Sedentary behaviour in stroke survivors with severe mobility disability living at home: An exploratory study

Nicola Joy Cornwall

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The candidate confirms that the work submitted is her own and that appropriate credit has been given where reference has been made to the work of others.

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Abstract

Background: As the detrimental effects of sedentary behaviour on health and well-being are well documented and with stroke survivors having an increased risk of poor health outcomes and being identified as being more sedentary than healthy adults (English et al., 2014), it was deemed important to address the gap in sedentary behaviour and stroke research by focusing on those stroke survivors who have severe mobility disability. The thesis aimed to investigate and better understand sedentary behaviour in stroke survivors with severe mobility disability living at home and identify the next steps needed for research into sedentary behaviour in this stroke population.

Methods: Two systematic reviews were undertaken to evaluate the existing literature. A Q-methodological study was conducted to explore sedentary behaviour from the perspectives of stroke survivors who have severe mobility disability, their carers and healthcare professionals. A second study investigated the energy requirements for activities of daily living in stroke survivors with severe mobility disability living at home using indirect calorimetry.

Results: Keeping moving and reducing sedentary behaviour following their stroke was an integral part of their rehabilitation, with an intervention and strategies to reduce sedentary behaviour in this stroke population being welcomed by the stroke survivors, carers and healthcare professionals involved in their care. The thesis also identified higher energy requirements for activities of daily living in stroke survivors with severe mobility disability compared to healthy adults and that it may be possible