. This will help you to prepare you to take control of your own programme
2. Try to set manageable and meaningful goals and actions with your therapist
3. Keep your progress records carefully. You may need to review or discuss them with your general practitioner or physiotherapist if you have any problems about your exercises and activities
4. Please review your progress. Reflecting on your experience and progress are important for you to recognise helpful ways to plan and regulate your actions to achieve your goals. Try to focus on learning from your positive changes and achievements. This can build up your motivation and confidence to help to continuously manage your exercises and activities
5. It is good to contact community organisations to seek social support and resources. This may help you to learn from different successful life stories about physical stroke rehabilitation via local groups
6. It is important to enrich your knowledge about your health, and exercises and activities after stroke. This can help you to cope with your physical rehabilitation in the long-term. Please try to regularly update your information. You may obtain new knowledge and skills through links in "Useful resources and networks"
7. Try to find an "exercise buddy" to do exercises with you. Your buddy can be your friend, family member or another stroke survivor from a social group. This can motivate you to keep working on your programme. You may discuss with your buddy to decide suitable ways of using available technology to provide ongoing support and regular feedback

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8. It is better to choose the existing technology that you think useful and easy to use, and have easy access to support you to manage your exercises and activities continuously. You may also need to consider if there is any available technical support for you to use that technology or not before you choose it to help you
9. You can use the technology to access and share up-to-date information about exercises and activities for stroke rehabilitation. You can also use your technology to find community resources and social networks to provide or get ongoing support, feedback and motivation from others, so as to encourage you to continuously manage your exercises and activities
10. You should contact your doctor or physiotherapist/occupational therapist if you are in doubt or have any physical discomfort, or concerns about your exercises, activities and progress
11. You may contact stroke related organizations and other stroke survivors to obtain further information and ongoing social support for you to cope with your problem from managing this programme. Using available technology may help you for this purpose at your convenience

Tips for user



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Personal data protection and security for using available information and communication technologies

Tips for user

1. You may refer to the links in "Useful resources and networks" section for further information
2. You should set up a strong log-in password. Please keep it secret. You may ask someone you trust to help you to remember the password if you need to
3. Try to use password and computer antivirus software to protect your computer or device, such as a smartphone. Please keep the antivirus software updated regularly
4. You may need to change your password if you think someone might have used your record / computer/ email without your permission
5. Please be careful about the security of your personal information and record if you use a shared computer or mobile device
6. Please think carefully before sharing your personal information and/or record with anyone. If you are about sharing your information, including anything stored in the memory stick, don't share it
7. You should tell someone you trust, if anyone asks you to share your personal information or record via any technologies if you are in doubt
8. Remember to log out your computer, email or any web-page when you have finished using it
9. Please be careful with printed copies and the storage of the memory stick. Please don't leave your manual, record, or memory card lying around
10. Please only share or leave your information, record or the memory stick with the people you trust



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Useful resources and networks



Links to healthcare resources: Here are the contacts for you to access professional information, services and resources for your exercises and rehabilitation (Disclaimer: the author, his supervisors and sponsors bear no responsibility for the services and information from the persons and/or organisations below)

Name	Contacts
General Practitioner	
Physiotherapist	
Occupational Therapist	
Personal Trainer / Exercise Professional	
NHS Direct (England & Wales)	Web-site: www.nhsdirect.nhs.uk Phone no: 0845 4647
NHS Improvement Programme, stroke	Web-site: www.improvement.nhs.uk/stroke
NHS Choice (stroke)	Web-site: www.nhs.uk/Conditions/Stroke
Local NHS community rehabilitation unit	
Referral to local residential care team for longer-term rehabilitation?	
Other	

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Links to social care and community resources:

Here are the contacts of social care resources or networks for you to access further information, services, resources and social networks to support you to manage your physical rehabilitation (Disclaimer: the author, his supervisors and sponsors bear no responsibility for the services and information provided by the following organisations)

Name	Contacts
Stroke Association A charity supporting stroke survivors living across the United Kingdom (UK) to make the best recovery they can	Web-site: www.stroke.org.uk Email (Head office): info@stroke.org.uk Phone (Head office): 020 7566 0300 (Stroke Helpline): 0303 303 3100
Different Strokes A charity providing a unique, free service to younger stroke survivors throughout the UK. It is run by stroke survivors for stroke survivors, for active self help and mutual support	Web-site / Facebook: www.differentstrokes.co.uk Email (Head office): info@differentstrokes.co.uk Twitter: diffstrokes Phone (StrokeLine): 0845 130 7172 or 01908 317618
Chest, Heart and Stroke Scotland A charity aiming to improve the quality of life of stroke survivors and people with chest and heart conditions in Scotland	Web-site: www.chss.org.uk Phone (Head office): 0131 225 6963 (Advice Line): 0845 077 6000

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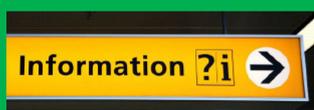
Northern Ireland Chest, Heart and Stroke A charity providing support to stroke survivors. It promotes stroke prevention, services and research in Northern Ireland	Web-site: www.nichsa.com Email: mail@nichs.org.uk Phone: 02890320184
Patient.co.uk A directory of the UK websites which provides information on health, disease and related issues	Web-site: www.patient.co.uk Phone: 0114 213 2803 Mobile: 07773 500 951 Discussion forum for stroke rehabilitation: http://www.patient.co.uk/forums/discuss/browse/stroke-rehabilitation-2105
Healthwatch England An independent consumer champion for health and social care in England	Web-site: www.healthwatch.co.uk Email: enquiries@healthwatch.co.uk Phone (Head office): 03000 683 000
The Disabled Living Foundation (DLF) A charity providing impartial advice, information and training on independent living for people with disability	Web-site: www.dlf.org.uk Email: info@dlf.org.uk / helpline@dlf.org.uk Phone (Helpline): 0300 999 0004 (Switchboard): 02072896111

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<p>Youreable</p> <p>It is an online community of and for disabled people. It allows disabled people support and help each other by sharing their experiences and offering advice on the forum. It is run by the DLF</p>	<p>Web-site: www.youreable.com</p>
<p>SSA Social Care & Community Services</p> <p>An independent agency to provide social care</p>	<p>Web-site: www.ssasocialwork.co.uk</p> <p>Email: info@ssa-sw.co.uk</p> <p>Phone: 0114 273 0777</p>
<p>Disability Information and Advice Line services (DIAL)</p> <p>A charity which is run by and for disabled people. DIAL groups provide information and advice to disabled people and others on all aspects of living with disability</p>	<p>Web-site: www.scope.org.uk/dial</p> <p>Email: dialnetwork@scope.org.uk</p> <p>Phone: 0130 231 0123</p>
<p>Disability Rights UK</p> <p>A charity run by and for people with lived experience of disability / health conditions in the UK</p>	<p>Web-site: www.disabilityrightsuk.org</p> <p>Email: enquiries@disabilityrightsuk.org</p> <p>Phone: 02072503222</p> <p>Fax: 020 7247 8765</p>

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<p>Queen Elizabeth's Foundation for Disabled People</p> <p>A charity with a mission to enable and support disabled people to increase independence and improve life skills</p>	<p>Web-site: www.qef.org.uk</p> <p>Email: info@qef.org.uk</p> <p>Phone: 01372 841100</p> <p>Fax: 01372 844657</p>
<p>Phab</p> <p>A charity with supporting networks to promote and encourage physically disabled and able-bodied people to come together on equal terms, to achieve complete inclusion within the wider community</p>	<p>Web-site: www.phab.org.uk</p> <p>Email: info@phab.org.uk</p> <p>Phone: 020 8667 9443</p> <p>Fax: 020 8681 1399</p>
<p>Other local social network / charity/ stroke related social network or group</p>	
<p>Social worker (when necessary)</p>	



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Links to personal data protection and security for using available technologies:

You may refer to the following links for further information about personal data protection and security for using information and communication technologies. (Disclaimer: the author, his supervisors and sponsors bear no responsibility for the services and information provided by the following organizations)

Name	Contacts
NHS Choices	(For health records, safety and security about online health and social care records) Web-site: www.nhs.uk/NHSEngland/thenhs/records/healthrecords/Pages/overview.aspx
Get safe online	Web-site: www.getsafeonline.org
Health and Social Care Information Centre	Website: www.hscic.gov.uk Email: enquiries@hscic.gov.uk Phone: 08453006016
Care record guarantee	Web-site: www.nigb.nhs.uk/pubs/crgengland
Age UK	Web-site: www.ageuk.org.uk Phone: 08001696565
Other	

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Access to other stroke self-management services for support

Name: Bridges Stroke Self-management programme

This was designed by Dr Fiona Jones in 2005 in collaboration with a group of stroke survivors. It aims to support stroke survivors to develop their self-management skills. It provides an individualised, client-held 'stroke workbook' which practitioners work through with clients to support their self-management. The workbook includes individual stories and strategies suggested by stroke survivors, as well as a space for the client to record personal goals and successes.

Contacts:

Bridges Self-Management Limited

Address: 2nd Floor Grosvenor Wing, St George's, University of London and Kingston University,
Cranmer Terrace, London SW17 0RE

Website: www.bridgesselfmanagement.org.uk

Email: info@bridgesselfmanagement.org.uk

Twitter: [bridgesselfmgmt](https://twitter.com/bridgesselfmgmt)

Facebook: [bridgesselfmanagement](https://www.facebook.com/bridgesselfmanagement)

Tel: 020 8725 2445

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Name: Stroke Workbook programme

This is a self-management programme based on behaviour change techniques. It was produced by NHS Lothian for people and families affected by stroke. It consists of a workbook with information about stroke and recovery using cognitive behavioural therapy techniques. A diary and audio relaxation CD are accompanied with the workbook.

Contacts:

The Heart Manual Programme

Stroke Workbook Team

Address: Astley Ainslie Hospital, Administration Building, 133 Grange Loan, Edinburgh, EH9 2HL, Scotland, United Kingdom

Website : www.theheartmanual.com

Email: heart.manual@nhslothian.scot.nhs.uk

Tel: 0131 537 9127/9137 Fax : 0131 537 9489

Other useful resources / information suggested by your therapist



Glossary

Items	Definition in this programme
Activity	Physical actions that a person can do with given abilities, such as walking or brushing teeth
Information and Communication Technology (ICT or ICTs)	Information and Communication Technology (or Technologies): For this programme, ICT refers to any technology providing access to information via telecommunications, with the focus on using the technology to receive and deliver information and communication over a distance. Commonly available ICTs include Internet, computer, email, online discussion forum, web-site, landline or mobile telephone, smartphone, text messaging DVD, video-recording and videoconferencing. Available technology refers to ICT in this programme.
Participation	The extent of an individual's involvement in social life, autonomy and interaction with others
Rehabilitation	A process to restore a health condition, capacity or normal life by intervention such as training, therapy and education
Self-management	It refers to the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and life style changes inherent in living with a chronic condition in this programme
Transient Ischemic Attack (TIA)	It is a transient episode of the loss of blood flow to the brain, which can resolve within a few minutes or 24 hours. It has the same underlying cause as stroke, and often be referred to as "mini-stroke".

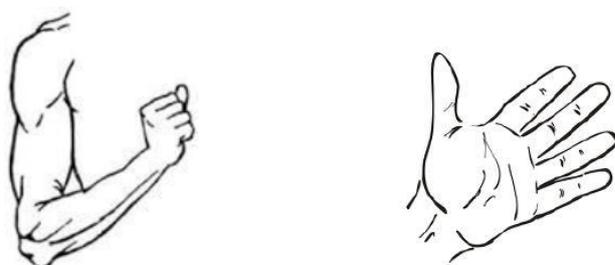


Appendix 9: Three case examples

Case study 1 (page 1 /2)

Case study 1: (Arm and hand)

This case story provides details about physical rehabilitation of a stroke survivor using exercises and available technology. The focus is on the physical recovery of the arm and hand.



Background

Mr. S, a 57 year old, had a stroke 6 years ago, preceded by several transient ischemic attacks. The right side of his body and coordination were affected. His physiotherapists and occupational therapist concentrated on providing exercises, aimed at improving strength, coordination and mobility of his right arm and hand before he was discharged from the community rehabilitation team. He has continued to practise these exercises.

He was given information about a local stroke club by his therapists. He enjoys meeting with his peers at this group and received further information about different exercises and activities. He likes chatting with the new friends he has made in the group using landline or mobile phone. He has gathered new information about relevant exercises, useful exercises equipment, and advice for different daily activities.

He enjoys sharing updated information that he got from the websites of stroke related organisations and the National Health Services (NHS). Occasionally, he asks his wife to help him send links to new information he has found, including websites and links of online videos to other stroke survivors that he knows.

He feels the ongoing support from his peers and wife encourages him to keep practising his exercises and activities. He reports that

the feedback from his wife and friends about the use of his right arm and hand encourages others to continue with their exercises.

Progress and achievement on physical recovery

Mr S now feels confident to self manage his physical condition.

He has learned how to manage his exercises and daily activities for the mobility, strength and coordination of his shoulder, arm and hand and now understands the importance of this.

He now uses his right arm and hand to prepare food for his 2 cats and plays with them every day. He enjoys tidying his garden with his wife. He aims to use his right hand to read the newspaper and hold the cup when he drinks coffee as he appreciates that these are good exercises.

He enjoys sending text messages with his mobile phone to his peer stroke survivors to encourage and remind them to keep doing their exercises at home. He thinks that this is a good chance to further the coordination of his hand and fingers as well.

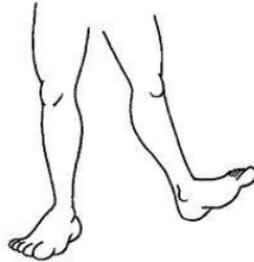
He thinks the use of different technologies can help him to receive ongoing support, feedback, information and skills for the recovery of his right arm and hand whenever he likes.

He would like to keep using his right arm and hand in his daily activities as much as he can, and believes this cannot be achieved without practising his exercises regularly.



Case study 2: (Leg)

This case story provides details about physical rehabilitation of a stroke survivor using exercises and available technology. The focus is on the physical recovery of the leg.



Background

Mr. C, 49 years old, had a stroke 1 year ago affecting his left side. He has weakness and drop-foot and now walks with a stick. He was given strengthening, mobilising and stepping exercises by his physiotherapist from the community rehabilitation team. He continued to practise these exercises after his discharge.

He received further information on different exercises and activities from a local stroke club and was introduced to his “exercise buddy”, Mr. A, in the club. Mr A is a stroke survivor with visual problem and right leg weakness, who needs to walk with a guide dog when he goes outside. Mr. C and his exercise buddy share information about different exercises and activities via emails. They use their mobile phones, for direct calls and text messages to remind each other to do their exercises and outdoor activities once a week.

Occasionally, they arrange a meeting via Skype©, (a videoconferencing system) especially if one of them cannot attend the group meeting in the club. Mr. C uses the webcam on his laptop computer, whilst Mr. A prefers to use his touch screen computer. They share the progress of their strength and control of their legs in performing daily activities, such as going outside for shopping and climbing stairs. They demonstrate new skills about

exercises such as how to do Tai Chi to strengthen knees and ankles. This allows them to provide and receive feedback.

Mr. C enjoys positive competition with Mr. A concerning who can increase the duration of walking without having any discomfort.

He also records information on his overall progress and uses this to review his overall progress every month.

Progress and achievement on physical recovery

Mr. C now feels motivated to continue practising his exercises with his buddy. He looks for further improvement in the movements and control of his left leg and thinks Mr. A's feedback is encouraging and motivating. He enjoys sharing and learning via different technologies.

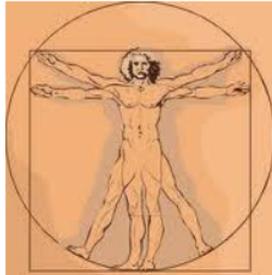
He feels his left leg is stronger with regular exercises. He can walk for about 30 minutes with his wife in a park nearby with less tiredness. He feels less unstable when he walks and climbs stairs as his legs are getting stronger and his balance is improving. He now has confidence and strength to squat down and stand up to pick things up from the floor.

He would like to maintain the strength and mobility of his left leg. Thus, he has increased the time he practises Tai Chi and other exercises for his legs.



Case study 3: (Arm, leg and trunk)

This case story provides details about physical rehabilitation of a stroke survivor using exercises and available technology. The focus is on the physical recovery of the arm, leg and trunk.



Background

Mrs. D, 51 years old, had a stroke 2 years ago. Both sides of her body were severely affected. Her left side was weaker than the right. She could only walk around her house with a walking aid under moderate assistance from her husband, because she felt unstable. Due to weakness and balance problems, she still stays in her wheelchair for most of the time. She was given mobilising, strengthening and balance exercises by her physiotherapist and occupational therapist from the community rehabilitation team. She continued to practise these exercises after her discharge.

Her husband helped her to open an account on Facebook®, which allows her to stay in touch with her friends and other stroke survivors to share and discuss her progress. She mainly uses her right hand to type. She enjoys chatting with her friends on Facebook®, which allows her to seek ongoing support, feedback and motivation to keep doing exercises. She thinks it is convenient to chat online as she can reply and share whenever she likes.

She thinks that feedback about her actions is important to motivate her to learn from her experience and achievements. Occasionally, she asks her husband to take video or photos using her smartphone when she practises sitting to standing or walking, or uses her computer. She shows it to her general practitioner to ask for feedback. She asks her husband to share the videos or

photos with her friends to ask for feedback via emails and Facebook©. She enjoys receiving comments about the changes of her performance which encourage her to keep practising her exercises and activities.

She also enjoys watching online videos about stroke rehabilitation and different exercises or activities for stroke survivors, including sitting Tai Chi. She reports that help her to learn how to improve her body movements, exercise skills and daily activities.

Progress and achievement on physical recovery

Mrs. D now feels encouraged to continue practising her exercises and activities. She feels her arms and legs are stronger. She looks for further improvement about her actions and the control of her arms and legs to perform different daily activities.

She feels her balance is better as well. She can walk for 10 metres with better stability before she needs to take a rest. She feels more confident when she walks and gets up from her wheelchair. Her husband reduced his assistance during these activities.

She can now type faster on Facebook© than a few months ago. She also feels stronger and less unstable when she gets up from her wheelchair and walks. She has less pain and better mobility and coordination over her shoulders, arms and legs as she practises her exercises regularly.

She likes using videos to monitor and review her progress about using her arms and legs for daily tasks. This also helps her to find the best ways to use her arms for different daily activities, including typing on her computer, and moving from sitting to standing. She feels confident to continue practising her exercises when she sees her progress on videos.



Appendix 10:

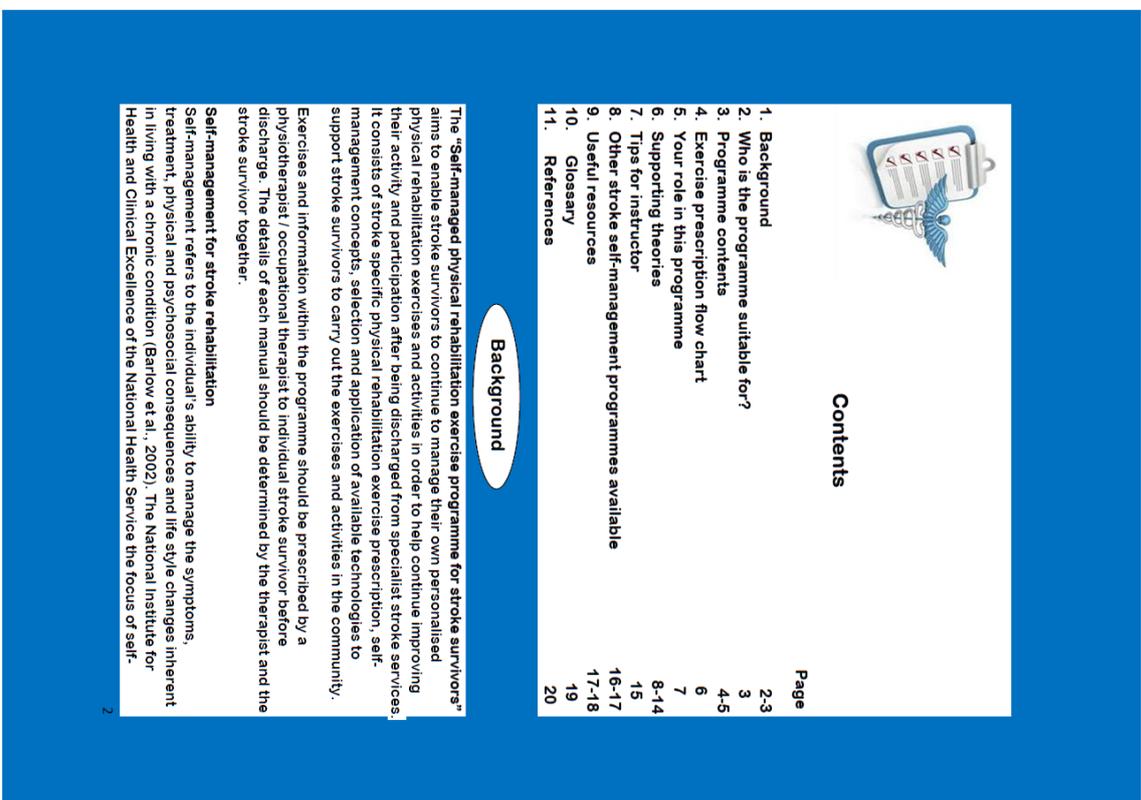
Instructor's handbook of "Self-managed physical rehabilitation exercise programme"

(Total: 20 pages in the handbook)



The cover features a blue background. At the top right, there is a circular diagram with three interlocking gears labeled 'Satisfaction', 'Technology', and 'Learning'. Below this, the title 'Self-managed physical rehabilitation exercise programme for stroke survivors' is written in white, followed by 'Instructor's handbook' in a larger font. Underneath, a subtitle reads '(A booklet for clinicians to tailor the individual self managed exercise programme)'. At the bottom, it says 'Empowering stroke survivors to manage their own physical rehabilitation exercises!'. In the center, there is a 3D illustration of a red figure pointing at a whiteboard with a blue figure sitting at a desk. The University of Sheffield logo is in the bottom right corner.

1



The page has a blue background. At the top right, there is an illustration of a clipboard with a checklist and a caduceus symbol. The title 'Contents' is centered. Below it is a table of contents with two columns: 'Page' and a list of 11 items. A white oval with the word 'Background' is positioned to the left of the table. At the bottom, there is a paragraph of text describing the handbook's purpose and a section titled 'Self-management for stroke rehabilitation'.

Page	
2-3	1. Background
3	2. Who is the programme suitable for?
4-5	3. Programme contents
6	4. Exercise prescription flow chart
7	5. Your role in this programme
8-14	6. Supporting theories
15	7. Tips for instructor
16-17	8. Other stroke self-management programmes available
17-18	9. Useful resources
19	10. Glossary
20	11. References

Background

The "Self-managed physical rehabilitation exercise programme for stroke survivors" aims to enable stroke survivors to continue to manage their own personalised physical rehabilitation exercises and activities in order to help continue improving their activity and participation after being discharged from specialist stroke services. It consists of stroke specific physical rehabilitation exercise prescription, self-management concepts, selection and application of available technologies to support stroke survivors to carry out the exercises and activities in the community. Exercises and information within the programme should be prescribed by a physiotherapist/occupational therapist to individual stroke survivor before discharge. The details of each manual should be determined by the therapist and the stroke survivor together.

Self-management for stroke rehabilitation

Self-management refers to the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and life style changes inherent in living with a chronic condition (Barlow et al., 2002). The National Institute for Health and Clinical Excellence of the National Health Service the focus of self-

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management is to enable sufferers of chronic illness to gain motivation and/or skills to improve the management of their conditions (Bury et al., 2005). Recent evidence shows that self-management is feasible, acceptable and beneficial for stroke rehabilitation (Lennon et al., 2013; Jones and Razi, 2011).

Using available information and communication technology for stroke rehabilitation
The use of telerehabilitation, including use of common information and communication technology (ICT) found in the home, has been found to be acceptable and beneficial for health and physical health after stroke (Audebert and Schwamm, 2009; Johansson and Wild, 2011). The use of available ICT has been shown to be effective for improving motor functions, functional health outcomes and overall health status post-stroke (Liebermann et al., 2006; Johansson and Wild, 2010; Johansson and Wild, 2011).

Available technologies including videoconference, email, text messaging and telephone, can provide alternative ways to provide ongoing support and access to assist the user to manage his/her own exercises and activities.

Alternatively, you might provide video examples and/or photos about how to do exercises/ activities on a DVD or a memory stick for example.

The instructor's handbook

This handbook provides information and guidance to professionals on how to establish the exercises prescription and provide the support that individual stroke survivor requires. The programme contents, a prescription flow chart and supporting theoretical information are provided in this handbook.

Information about self-management, the application of information and communication technologies (ICTs), other stroke self-management programmes and health and social care resources for stroke rehabilitation are also included.

Who is the programme suitable for?

It is designed for stroke survivors with physical difficulties in performing activities of daily living, who are to be discharged from specialist stroke rehabilitation services. Any stroke survivor will be suitable to use this programme if he/she fulfils the following criteria:

- Adult, who agrees to manage his/her own physical exercises after discharge
- Have at least one physical barrier affecting his/her daily activity and participation
- Sufficient cognitive and reading ability to understand and carry out instructions independently and safely
- Willing to use available technology to help him/her to manage his/her programme

3

Programme contents

There are 2 main components of this programme: a clinical checklist and a personalised exercise manual. Two books and a USB memory stick are included with each manual.

Book A: Clinical checklist

Book A is designed to be used by therapist and stroke survivor together to assess and determine the components for individual needs and health conditions for the programme. All details should be determined based on the stroke survivor's personal choices and needs. It is designed to be stored by your community stroke rehabilitation service unit as a clinical record. The user can request to keep an electronic copy and/ or photocopy of the checklist for him /her. The following 4 sections are included:

1. Needs assessment
 - a. Basic personal characteristics and health conditions
 - b. Goal-setting for activity and participation
2. Selection of stroke specific physical rehabilitation exercises
3. Selection of technology available for support)
4. Assistance for self-managing physical rehabilitation exercises

Book B: My stroke exercise manual

Book B is designed to be used by the stroke survivor. It consists of information about the programme, summaries of assessment results from Book A, goal-setting and action planning, personalised exercise prescription, and useful resources and contacts about physical rehabilitation, and other support.

Personalisation

You need to individualise the exercise for each user in Book B using the results of Book A. Your understanding about his/her health and social conditions, and his/her prognosis for rehabilitation for activity and participation, clinical reasoning, current guidance and evidence for physical stroke rehabilitation may also help you to prescribe the programme. You may provide information about potential barriers and risks whilst prescribing safe exercises and activities to the stroke survivor to self-manage. You need to educate the user about how to plan and manage the barriers.

Case study examples

A case study section is included in Book B. You need to choose a case story from a stroke survivor who has similar needs and conditions to that of the stroke survivor you are providing this programme for. This is to assist him/her to learn from the experiences about managing own exercises and activities with the use of available information and communication technologies from the successful story.

4

Self monitoring
 A monthly self-monitored progress record is included for the stroke survivor to monitor and regulate his/her progress. Reflecting on the progress may assist the stroke survivor to learn from his/her own experience to manage this programme. The record may help him/her to communicate with healthcare professionals for further progress or any difficulties.

You may educate your stroke survivors to use the Rating of Perceived Exertion, RPE scale (Borg scale 6-20) to monitor the intensity of exercises and activities. This may help to ensure he/she can manage his/her programme safely. The RPE is commonly used to check the subjective level of exertion (Gunnar Grimby, 2010). The suggested ranges of RPE for stroke survivors are listed below:

Aerobic training: RPE: 12-15 (slightly to moderately out of breath)
 Strengthening: RPE: 12-13
 Muscular endurance: RPE: 9-11

P. S. Range of RPE Borg scale: 6 (normal resting status, no exertion) 20 (maximum exertion)

The stroke survivor can complete the record either by writing on printed copy, or on a computer using the electronic copy within the USB memory stick of this manual.

USB memory stick
 A 1GB USB memory stick is attached with the manual. It contains the electronic copy of books A and B. You can save personal information, progress record, pictures and specific advice on personal exercises and activities, self-management and the use of available technology for your stroke survivors' needs.

You can also save video recordings, web links, written materials and contacts about local health and social care resources and supporting networks on the stick for him/her, according to the individual's needs.

When to prescribe
 You are advised to prescribe this programme 2-3 weeks before discharging the stroke survivor from specialist stroke rehabilitation services. This is to allow adequate time for him/her to try the programme and ask any questions, whilst he/she is still in touch with his / her physiotherapist / occupational therapist.

The following flow chart in Figure 1 may help you to prescribe this programme. Some sections might have been covered in your previous visits to the stroke survivor.



5

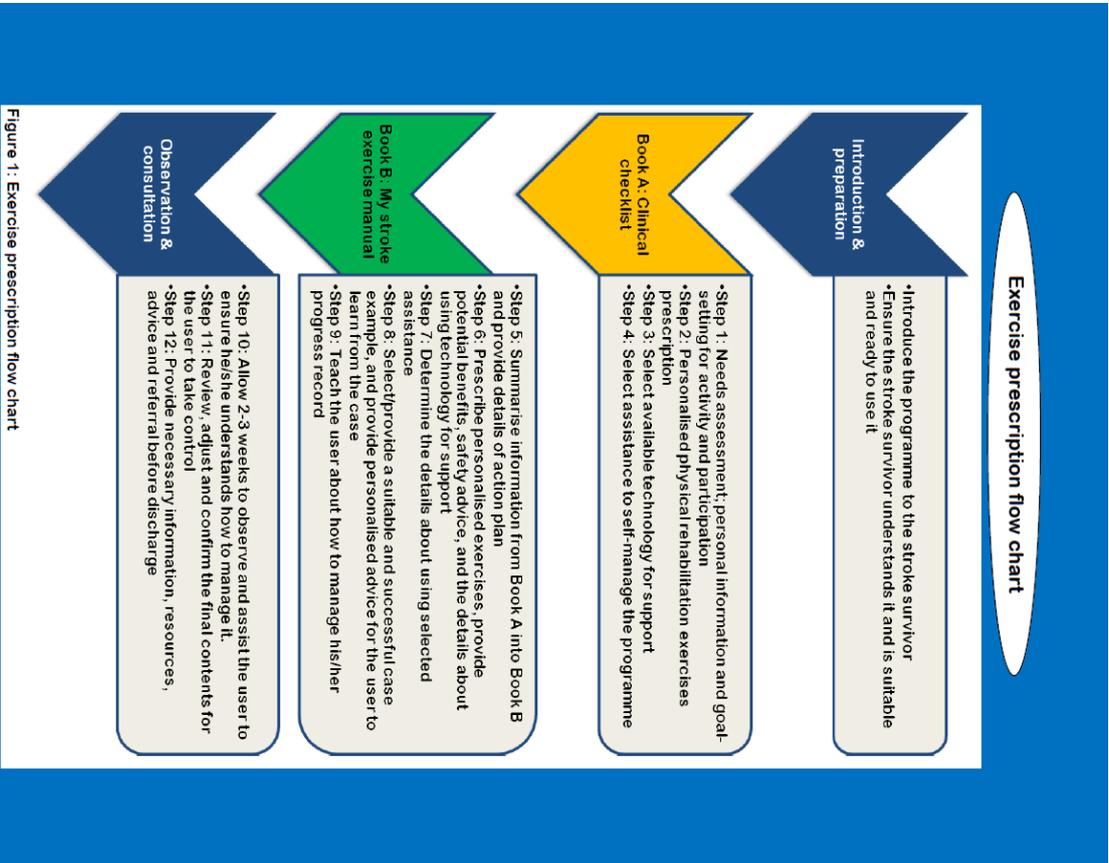


Figure 1: Exercise prescription flow chart

6

Your role in this programme

You act as the instructor, educator and facilitator when providing this programme.

Being an instructor

You need to provide professional and stepwise instructions to direct the stroke survivor to practise their exercises and activities based on the information collected with Book A and the individual's clinical conditions. You may need to provide personalised advice to assist the user to manage his/her programme.

Being an educator

You need to educate your stroke survivor to manage and monitor his/her programme. You may need to provide specific knowledge, skills and supplementary information to enable the user to manage it. It is important for you to provide basic knowledge about the benefits of the prescribed exercises and activities for his/her physical functioning.

You may teach him/her when, what, and where to seek for necessary information, skills and advice to enable the user to utilise relevant community resources to cope with any issue from his/her exercises and activities in the long-term.

You may also educate the stroke survivor to set up realistic and meaningful goals for physical rehabilitation for activity and participation based on clinical information and needs assessment results. You need to educate the user about how to manage his/her progress record to monitor and regulate the personalised programme.

Stroke survivor's safety is important for this programme. You need to teach him/her how to recognise possible risks. You also need to provide potential solutions for the user to cope with possible problem with the prescribed exercises and activities and/or about the use of the selected technology. This is to enable the stroke survivor can self-manage this programme safely.

Being a facilitator

It is important for you to collaborate with the stroke survivor to prescribe this personalised programme. You need to invite and encourage him/her to actively participate in the decision-making process to decide the components and the details with you. You need to facilitate him/her to take control over the management of his/her programme with the use of available technology via provision of advice, relevant information and resources.

You need to be aware of the theories and model that underpin this programme, which are detailed in the next section.



7

Supporting theories

This programme was developed with 3 supporting core theories: self-efficacy, learning theories and the technology acceptance model. A set of gears is used as a model to demonstrate the integrated relationships among these theories in providing cohesive theoretical support for this programme. This is illustrated with a gear model in Figure 2 below:

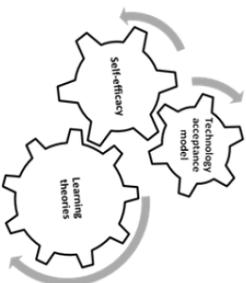


Figure 2: The gear model showing 3 supporting core theories for this programme

Self-efficacy

This is a key construct of Social Cognitive Theory and the key element for stroke self-management (Lennon et al., 2013; Jones and Razi, 2011).

It refers to the belief in one's abilities to organise and perform the action required to manage prospective situations and attain goals.

Key features

The 4 main sources of self-efficacy are described in Figure 3 below:

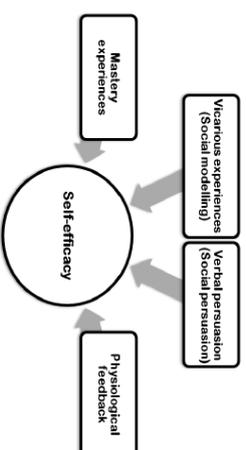


Figure 3: Four main sources of self-efficacy

8

How can I use it?

You may consider the following suggestions to enhance the individual stroke survivor's self-efficacy to manage this programme.

For Mastery experiences

This involves positive experiences in doing a task. Success can strengthen one's sense of self-efficacy.

You can encourage the stroke survivor to keep a personal progress record using the manual, USB stick or any other available technology from the beginning of the programme to record their positive experiences in a physical task / skills and/or successful performance. This enables him/her to review his/her successful experiences and progress to strengthen self-confidence. You can encourage the user to focus on positive aspects and related details when reviewing his/her progress. This can remind the user to reflect on his/her positive experiences and achievements to enhance his/her confidence in managing exercises.

You can suggest individual stroke survivor to share his/her positive experiences with others about doing exercises and / or performing daily tasks via selected technology including other stroke survivors, friends and family members. This can facilitate the user to recognise his/her successes.

For Vicarious experiences

Seeing people similar to oneself succeed can enhance an individual's self-efficacy.

You may use a successful case example to motivate the user to learn about how to identify and use necessary resources, available technology and social networks to manage exercises and activities for functional rehabilitation. You can choose a case study provided by the manual or offer case examples to provide successful experiences from other stroke survivors who have improved their abilities in activities and participation through practising physical rehabilitation exercises and the use of technology. This can motivate the individual to learn from the successful story to promote his/her self-efficacy to manage his/her exercises and activities.

You can encourage the stroke survivor to contact local stroke survivors via engaging local charity and social groups. This allows the user to learn from other stroke survivors' experiences in managing exercises, using technology and social networks in the community. You can encourage the stroke survivor to use available technology to exchange his/her successful experiences and achievement with other stroke survivors to reinforce his/her self-efficacy.

For Verbal persuasion

This promotes an individual's belief in personal skills of using persuasion and verification from others, such as healthcare professional, family member or peer stroke survivor. Verbal feedback can convince learners to accomplish daily tasks.

Using available technology can enable the stroke survivor to provide and receive positive feedback and influences from others at any time they like. You can encourage the user to use the selected technology to deliver and receive verbal feedback about his/her performance from other stroke survivors, friends and family members. This can motivate the user to practise his/her exercises and activities. You can convince the individual to take control of his/her exercises/ activities using the case story provided in the manual or by you.

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For Physiological feedback

This is about efficacy beliefs generated from feedback given by the individual's physical health state. Physical and emotional states reflect the learners' perception of their self-efficacy and they affect their performance. Self-efficacy can be increased by positive interpretation of individual's physical and emotional feelings.

You need to advise the stroke survivor to be aware of any change of his/her health condition when using this programme.

You can teach the stroke survivor about how to use the progress record to record and monitor the changes of his/her health condition, activity and participation. You can educate the user about how to reflect on the change and progress to regulate his/her action plan, exercises and activities for his/her functional goal.

Learning theories

The gear of learning theories consists of 3 theories for learning: andragogy, self-regulated learning, motor learning theory. They are incorporated and applied together to provide theoretical support to assist the user to learn how to self-manage exercises and activities. This is shown in Figure 4 below:

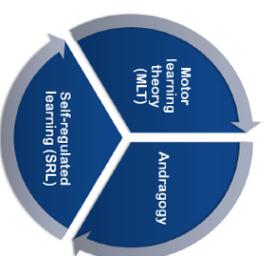


Figure 4: Three theories within the gear of the learning theories

Learning theories: Andragogy

Adult learners often control their own learning process. Andragogy is an adult learning theory related to adult education. It describes the learning process of adults gaining knowledge and expertise.

Key features

Six core principles as shown in Figure 5 below:

10

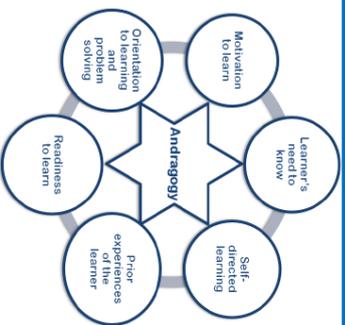


Figure 5: Six core principles of andragogy

How can I use it?

You may apply andragogy whilst prescribing this programme to your stroke survivors, who are adults, using the following concepts.

For Learner's need to know

You need to help the stroke survivor to understand the reasons why he / she needs to learn to manage his / her exercises and activities. You can provide knowledge on the benefits of practising exercises for physical stroke rehabilitation to enable the user to understand the purposes of learning how to manage the exercises/activities.

For Self-directed learning

You need to encourage the stroke survivor to determine the goal, plan and details with you. This is to enable him/her to make decision and encourage him/her to take control for monitoring and regulating his/her personalised programme.

For Prior experiences of the learner

You need to remind the stroke survivor to recall and use his / her previous successful experiences in learning an exercise or skill to perform a daily activity. You can also encourage him/her to use prior experiences during goal-setting and action planning to determine the details of related steps.

For Readiness to learn

You need to ensure the stroke survivor is ready to learn how to manage his/her exercises and activities according to your knowledge of his / her health conditions, physical ability, available resources, and technical and social support.

For Orientation to learning and problem solving

Adults are often task-centred or problem-centred in their orientation to learning. You can use Book A to help the stroke survivor to understand his/her problems in performing tasks. Then you can facilitate the stroke survivor to set up personal

goals for functional rehabilitation based on the identified problems from physical difficulties, restricted activities and participations. You can help him/her to establish a stepwise action plan to achieve each goal, so as to cope with the identified problems in performing activities for his/her physical function and participation.

For Motivation to learn

You need to be aware of the potential motivators of the stroke survivors to practise exercises, especially internal motivators, such as the desire for self-esteem, quality of life and personal preferences, particularly when identifying assistance. This may motivate the individual to keep learning and doing exercises and activities.

Learning theories: Self-Regulated Learning (SRL)

It is a learning theory to supplement the principle of andragogy in this programme. SRL is a way for learners to master their learning, via actions and processes directed at acquisition of information or skills.



Key Features

Under SRL, the learning process is guided by thinking about one's thinking including the use of feedback, planning, monitoring, and evaluating personal progress to attain personal goals, and motivation to learn. The 6 core elements of SRL are shown in Figure 6 below:

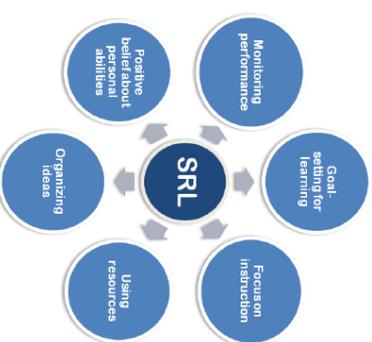


Figure 6: Six core elements of self-regulated learning

How can I use it?

The SRL is adopted to supplement the self-directed learning concept in andragogy. You need to know the stroke survivor's goals of functional rehabilitation for activities and participations. This allows you to determine how to help him/her to learn to self-manage exercises. You need to help the stroke survivor to set up realistic and functionally meaningful goals for learning how to manage exercises and activities.

You can provide stepwise instructions to guide the user for his/her action plans.

You need to motivate the user to believe in his / her abilities to manage and monitor his/her programme. You may use the case study to encourage him/her to think positively. You can reassure the stroke survivor about his/her abilities to practise his/her exercises and activities based on the assessment results in Book A and previous visits. You can teach the user about how to monitor his/her performance with the progress record, and learn from his/her positive experience and achievement to reinforce the individual's confidence to manage his/her exercises.

You can guide the user to use health and social care resources and networks according to his/her needs (shown in Book B). You need to help the user to prioritise his /her goals with the consideration of his/her needs and health conditions, so as to plan and decide what resources to use.

Learning theories: Motor Learning Theory (MLT)

This is about acquisition and modification of skills for motor movement. It involves the analysis and training of specific tasks for stroke rehabilitation. Providing feedback on the change of physical movement and motor performance is important for motor learning for stroke survivors to improve motor functions.



Key features

The focus of motor relearning is on the active participation of the stroke survivor with guidance and feedback. Providing feedback in terms of the knowledge of performance (KP) and the knowledge of result (KR) are important for motor learning.

How can I use it?

It is important to include the concepts of MLT to assist the stroke survivor to regain the motor control and skills in this programme. Thus, both KP and KR should be applied when you provide this programme. This can motivate the user to keep practising his/her exercises/activities and take action to improve.

For the knowledge of performance

You can teach the stroke survivor to record and describe the details of the change of his/her movement and daily function using the progress record. This may help the user to learn about how to regulate his/her motor performance.

For the knowledge of results

You can teach the stroke survivor to record the success of his/her movement or daily task using the progress record. He/she can review the record to learn from the results for his/her activities and participations. This may motivate the user to learn the movement and perform the functional task.

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Technology Acceptance Model (TAM)

This is the underpinning model adopted to support the selection and application of available technology in this programme. It is about the understanding and explanation of users' underlying psychology, internal beliefs, behaviours, intentions, attitudes and acceptance towards using technology.



Key features

The perceived usefulness and perceived ease of use are the key constructs of TAM. These factors may influence the individual's attitude, belief and the actual use of technology. This is illustrated in Figure 7 below:

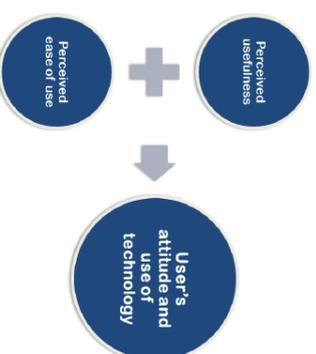


Figure 7: Two key constructs of technology acceptance model

How can I use it?

When choosing available technology to support the user, the perceived usefulness and ease of use of available technology should be considered.

These concepts are important whilst determining which available technology to choose and planning how to use the selected technology to facilitate the user to manage his/her personal exercises and activities in the community.

You can remind the user to consider these factors whilst selecting appropriate technology from the list in Book A. You may also remind the user to consider these factors when he/she needs to select and use any available technology to support him/her to self-manage his/her exercise and activities in the future.

14



Tips for instructors

- Try to work together with the stroke survivor to set up realistic and functional goals with stepwise action plans. You may provide your knowledge and experience to help him/her to understand why and how to do so
- It's important to individualise the contents for each stroke survivor
- Try to consider the supporting theories and model in the gear model whilst you prescribe the programme
- You may combine the information from the case examples, user's preference and health condition and your clinical reasoning process for physical functional stroke rehabilitation to prescribe this programme
- Try to motivate the user to be a "life-long learner" to keep learning and updating his/her knowledge about physical health, exercises and activities
- You may remind the user to focus on his/her positive experience and achievement in exercises and activities. You may encourage him/her to learn from their positive experiences to identify a suitable way to manage his/her exercises and activities. This is to provide positive feedback to motivate the user to keep practising his/her exercises
- Try to encourage the stroke survivor to use the selected available technology to receive ongoing support, positive feedback and influence from others to promote his/her self-efficacy to manage this programme
- You may encourage him/her to use the selected technology to find new information about exercises and activities for his/her physical functions
- Please provide your advice on safety issues for the user to manage his/her programme. You may suggest possible solutions to cope with potential barriers and risks, including any technical issues about using the selected technology and prescribed exercise/activities, using stepwise instruction
- You may refer to the "Useful resources" section in this handbook for further information for you to prescribe personalised exercises and activities to tailor this programme for individual user. You may suggest other information, resources and contacts to enable the user to self-manage
- Try to avoid using professional terminology and jargon



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Other stroke self-management programmes available

This programme mainly focuses on managing physical exercises and activities for the purpose of the rehabilitation for physical functioning post-stroke. You may refer your stroke survivors to the following stroke specific self-management programmes in the United Kingdom for their multiple health and social needs in order to provide comprehensive stroke rehabilitation in the community.

Name: Bridges Stroke Self-management programme

This was designed by Dr Fiona Jones in 2005 in collaboration with a group of stroke survivors. It aims to support stroke survivors to develop their self-management skills.

It was developed with the use of self-efficacy theory. It is made up of 2 parts:

1. Teach practitioners, who are health and social care workers who work with people who have had a stroke, about self-management principles, and how to use the Bridges approach on a one to one basis with stroke survivors.
2. Provide an individualised, client-led 'stroke workbook' which practitioners work through with clients to support their self-management. The workbook includes individual stories and strategies suggested by stroke survivors, as well as a space for the client to record personal goals and successes.

Contacts:

Bridges Self-Management Limited
Address: 2nd Floor Grosvenor Wing, St George's, University of London and Kingston University, Cranmer Terrace, London, SW17 0RE
Website: www.bridgesselfmanagement.org.uk
Email: info@bridgesselfmanagement.org.uk
Twitter: [bridgesselfmgmt](https://twitter.com/bridgesselfmgmt)
Facebook: [bridgesselfmanagement](https://www.facebook.com/bridgesselfmanagement)
Tel: 020 8725 2445

Name: Stroke Workbook programme

This is a self-management programme based on behaviour change techniques. It was produced by NHS Lothian for people and families affected by stroke. It consists of a workbook with information about stroke and recovery using cognitive behavioural therapy. A diary and audio relaxation CD accompanies the workbook.

Contacts:

The Heart Manual Programme
Stroke Workbook Team
Address: Aistley Ainslie Hospital, Administration Building, 133 Grange Loan, Edinburgh, EH9 2HL, Scotland, United Kingdom
Website: www.theheartmanual.com
Email: heart.manual@nhslothian.scot.nhs.uk
Tel: 0131 537 9127/9137 Fax: 0131 537 9489

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Useful resources

Lists of health and social care resources is provided in Book 8 to address the user's multiple health and social needs of physical rehabilitation. You may provide additional information and contacts of health and social care resources and networks across the UK for the individual to manage this programme.

You may educate the stroke survivor about when, what and where he/she should seek further information and advice after discharge. You may refer to the following guidelines to prescribe personalised stroke exercises and activities for the user.

Guidelines	Links
Royal College of Physicians (RCP) National Clinical Guideline for Stroke (4th edition) (ISWP, 2012)	http://www.rcplondon.ac.uk/sites/default/files/national-clinical-guidelines-for-stroke-fourth-edition.pdf
National Institute for Health and Care Excellence (NICE) Stroke Rehabilitation: Long-term Rehabilitation after Stroke (NICE, 2013)	NICE clinical guideline 162 (stroke rehabilitation) http://guidance.nice.org.uk/cg162 NICE pathway for stroke rehabilitation http://pathways.nice.org.uk/pathways/stroke
Scottish Intercollegiate Guidelines Network (SIGN) management of patients with stroke, Rehabilitation, Prevention and Management of Complications, and Discharge Planning (SIGN, 2010)	http://www.sign.ac.uk/pdf/sign118.pdf
Best Practice Guidance for the Development of Exercise after Stroke services in Community settings (Best et al., 2010)	http://www.exerciseafterstroke.org.uk/resources/Exercise_After_Stroke_Guidelines.pdf
Stroke, in "Physical Activity in the Prevention and Treatment of Disease" (Gunnar Grimby, 2010)	http://www.fhi.se/PageFiles/10682/Physical-Activity/Prevention-Treatment-Disease-10682.pdf

You may refer to the following books and DVD to obtain stroke specific information to tailor your prescription for individual stroke survivors.

Books / DVD	Notes
Book: Exercise and Fitness Training After Stroke: A Handbook for Evidence-Based Practice (Mead, 2013) Editors: Professor Gillian Mead and Dr Frederike van Wijck	This book provides professional information about exercise after stroke for healthcare and/or exercise professionals to prescribe and provide exercises and physical trainings to stroke survivors
Book: The Successful Stroke Survivor: The new guide to functional recovery from stroke (Balchin, 2011) Author: Dr Tom Balchin	This book contains information about doing exercises and performing daily activities for the rehabilitation of daily functions after stroke

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DVD: You Care, They Care, We Care: a practical stroke guide from NHS Five
Developed by: NHS Five and Chest, Heart & Stroke Scotland (CHSS)

This DVD contains practical information about doing exercises and performing physical skills for functional tasks in the community after stroke.
Video clips of the DVD can be downloaded on www.stroked4carers.org
Please contact NHS Five for further details.
Direct Tel: 01383 565379

You may also contact the following organisations for further professional information and trainings about providing exercises after stroke in the UK.

Professional training courses	Notes
L4 Exercise and Fitness Training after Stroke Specialist Instructor Qualification Provided by: Later Life Training Website: www.laterlifetraining.co.uk Email: info@laterlifetraining.co.uk Phone: 01838 300310	This is a specialist training course for healthcare and/or exercise professionals working with stroke survivors who would like to further train up into exercise after stroke and obtain <i>Exercise After Stroke Instructor</i> qualification in the UK Please contact "Later Life Training" for further information
Functional Rehabilitation and Training after Stroke Qualification course Provided by: The Action for Rehabilitation from Neurological Injury (ARNI) and Middlesex University Web-site: www.arni.uk.com Email: tom@arni.uk.com Phone: 07712 211378	This is a training course for qualified therapists or exercise trainers to learn how to teach stroke survivors to perform functional rehabilitation exercises Please contact "The ARNI Trust central" for further details

(Disclaimer: the author of this programme, his supervisors and sponsors bear no responsibility for the services and information provided by the above organisations)

18

Glossary

Terms	Definition in this programme
Activity	Physical actions that a person can do with given abilities, such as walking or brushing teeth
Andragogy	Adult learning theory related to adult education. It describes the learning process of adults gaining knowledge and expertise. It consists of 6 core principles
Information and Communication Technology (ICT or ICTs)	Information and Communication Technology (or Technologies): For this programme, ICT refers to any technology providing access to information via telecommunications, with the focus on using the technology to receive and deliver information and communication over a distance. Commonly available ICTs include internet, computer, email, online discussion forum, web-site, landline or mobile telephone, smartphone, text messaging DVD, video-recording and videoconferencing. Available technology refers to ICT in this programme.
Motor Learning Theory (MLT)	A theory about skill acquisitions and the modification of motor movement. Providing feedback in terms of the knowledge of performance and the knowledge of result are important for motor relearning process
Participation	The extent of an individual's involvement in social life, autonomy and interaction with others
Rehabilitation	A process to restore a health condition, capacity or normal life by intervention such as training, therapy and education
Self-efficacy	A key construct of Social Cognitive Theory. It refers to the belief in one's abilities to organise and perform the action required to manage prospective situations and attain goals
Self-management	It refers to the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and life style changes inherent in living with a chronic condition in this programme
Self-regulated learning (SRL)	The learning process is guided by the use of feedback, planning, monitoring, and evaluating personal progress to attain personal goals, and motivation to learn
Technology Acceptance Model (TAM)	A model about the understanding and explanation of users' underlying psychology, internal beliefs, behaviours, intentions, attitudes and acceptance towards technology. The perceived usefulness and perceived ease of use are the key constructs
Tele-rehabilitation	It refers to remote delivery of rehabilitation services to people with disabilities and chronic conditions using information and communication technologies at a distance in this programme.



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References

- AUDEBERT, H. J. & SCHWAMM, L. (2009) Telerehabilitation: scientific results. *Cerebrovascular Diseases*, 27, 15-20.
- BALCHIN, T. (2011) *The Successful Stroke Survivor: The new guide to functional recovery from stroke*. Surrey, the UK, Bagwyn.
- BANDURKA, A. (1997) The nature and structure of self-efficacy. *Self-efficacy: the exercise of control*. New York: WH Freeman and Company.
- BANDURKA, A. (2000) Social-cognitive theory. *Encyclopedia of Psychology*, 7, 329-332.
- BARLOW, J., WRIGHT, C., SHEASBY, J., TURNER, A. & HAINSWORTH, J. (2002) Self-management approaches for people with chronic conditions: a review. *Patient Education and Counselling*, 46, 177-187.
- BEST, C., VAN WILCK, F., DINAN-YOUNG, S., DENNIS, J., SMITH, M., FRASER, H., DONAGHY, M. & MEAD, G. (2010) *Best Practice Guidance for the Development of Exercise after Stroke Services in Community Settings*. The University of Edinburgh.
- BURRY, M., NEWBOLD, J., TAYLOR, D., HEALTH, N. I. F. & C. E. (2005) *A rapid review of the current state of knowledge regarding lay-led self-management of chronic illness: evidence review*. National Institute for Health and Clinical Excellence London.
- CARR, J. H. & SHEPHERD, R. B. (1989) A motor learning model for stroke rehabilitation. *Physical Therapy*, 75, 372-380.
- DAVIS, F. D. (1989) Perceived usefulness, perceived ease of use, and user acceptance of information technology. *MIS quarterly*, 319-340.
- GUNNAR GRIMBY, C. W., MARGARETA ENGARDT, KATHARINA STIBRANT SUNNERHAGEN (2010) Stroke. IN PROFESSIONAL ASSOCIATIONS FOR PHYSICAL ACTIVITY, S. (Ed.) *Physical Activity in the Prevention and Treatment of Disease*. 2nd ed., Swedish National Institute of Public Health, Sweden.
- ISWF (2012) *National clinical guideline for stroke*. Royal College of Physicians of London.
- JOHANSSON, T. & WILD, C. (2011) Telerehabilitation in stroke care—a systematic review. *Journal of Telemedicine and Telecare*, 17, 1.
- JOHANSSON, T. & WILD, C. (2010) Telemedicine in acute stroke management: systematic review. *International Journal of Technology Assessment in Health Care*, 26, 149-155.
- JONES, F. & RIAZI, A. (2011) Self-efficacy and self-management after stroke: a systematic review. *Disability & Rehabilitation*, 33, 797-810.
- JONES, F., MANDY, A. & PARTRIDGE, C. (2009) Changing self-efficacy in individuals following a first-time stroke: Preliminary study of a novel self-management intervention. *Clinical Rehabilitation*, 23, 522-533.
- KNOWLES, M. S., HOLTON III, E. F. & SWANSON, R. A. (2012) The adult learner. Routledge.
- LENNON, S., MCKENNA, S. & JONES, F. (2013) Self-management programmes for people post stroke: a systematic review. *Clinical Rehabilitation*, 27, 867-878.
- LEBERMANN, D. G., BUCHMANN, A. S. & FRANKS, I. M. (2006) Enhancement of motor rehabilitation through the use of information technologies. *Clinical Biomechanics*, 21, 8-20.
- MEAD, F. V. W. A. G. (Ed.) (2013) *Exercise and Fitness Training After Stroke: a handbook for evidence-based practice*. Elsevier Ltd.
- NICE (2013) *Stroke rehabilitation: long-term rehabilitation after stroke*. London, the United Kingdom, National Institute for Health and Care Excellence.
- SIGN (2010) *Management of patients with Stroke: Rehabilitation, Prevention and Management of Complications and Discharge Planning: a national clinical guideline*. Edinburgh, the United Kingdom, Scottish Intercollegiate Guidelines Network, Healthcare Improvement Scotland.
- ZIMMERMAN, B. J. (1990) Self-regulated learning and academic achievement: An overview. *Educational Psychologist*, 25, 3-17.

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Appendix 10: USB memory card

Size:

-before opening the card: 8cm x5cm (the upper one)

-after opening the card: 11 cm x 5cm (the lower one)



Appendix 11: Supplementary note for instructor

Supplementary note for instructor

Introduction

This supplementary note aims to provide information to assist you to better personalise the contents of each manual for the individual stroke survivor in practice. Three sections are included in this note as below.

Sections

1. Stroke-specific exercise manual for physical functional recovery

- it provides a list of exercise components for you to prescribe a stroke-specific exercise manual
- it is generated from the reviews of relevant evidence and guidelines about stroke exercise
- it contains summarised information about the core exercises and dosages for stroke survivors' physical functional recovery to provide reference to the instructor

2. Suggestions for clinician to identify the stroke survivors' attitudes toward taking control of the management their own exercise to facilitate the delivery process

- it provides additional suggestions to the instructor to personalise the contents of each exercise manual with the considerations of the individual stroke survivors' attitudes
- it serves to facilitate the communicate between the provider and user of the manual during prescription process
- suggestions are generated from the opinions of stroke survivors with physical disabilities

3. Suggestions for selecting suitable available technology with stroke survivors

- it provides additional suggestions to the instructors to determine the suitable available technology to support the individual stroke survivor to continue to manage their own exercise
- it serves to facilitate the decision-making process when selecting the desirable technology
- suggestions are generated from the opinions of stroke survivors with physical disabilities

Section 1: Stroke-specific exercise manual for physical functional recovery

It aims to suggest a list of evidence-based exercise components for you to consider for your prescription. You may need to personalise the contents of each exercise manual according to your findings from using the Book A and Book B of this programme with the patient.

In general, there are 2 stages included for stroke exercise programme: (1) pre-exercise assessment and (2) exercise sessions:

(1) In the pre-exercise assessment session, medical and activity history, physical examination, exercise tests, contraindications, risk assessment, and information provision are involved. This is to obtain an overview of the stroke survivor’s impairments to tailor the exercise programme to the individual stroke survivor.

(2) For the exercise session, it is often being divided into 3 sub-sections: warm-up, training and cool down. Exercises ranging from stretching, aerobic, muscular strengthening, balance and coordination training.

The following table suggests common components according to recent evidence and guidelines about physical exercise for physical stroke rehabilitation.

Stage	Section	Mode	Recommendation
(1) Pre-exercise assessment session	<ul style="list-style-type: none"> • Introduction • Basic base-line assessment • Individual exercise program design • Exercise testing & individual exercise prescription • Information provision 		<ul style="list-style-type: none"> • General and stroke related medical history • Medication relevant to exercise restriction • Physical health status, blood pressure, heart rate, motor control, balance, gait, functional abilities, visuospatial problems, cognition and communication • Risk assessment
(2) Exercise session	Warm up (15-20mins)	Flexibility exercises (include stretching & mobilising exercises)	<ul style="list-style-type: none"> • Before each aerobic and strength training • Include circulation booster; march • 2-3 days/week • Hold each stretch for 10-30 seconds

Continue appendix 11

Stage	Section	Mode	Recommendation
	Training section	Aerobic training	<ul style="list-style-type: none"> • Include walking, stepping, sit to stand, stair-climbing, cycling • 2-5 days/week • 10-60 mins/session (multiple 10 mins sessions) • Rating of Perceived Exertion (RPE): 11-16 (6-20 scale) • Gradually increase from 15 minutes • Intensity: 40-70% heart rate reserve/ 55-80% Maximal Heart Rate (HRmax)
		Resistance (strengthening) training	<ul style="list-style-type: none"> • upper and lower limbs functional trainings: sit-to-stand, stair-climbing, resistance & free weights • 1-3 days/week • 8-10 exercises • 7-15 repetitions • 1-3 sets • 50-80% 1 RM (repetition maximum) • RPE: 12-13 (6-20 scale) • Major muscle groups
		Muscular endurance training	<ul style="list-style-type: none"> • include: circuit training, walking • 1-3 sets • 25-50 repetitions • 1-5 times/week • 30-50% 1RM • RPE: 9-11 (6-20 scale)
		Neuromuscular training	<ul style="list-style-type: none"> • Balance and coordination trainings • Such as steadily paced lateral stepping • 1-3 days/week • Include tai chi, yoga etc.
		Task-oriented functional training	<ul style="list-style-type: none"> • such as constraint-induced movements therapy (CIMT), tai chi, yoga, recreational activities & functional movement training
	Cool down (10-20 minutes)	Flexibility exercises (include stretching & mobilising exercises)	<ul style="list-style-type: none"> • After each type of training • Hold each stretch for 10-30 seconds • Include circulation exercise

Continue appendix 11

Section 2: Suggestions for clinician to identify the stroke survivors' attitudes toward taking control of the management their own exercise to facilitate the delivery process

The following attitudes of the stroke survivor may influence the individual to take control of the exercise programme in your prescription and follow-up sections:

- **Independent**
- **Determined**
- **Positive**

Recognising the above attitudes may facilitate your rapport with your stroke survivor during your prescription in order to encourage him/her to take up the management of his/her own exercise programme. You may consider the above factors in addition to the concepts provided inside the instructor's handbook including self-efficacy and self-regulatory learning.

Section 3: Suggestions for selecting suitable available technology with stroke survivors

This section suggests what the patient may consider when choosing technology for supporting the self-management of their own exercise. This may help you to better communicate with your patient to determine suitable technology to use. The following factors may influence the stroke survivors to decide which available technology to use to support him/her to continue to manage the personalised exercise manual. You may consider the following factors when you determine the technology with your patient.

- **Personal preference**
- **Ease of understanding**
- **Tailored to the user condition**
- **Allow easy communication and interaction**

Appendix 12: Chapter 2 review 2.2a data extraction form for review 1

Title of review
General information
Title of article
Title of journal
Year/ volume/issues
Authors
Type of publication
Study details
Study type
Aim
Objective
Country/location study done
Setting
Number of participants
Characteristics of participants
Methods
Study design
Inclusion criteria
Exclusion criteria
Data collection method
Type of intervention
Description of intervention
Intervention group
Comparison group
Random allocation
Blinding methods
Equivalent treatment other than the intervention
Complete follow-up or not
Analysis of withdrawal (intention-to-treat analysis)
Results
Outcome measures
Key findings
Discussion
Major findings
Limitation
Conclusion
Effect of the intervention
Implication

Appendix 13: Chapter 2 review 2.2a table 2.2a.1-2.2a.5 summaries of trials

Table 2.2a.1 Summary of the reviewed trials: mobility exercise (n=3)

Type of exercise & number of trials	Total number of participants involved	Code no.	Authors, year & number of participants (n)	Intervention & comparison intervention	Outcome measures	Results
Mobility (n=3)	97	1	(Cho et al., 2015) (n=12)	experimental group, which did perform cervical range of motion exercises control group, which did not perform exercises	-forced vital capacity -forced expiratory volume at one second -peak cough flow rate	-cervical range of motion exercises can effectively improve the pulmonary function and coughing ability of stroke patients intubated with tracheostomy tubes -cervical range of motion exercises can help to remove tracheostomy tubes
		2	(Tseng et al., 2007) (n=59)	range-of-motion exercise protocols were similar in both intervention groups, and consisted of full range-of-motion exercises of the upper and lower extremities	- joint angles - activity function - perception of pain	- improvement in joint angles, activity function, perception of pain compared with the usual care group -a nurse-led range-of-motion exercise programme can generate positive effects in enhancing physical and psychological function of bedridden older people with stroke
		3	(McClellan and Ada, 2004) (n=26)	experimental group participated in a six-week, home-based mobility program control group participated in a six-week, home-based program of upper-limb exercises (i.e. 'sham' mobility exercises)	- standing (Functional Reach) - Item 5 of the Motor Assessment Scale (for walking)	-subjects in the experimental group demonstrated significant improvement in standing compared to the control group -mobility program was effective in improving some of the mobility in people after discharge from stroke rehabilitation

Table 2.2a.2 Summary of the reviewed trials: aerobic (n=3) and walking exercises (n=15)

Type of exercise & number of trials	Total number of participants involved	Code no.	Authors, year & number of participants (n)	Intervention & comparison intervention	Outcome measures	Results
Aerobic (n=3)	198	4	(Jin et al., 2013) (n=128)	a 12-week progressive aerobic cycling training group or a control group	-Peak exercise capacity (VO ₂ peak) - muscle strength -6MWT -hear rate recovery (HRR)	- cycling training leads to significant increase in peak VO ₂ , HRR, muscle strength and 6MWT distance - aerobic cycling training can favorably modify HRR in stroke survivors
		5	(Toledano-Zarhi et al., 2011) (n=28)	All participants were instructed in home practice to achieve strength and flexibility, and were asked to continue their normal community routine. Intervention group participants performed a supervised exercise training program	-6-minute walk distance test (6MWT) -modified Bruce treadmill test	- only the intervention group participants showed a significant clinical change in 6MWT -early supervised aerobic training after minor ischemic stroke is well tolerated and associated with improved walking endurance
		6	(Potempa et al., 1995) (n=42)	experimental group (a 10-week aerobic exercise training program) control group (a 10-week program of passive range-of-motion exercise)	-exercise metabolic parameters (oxygen consumption (VO ₂), expiration per minute (VE), carbon dioxide production (VCO ₂), respiratory exchange ratio (RER) -heart rate resting and submaximal blood pressures -workload (electronically braked ergometer) -exercise time (i.e. total amount of time in seconds of the graded exercise test counted from the first downward stroke of the ergometer pedal until the subject stopped pedaling) - Fugl-Meyer Assessment (FMA) (for sensorimotor function)	- improvement in maximal oxygen consumption, workload, and exercise time. -improvement in sensorimotor function was significantly related to the improvement in aerobic capacity - stroke patients may improve their aerobic capacity and submaximal exercise systolic blood pressure response with training -sensorimotor improvement is related to the improvement in aerobic capacity - moderately disabled, chronically hemiparetic stroke patients may improve their aerobic capacity with adequate exercise training - subjects undergoing aerobic exercise also demonstrated improvement in functional

Continue table 2.2a.2

Type of exercise & number of trials	Total number of participants involved	Code no.	Authors, year & number of participants (n)	Intervention & comparison intervention	Outcome measures	Results
						workload and exercise time to a greater extent than expected for the increase in aerobic capacity - improvement in aerobic capacity was significantly related to improvement in sensorimotor function, which indicates that exercise training functionally benefits those subjects able to train at an intensity high enough to increase aerobic capacity
Walking (n=15)	1340	7	(Treger et al., 2014) (n=86)	intervention group received detailed instructions for 14 exercises and was instructed to walk for at least 30 minutes daily control group received only standard discharge forms	-10-metre walk test (10MWT) -6-minute walk test (6-MWT) -Timed-Up-and-Go (TUG)	-improved time of 10-MWT, 6-MWT, TUG
		8	(Gordon et al., 2013) (n=128)	intervention group walked overground for 30 minutes, 3 times per week for 12 weeks. control group received massage to the affected side	-Barthel index -Older Americans resources and services scale -6MWT -Motricity index	-greater improvement for physical health component of SF-36 -greater improvement of distance walked in 6MWT -Aerobic walking improves the physical health component of quality of life and endurance
		9	(Nadeau et al., 2013) (n=408)	A group received walking training on a treadmill using body-weight support and practice overground at clinics (locomotor training program) another impairment-based strength and balance exercise at home	- comfortable walking speed - fast walking speed - 6MWT - step activity monitor, - number of steps per day - Stroke Impact Scale - FMA - Berg's balance scale (BBS)	-either walking training on a treadmill and overground, or strength and balance exercises improved walking, regardless of severity of initial impairment

Continue table 2.2a.2

		10	(Høyer et al., 2012) (n=60)	<p>one received 30 sessions of treadmill training with body weight support plus traditional training</p> <p>the other traditional walking training alone</p>	<p>- functional ambulation category (FAC) score</p> <p>-Walking</p> <p>-FIM</p> <p>-shorter transfer and stairs</p> <p>-10MWT</p> <p>- 6MWT</p>	<p>- improvements in walking and transfer were shown within both treadmill training with body weight support and traditional walking training groups</p>
		11	(Franceschini et al., 2009) (n=97)	<p>conventional rehabilitative treatment plus gait training with body weight support on a treadmill (experimental group)</p> <p>conventional treatment with overground gait training only (control group)</p>	<p>-Motricity index</p> <p>-trunk control test</p> <p>-Barthel index</p> <p>-functional ambulation categories</p> <p>-10MWT</p> <p>-6MWT</p> <p>-Walking handicap scale</p>	<p>- both groups showed improvement in all outcome measures</p>
		12	(Peurala et al., 2009) (n=56)	<p>A group do gait trainer exercise</p> <p>Another group walking training over ground or conventional treatment</p>	<p>- functional ambulation category (FAC) score</p> <p>- Berg's balance scale (BBS)</p>	<p>- walking training improved gait function irrespective of the method used, but the time and effort required to achieve the results favour the gait trainer exercise</p> <p>-early intensive gait training resulted in better walking ability than did conventional treatment</p>
		13	(Luft et al., 2008) (n=71)	<p>one group received progressive task-repetitive treadmill exercise</p> <p>the other group received stretching on walking or aerobic fitness training</p>	<p>-treadmill walking velocity</p> <p>-cardiovascular fitness</p> <p>-functional MRI</p>	<p>-improved treadmill-walking velocity, cardiovascular fitness and recruits cerebellum-midbrain circuits which is associated with better walking</p> <p>- progressive task-repetitive treadmill exercise promotes gait recovery of stroke survivors with long-term mobility impairment and provide evidence of neuroplastic mechanisms that could lead to improve functional outcomes</p>
		14	(Yen et al., 2008) (n=40)	<p>experimental group received additional body weight-supported treadmill training</p>	<p>- Berg's balance scale (BBS)</p> <p>-gait parameters</p> <p>-focal transcranial magnetic stimulation</p>	<p>-improved on BBS</p> <p>-walking speed</p> <p>-step length</p> <p>-additional gait training improve balance and gait performance and may induce changes in corticomotor excitability</p>

Continue table 2.2a.2

Type of exercise & number of trials	Total number of participants involved	Code no.	Authors, year & number of participants (n)	Intervention & comparison intervention	Outcome measures	Results
		15	(Macko et al., 2005) (n=61)	progressive treadmill aerobic training or a reference rehabilitation program of stretching plus low-intensity walking (control)	- VO2peak -O2 consumption during submaximal effort -6MWT -walking impairment questionnaire -rivermead mobility index	-improved ambulatory performance on 6MWT, mobility function, VO2 peak - treadmill walking training improves both functional mobility and cardiovascular fitness in patients with chronic stroke and is more effective than reference rehabilitation common to conventional care
		16	(Peurala et al., 2005) (n=45)	3 groups: (1) gait trainer exercise with functional electric stimulation (2) gait trainer exercise without stimulation (3) walking overground	-10MWT -6MWT -lower-limb spasticity -muscle force -Scandinavian Stroke Scale -modified motor assessment scale -functional independence measure (FIM)	-faster gait -both body weight-supported training and walking exercise training programs resulted in faster gait after the intensive rehabilitation program -patients' motor performance remained improved
		17	(Pohl et al., 2002) (n=60)	3 different gait therapies: 20 subjects were treated with structured speed-dependent treadmill training (STT) 20 subjects were trained to walk on a treadmill with a 20% increase of belt speed over the treatment period; limited progressive treadmill training (LTT) 20 subjects were treated with conventional gait training (CGT)	-overground walking speed -cadence -stride length -functional ambulation category (FAC) score	-structured speed-dependent treadmill training group resulted in better walking abilities -gait training strategy provides a dynamic and integrative approach for the treatment of gait dysfunction after stroke

Continue table 2.2a.2

		18	(Werner et al., 2002) (n=30)	One group received gait trainer therapy, and the other group received treadmill therapy	<ul style="list-style-type: none"> - functional ambulation category (FAC) score - gait velocity -required physical assistance during both kinds of locomotor therapy -Rivermead motor assessment score - modified Ashworth score (for ankle spasticity) 	- during treatment, the FAC, gait velocity, and Rivermead scores improved in both groups, and ankle spasticity did not change
		19	Laufer Y et al, 2001 (n=25)	<p>In addition to conventional physical therapy, the experimental group participated in 15 treadmill-training sessions in which a handrail was used for external support</p> <p>control group received the same number of equal length sessions of over-ground ambulation</p>	<ul style="list-style-type: none"> -functional walking ability -walking speed -stride length -temporal characteristics of gait - electromyographic activity of calf muscles 	- treadmill training may be more effective than conventional gait training for improving some gait parameters such as functional ambulation, stride length, percentage of paretic single stance period, and gastrocnemius muscular activity
		20	(Nilsson et al., 2001) (n=73)	<p>treatment group received walking training on a treadmill with BWS</p> <p>control group received walking training according to the Motor Relearning Programme but not including treadmill training</p>	<ul style="list-style-type: none"> - Functional Independence Measure (FIM) -walking velocity for 10 m -Functional Ambulation Classification (FAC) -Fugl-Meyer Assessment (FMA) - Berg's balance scale (BBS) 	-treadmill training with BWS at an early stage of rehabilitation after stroke is a comparable choice to walking training on the ground
		21	(Visintin et al., 1998) (n=100)	<p>one group subjects were trained to walk with up to 40% of their body weight supported (BWS) by a BWS system with overhead harness (BWS group)</p> <p>other subjects were trained to walk bearing full weight on their lower extremities (no-BWS group)</p>	<ul style="list-style-type: none"> -Berg's balance scale (BBS) -Stroke rehabilitation assessment of movement (STREAM) -functional balance -motor recovery -overground walking speed -overground walking endurance -motor recovery 	retraining gait in patients with stroke while a percentage of their body weight was supported resulted in better walking abilities than gait training while the patients were bearing their full weight

Table 2.2a.3 Summary of reviewed trials: strengthening exercise (n=8)

Type of exercise & number of trials	Total number of participants involved	Code no.	Authors, year & number of participants (n)	Intervention & comparison intervention	Outcome measures	Results
Strengthening (n=8)	342	22	(da Silva et al., 2015) (n=20)	2 groups: one that performed the task-oriented therapy without load and another one performed task-oriented therapy with personalized resistance	- upper extremity performance test - shoulder flexor and handgrip strength (Jamar hydraulic hand dynamometer) in kilograms and pounds respectively - shoulder active range of motion - FMA - Modified Ashworth Scale	- strength training was able to intensify the upper-limb rehabilitation - muscle strength training might be a pivotal element of the task-oriented rehabilitation program of chronic patients with mild impairment after stroke
		23	(Kim et al., 2015) (n=40)	experimental group received chest expansion resistance exercise control group performed passive range of motion exercise with automatic instruments	-vital capacity (VC) -forced vital capacity (FVC) -forced expiratory volume in one second (FEV1) -6MWT	-increased chest expansion -improved VC, FVC, FEV1 and 6-MWT -showed importance of respiratory exercise for stroke rehabilitation
		24	(Lee et al., 2013) (n=33)	close kinetic chain (CKC) exercise and open kinetic chain (OKC) exercise	-electromyogram (EMG) measures (for muscle activities) -Good Balance System Ver. 3.06 (for balance)	- muscle activation of rectus femoris and biceps femoris was significantly increased in both CKC exercise and OKC exercise groups, compared to the control group - muscle activation of gastrocnemius and tibialis anterior was significantly increased in only the CKC exercise group - antero-posterior and medio-lateral sway velocities were decreased with the application of CKC exercise - CKC exercise improves lower limb muscle strength, and balance in chronic stroke, and it may carry over into an improvement in functional performance

Continue table 2.2a.3

		25	(Lee and Kang, 2013) (n=20)	<p>both groups performed conventional physical therapy for six weeks</p> <p>experimental group also performed isokinetic eccentric resistance exercises for the hip flexor and extensor muscles</p>	<p>-hip muscle strength -stair up and down time -TUG time -10 m gait velocity</p>	<p>-isokinetic eccentric resistance exercises for hip flexor and extensor muscles combined with conventional physical therapy improved hip muscle strength, stair up and down time, TUG time and 10 m gait velocity.</p>
		26	(Britto et al., 2011) (n=18)	<p>interventions were based on home-based training, with resistance adjusted biweekly to 30% of maximal inspiratory pressure for the experimental group.</p> <p>control group underwent the same protocol without the threshold resistance valve</p>	<p>- maximal inspiratory pressure (MIP) - inspiratory muscular endurance (IME) - cycle ergometer test and Human Activity Profile were used to assess functional performances</p>	<p>-short-term effects of inspiratory muscular training (IMT) program for inspiratory strength and endurance were observed in chronic stroke survivor</p> <p>-findings gave some indications that IMT may benefit people with stroke</p>
		27	(Mead et al., 2007) (n=66)	<p>progressive endurance and resistance training</p>	<p>- FIM -Nottingham Extended Activities of Daily Living -Rivermead Mobility Index -functional reach -sit-to-stand -elderly mobility score - TUG</p>	<p>- exercise training for ambulatory stroke patients was feasible and led to significantly greater benefits in aspects of physical function and perceived effect of physical health on daily life</p>
		28	(Thielman et al., 2004) (n=12)	<p>Training (trunk unrestrained) using the paretic limb was 4 weeks (12 sessions)</p>	<p>Kinematic analysis of arm trajectory -Peak performance system -Motor Assessment Scale -Rivermead Motor Assessment</p>	<p>-Increased trunk use at the target ipsilateral to the moving arm</p>

Continue table 2.2a.3

			<p>task-related training (TRT) involved reaching to objects placed across the workspace</p> <p>progressive resistive exercise (PRE) involved whole-arm pulling against resistive therapeutic tubing in planes and distances similar to that in TRT</p>		
		29	<p>(Moreland et al., 2003) (n=133)</p> <p>both groups received conventional physical therapy programs</p> <p>experimental group performed 9 lower-extremity progressive resistance exercises 3 times a week for the duration of their stay</p> <p>control group did the same exercises and for the same duration but without resistance</p>	<p>- Disability Inventory of the Chedoke-McMaster Stroke Assessment</p> <p>- 2-minute walk test (2MWT)</p>	<p>- progressive resistance strengthening exercises were not effective when compared with the same exercises given without resistance</p>

Table 2.2a.4 Summary of reviewed trials: balance (n=3)

Type of exercise & number of trials	Total number of participants involved	Code no.	Authors, year & number of participants (n)	Intervention & comparison intervention	Outcome measures	Results
Balance (n=3)	95	30	(Karthikbabu et al., 2011) (n=30)	task-specific trunk exercises on an unstable surface (physio ball) while the control group performed them on a stable surface (plinth)	-trunk impairment scale -brunel balance assessment	- trunk exercises performed on the physio ball are more effective than those performed on the plinth in improving both trunk control and functional balance in acute stroke patients, suggesting a task-specific effect
		31	(Fu-Ling et al., 2010) (n=32)	Subjects in the experimental group received additional sit-to-stand training for 15 minutes each time	- weight-bearing distribution during quiet standing -directional control and maximal excursion during limits of stability test -BBS - extensor muscle strength of lower extremity	- improvements in directional control anteriorly - improvement in affected hip extensor strength - improvements were noted only in the experimental group after treatment, including bilateral extensors, except the affected plantar flexors, the weight distribution in standing - additional sit-to-stand training is encouraged due to effects on dynamic balance and extensor muscles strength in subjects with stroke
		32	(Verheyden et al., 2009) (n=33)	In addition to conventional therapy, the experimental group received 10 hours of individual and supervised trunk exercises	- Trunk Impairment Scale (TIS) and its subscales of static and dynamic sitting balance and coordination	- trunk exercises aimed at improving sitting balance and selective trunk movements have a beneficial effect on the selective performance of lateral flexion of the trunk after stroke

Table 2.2a.5 Summary of reviewed trials: combined aerobic and strengthening exercises (n=2) and combined task-oriented functional movements (n=15)

Type of exercise & number of trials	Total number of participants involved	Code no.	Authors, year & number of participants (n)	Intervention & comparison intervention	Outcome measures	Results
Combined aerobic and strengthening (n=2)	92	33	(Lee et al., 2008) (n=52)	individuals underwent aerobic cycling plus sham progressive resistance training (PRT), or sham cycling plus PRT, or aerobic cycling plus PRT, or sham cycling plus sham PRT	-6MWT -habitual and fast gait velocities -stair climbing power -cardiorespiratory fitness -muscle strength -power -endurance	-neither aerobic nor strength improved walking distance or gait velocity more than sham exercise -strength improved stair climbing power, muscle strength, power, and endurance, cycling peak power output and self-efficacy -aerobic improved cardiorespiratory fitness only -cycling plus strengthening training produced larger effects
		34	(Carr and Jones, 2003) (n=40)	both groups were then required to exercise aerobically at a moderate intensity only the aerobic & strength (A&ST) group was required to do a series of eight strength-training activities	-maximal VO2 stress test -Biodex strength assessment	-improved VO2 max -increased in knee flexion -increased both shoulder flexion and extension -both groups demonstrated significant changes in functional strength, but the A&ST group experienced larger increases
Combined task-oriented functional movements (n=15)	950	35	(Kim et al., 2014) (n=28)	task-oriented gross motor group exercise 2 groups performed morning exercise led by a trainer. Experimental group performed a gross motor group exercise in addition	-Modified Barthel Index (MBI) -neuromusculoskeletal and movement-related functions in Chapter 7 of International Classification of Functioning, Disability and Health (for neuromuscular skeletal and motor-related functions)	-improvements were found in the experimental group's neuromusculoskeletal and motor-related functions and MBI test, except for the stability of joint functions - gross motor group exercise based on motor development is recommended for chronic stroke patients with severe handicaps

Continue table 2.2a.5

		36	(Langhammer et al., 2014) (n=37)	<p>Inpatient training was functional task-oriented training tailored according to their specific needs during the acute period of rehabilitation</p> <p>intensive exercise group received scheduled training</p> <p>regular exercise group did not receive any compulsory treatment</p>	<p>-Barthel Index</p> <p>-Personal Activities of Daily Living (PADL)</p> <p>-Motor Assessment Scale (MAS)</p> <p>-BBS</p> <p>- TUG</p> <p>-6MWT</p> <p>- bilateral grip strength (Martin vigorimeter)</p> <p>- Instrumental Activities of Daily Living (IADL) tested according to Fillenbaum</p>	<p>-both groups maintained function and had a relatively active life style 4 years after the acute incident</p> <p>-the results underline the importance of follow-up testing and encouragement to exercise, to motivate and sustain physical activity patterns, to maintain physical function, not only in the acute but also in the chronic phase of stroke</p>
		37	(Taylor-Piliae et al., 2014) (n=145)	<p>Yang style 24-posture short-form tai chi (TC), strength and range of movement exercises (SS), or usual care (UC) for 12 weeks.</p> <p>TC and SS groups attended a 1-hour class 3 times per week, whereas the UC group had weekly phone calls</p>	<p>-Short physical performance battery</p> <p>-fall rates</p> <p>-2-minute step test</p>	<p>-both tai chi and strength and range of movement exercises improved aerobic endurance</p> <p>-tai chi is more effective in reducing fall rates than strength and range of movement exercise, and usual care</p>
		38	(Schmid et al., 2014) (n=47)	<p>therapeutic yoga (twice a week/8 weeks) delivered in a standardized and progressive format with postures, breathing, and meditation, and relaxation in sitting, standing, and supine.</p>	<p>-Pain was assessed with the PEG (a 3-item functional measure of pain: P is the average Pain intensity, E is the interference with Enjoyment in life, and G is the interference with General activity)</p> <p>-ROM included neck and hip active and passive ROM measurements)</p> <p>-upper and lower extremity strength were assessed with the arm curl test and chair-to-stand test respectively.</p> <p>-endurance was assessed with 6MWT and modified 2-min step test</p>	<p>-pain, neck ROM, hip passive ROM, upper extremity strength, and the 6-min walk scores all significantly improved after 8 weeks of engaging in yoga</p> <p>- a group therapeutic-yoga intervention may improve multiple aspects of physical functioning after stroke</p>

Continue table 2.2a.5

Type of exercise & number of trials	Total number of participants involved	Code no.	Authors, year & number of participants (n)	Intervention & comparison intervention	Outcome measures	Results
		39	(Mayo et al., 2013) (n=87)	One group exercised on a stationary bicycle, the second group carried out mobility exercises and brisk walking	-6MWT -comfortable walking speed with usual assistive device (timed five-meter walk) -BBS -Community Balance and Mobility Scale -SIS (Physical) - Physical Function Index of the Medical Outcomes Study RAND-36 Item Health Survey (RAND-36)	-no significant effects of group or time were revealed for stationary cycling -stationary cycling, mobility exercises and brisk walking were effective in maintaining walking capacity after discharge from stroke rehabilitation; or were equally ineffective in improving walking capacity
		40	(van Delden et al., 2013) (n=60)	modified constraint-induced movement therapy, modified bilateral arm training with rhythmic auditory cueing, and a dose-matched conventional treatment	-action research arm test (ARAT)	- all groups demonstrated significant improvement on ARAT
		41	(Wu et al., 2013) (n=33)	mirror therapy group received upper extremity training involving repetitive bimanual, symmetrical movement practice, in which the individual moves the affected limb while watching the reflective illusion of the unaffected limb's movements from a mirror The control group received task-oriented upper extremity training	-FMA -kinematic variables, including reaction time, normalized movement time, normalized total displacement, joint recruitment, and maximum shoulder-elbow cross-correlation -Revised Nottingham Sensory Assessment -Motor Activity Log -Abilhand questionnaire	-mirror therapy after stroke might result in beneficial effects on movement performance, motor control, and temperature sense, but may not translate into daily functions in the population with chronic stroke

Continue table 2.2a.5

		42	(Holmgren et al., 2010) (n=34)	intervention program contained high intensity functional exercises (HIFE) implemented to real-life situations together with education on falls and security aspects	-BBS -Barthel Index - Falls Efficacy Scale – International -number of falls secondarily -Frenchay Activities Index last 3 months	-improved performance of everyday life activities, falls efficacy in stroke subjects with risk of falls
		43	(Wolf et al., 2010) (n=192)	constraint-induced movement therapy (CIMT)	-Wolf Motor Function test (WMFT) -Motor Activity Log (MAL) -Stroke Impact Scale (SIS)	-improved WMFT, MAL, SIS (hand and activities domains) -the earlier CIMT group showed greater improvement than the delayed CIMT group
		44	(Dromerick et al., 2009) (n=52)	constraint-induced movement therapy (CIMT)	-action research arm test (ARAT)	- CIMT was equally as effective but not superior to an equal dose of traditional therapy during inpatient stroke rehabilitation -higher intensity CIMT resulted in less motor improvement at 90 days, indicating an inverse dose-response relationship
		45	(Desrosiers et al., 2005) (n=41)	the experimental group received an arm therapy programme based on repetition of unilateral and symmetrical bilateral tasks control group received additional usual arm therapy of a similar duration and frequency to the experimental treatment	-arm impairments (motor function, grip strength, gross and fine manual dexterity and motor co-ordination) - arm disabilities in tasks related to daily activities - functional independence in activities of daily living (ADL) and instrumental ADL (IADL).	- arm training programme based on repetition of unilateral and symmetrical bilateral practice did not reduce impairment and disabilities nor improve functional outcomes in the subacute phase after stroke more than the usual therapy

Continue table 2.2a.5

		46	(Hart et al., 2004) (n=18)	study group (SG) received Tai Chi exercises and the control group (CG) physiotherapy exercises focused on improvement of balance	<ul style="list-style-type: none"> -Romberg's test -standing on the unaffected leg -Emory fractional ambulation profile -BBS -TUG -duke health profile 	<ul style="list-style-type: none"> -tai chi exercise showed improvement in social and general functioning - SG subjects showed improvement in social and general functioning whereas CG subjects showed improvement in balance and speed of walking
		47	(Duncan et al., 2003) (n=92)	intervention was a structured, progressive, physiologically based, therapist-supervised, in-home program of thirty-six 90-minute sessions over 12 weeks targeting flexibility, strength, balance, endurance, and upper-extremity function	<ul style="list-style-type: none"> -ankle and knee isometric peak torque -grip strength -FMA -BBS -functional reach -peak aerobic capacity and exercise duration -Wolf motor function test -timed 10-MWT -6-minute walk distance 	<ul style="list-style-type: none"> -improved in strength, balance, upper and lower-extremity motor control, upper-extremity function, gait velocity -gained in endurance, balance, and mobility
		48	(Page et al., 2002) (n=40)	<p>4 patients participated in half-hour, structured physical and occupational therapy sessions that emphasized affected arm use in valued functional activities. Their less affected upper limbs were restrained 5 days per week during 5 hours identified as times of frequent use modified constraint-induced therapy i.e. mCIT</p> <p>5 patients received regular therapy with similar therapeutic contact time to mCIT</p> <p>5 patients received no therapy (CON)</p>	<ul style="list-style-type: none"> -FMA -action research arm test -motor activity log 	<ul style="list-style-type: none"> -modified constraint-induced therapy improves affected arm function and use in stroke patients with learned nonuse

Continue table 2.2a.5

		49	(Dean et al., 2000) (n=12)	<p>exercise class for the experimental group focused on strengthening the affected lower limb and practicing functional tasks involving the lower limbs</p> <p>control group practiced upper-limb tasks</p>	<p>-walking speed and endurance</p> <p>-peak vertical ground reaction force</p> <p>-sit-to-stand</p> <p>-step test</p>	<p>-improvement in walking speed and endurance, force production through the affected leg during sit-to-stand, and the number of repetitions of the step test</p>
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Appendix 14: Chapter 2 review 2.2a table 2.2a.6 summaries of systematic reviews

Table 2.2a.6 Summary of the included systematic reviews (n=10)

Type of exercise: Aerobic exercise (n=3)				
Code no	Author, year & number of studies included (n)	Intervention	Outcome measures	Results
2.1	(Stoller et al., 2012) (n=11)	Cardiovascular exercise	Peak oxygen uptake, 6-minutes walk test, gait speed	Stroke survivors may benefit from cardiovascular exercise during sub-acute stage to improve peak oxygen uptake and walking distance. Concepts to influence and evaluate aerobic capacity in severely affected individuals with sub-acute stroke, as well as in the very early period after stroke, are lacking
2.2	(Pang et al., 2006) (n=9 articles (7 RCTs))	Aerobic exercise	aerobic capacity (peak oxygen consumption (VO ₂), peak workload), walking velocity, walking endurance	Good evidence that aerobic exercise is beneficial for improving aerobic capacity in people with mild and moderate stroke Aerobic exercise should be an important component of stroke rehabilitation
2.3	(Meek et al., 2003) (n=3)	Cardiorespiratory trainings	Impairments: gait speed, strength, endurance, balance, flexibility, tonus, exercise capacity Disability: global dependency, functional independence, extended activities of daily living	Cardiovascular exercise not better than no exercise

Continue table 2.2a.6

Types of exercise: Strengthening exercise (n=2)				
2.4	(Ada et al., 2006) (n=21)	Strength training	Manual muscle tests (for strength), modified Ashworth Scale, a custom made scale, Pendulum test (for spasticity), 10-meters walk test, Box and Block test, Barthel Index (for activity)	Strengthening programmes increase strength, improve activity, and do not increase spasticity. Strengthening programmes should be part of rehabilitation after stroke.
2.5	(Morris et al., 2004) (n=8)	Resistive strengthening training	Change in body function, physical activity or societal participation	Progressive resistive strengthening training programmes reduces musculoskeletal impairment after stroke. Unknown whether strengthening enhances the performance of functional activities or participation in societal roles
Type of exercise: Combined aerobic and strengthening exercises (n=2)				
2.6	(Saunders et al., 2013) (n=45)	Cardiorespiratory Resistance Mixed training	Walking speed, preferred gait speed, walking capacity, Berg balance scale	Cardiorespiratory training reduces disability after stroke and this may be mediated by improved mobility and balance. Sufficient evidence to incorporate cardiorespiratory and mixed training, involving walking, within post-stroke rehabilitation programs to improve the speed and tolerance of walking; improvement in balance may also occur. Insufficient evidence to support the use of resistance training
2.7	(van de Port et al., 2007) (n=21)	lower-limb strengthening, cardiorespiratory fitness, or gait-oriented tasks in improving gait, gait-related activities, and health-related quality of life after stroke	lower-limb strengthening, cardiorespiratory fitness, gait-oriented training	Gait-oriented training, targeting improved strength and cardiorespiratory fitness, is the most successful method to improve gait speed and endurance

Continue table 2.2a.6

Type of exercise: Balance exercise (n=1)				
2.8	(Sorinola et al., 2014) (n=6)	Trunk exercises	Trunk performance, standing balance, walking ability, functional independence	Moderate evidence that addition of specific trunk exercise to improve standing balance and mobility Weak evidence for the effect of additional trunk exercise on trunk performance and in functional independence
Type of exercise: Combined task-oriented functional movements (n=2)				
2.9	(French et al., 2007) (n=40)	Task-specific training for functional ability	Walking distance, walking speed, sit-to-stand, functional ambulation and global motor function	Repetitive task training resulted in modest improvement in lower limb function, but not upper limb function. Training may be sufficient to impact on daily living function. No evidence of adverse effects. No evidence that improvements are sustained once training has ended.
2.10	(van der Lee, 2001) (n=13)	Arm function trainings	Arm function test	6 studies reported positive results on arm function test Insufficient evidence to draw definitive conclusions about the effectiveness of exercise on arm function in stroke patients

Appendix 15: Chapter 2 review 2.2a table 2.2a.7 quality assessment of trials

Type of exercise & number of included trials	no	Authors, year & number of participants (n)	Random allocation	Blinding of patients	Blinding of assessor	Group comparable at baseline	Equivalent treatment other than interventions	Complete follow-up	Analysis of withdrawal
Mobility (n=3)	1	(Cho et al., 2015) (n=12)	Yes	No	No	Yes	No	Yes	No
	2	(Tseng et al., 2007) (n=59)	Yes	No	Yes	Yes	No	No	No
	3	(McClellan and Ada, 2004) (n=26)	Yes	Yes	Yes	Yes	Yes	No	No
Aerobic (n=3)	4	(Jin et al., 2013) (n=128)	Yes	No	No	Yes	No	No	No
	5	(Toledano-Zarhi et al., 2011) (n=28)	Yes	No	No	Yes	Yes	No	Yes
	6	(Potempa et al., 1995) (n=42)	Yes	No	No	Yes	Yes	Yes	No
Walking (n=15)	7	(Treger et al., 2014) (n=86)	Yes	No	No	Yes	No	No	No
	8	(Gordon et al., 2013) (n=128)	Yes	No	Yes	Yes	No	No	Yes
	9	(Nadeau et al., 2013) (n=408)	Yes	No	Yes	No	No	No	Yes
	10	(Høyer et al., 2012) (n=60)	Yes	No	Yes	Yes	Yes	Yes	No
	11	(Franceschini et al., 2009) (n=97)	Yes	No	Yes	Yes	No	No	No
	12	(Peurala et al., 2009) (n=56)	Yes	No	No	Yes	No	No	No
	13	(Luft et al., 2008) (n=71)	Yes	No	Yes	Yes	No	No	No
	14	(Yen et al., 2008) (n=40)	Yes	No	No	Yes	Yes	Yes	No
	15	(Macko et al., 2005) (n=61)	Yes	No	No	Yes	No	No	No
	16	(Peurala et al., 2005) (n=45)	Yes	No	No	Yes	Yes	No	No
	17	(Pohl et al., 2002) (n=60)	Yes	No	Yes	Yes	No	No	No
	18	(Werner et al., 2002) (n=30)	Yes	No	Yes	Yes	Yes	Yes	No
	19	(Laufer et al., 2001) (n=25)	Yes	No	No	Yes	Yes	No	No
	20	(Nilsson et al., 2001) (n=73)	Yes	No	Yes	Yes	Yes	No	No
	21	(Visintin et al., 1998) (n=100)	Yes	No	Yes	Yes	Yes	No	Yes

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Type of exercise & number of included trials	no	Authors, year & number of participants (n)	Random allocation	Blinding of patients	Blinding of assessor	Group comparable at baseline	Equivalent treatment other than interventions	Complete follow-up	Analysis of withdrawal
Strengthening (n=8)	22	(da Silva et al., 2015) (n=20)	Yes	No	Yes	Yes	No	Yes	No
	23	(Kim et al., 2015) (n=40)	Yes	No	No	Yes	No	Yes	No
	24	(Lee et al., 2013) (n=33)	Yes	No	No	Yes	No	No	No
	25	(Lee and Kang, 2013) (n=20)	Yes	No	No	Yes	Yes	No	No
	26	(Britto et al., 2011) (n=18)	Yes	No	No	Yes	Yes	Yes	No
	27	(Mead et al., 2007) (n=66)	Yes	Yes	Yes	Yes	Yes	No	Yes
	28	(Thielman et al., 2004) (n=12)	Yes	No	No	Yes	No	No	No
	29	(Moreland et al., 2003) (n=133)	Yes	No	Yes	Yes	Yes	No	Yes
Balance (n=3)	30	(Karthikbabu et al., 2011) (n=30)	Yes	No	Yes	Yes	Yes	Yes	Yes
	31	(Fu-Ling et al., 2010) (n=32)	Yes	No	Yes	Yes	Yes	Yes	No
	32	(Verheyden et al., 2009) (n=33)	Yes	No	Yes	Yes	Yes	Yes	Yes
Combined aerobic and strengthening (n=2)	33	(Lee et al., 2008) (n=52)	Yes	No	Yes	Yes	No	No	Yes
	34	(Carr and Jones, 2003) (n=40)	Yes	No	No	No	Yes	No	No
Combined task-oriented functional movements (n=15)	35	(Kim et al., 2014) (n=28)	Yes	No	No	Yes	Yes	No	No
	36	(Langhammer et al., 2014) (n=37)	Yes	No	No	Yes	No	No	Yes
	37	(Taylor-Piliae et al., 2014) (n=145)	Yes	No	No	Yes	No	No	Yes
	38	(Schmid et al., 2014) (n=47)	Yes	No	No	No	No	No	No
	39	(Mayo et al., 2013) (n=87)	Yes	No	Yes	Yes	Yes	No	Yes
	40	(van Delden et al., 2013) (n=60)	Yes	No	No	Yes	No	No	No
	41	(Wu et al., 2013) (n=33)	Yes	No	Yes	Yes	No	Yes	No
	42	(Holmgren et al., 2010) (n=34)	Yes	Yes	Yes	Yes	No	No	No

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	43	(Wolf et al., 2010) (n=192)	Yes	No	No	Yes	Yes	No	No
	44	(Dromerick et al., 2009) (n=52)	Yes	No	Yes	Yes	Yes	No	No
	45	(Desrosiers et al., 2005) (n=41)	Yes	No	No	Yes	Yes	No	No
	46	(Hart et al., 2004) (n=18)	Yes	No	No	Yes	No	No	No
	47	(Duncan et al., 2003) (n=92)	Yes	No	Yes	No	No	No	Yes
	48	(Page et al., 2002) (n=40)	Yes	No	No	Yes	No	No	No
	49	(Dean et al., 2000) (n=12)	Yes	No	No	No	No	No	No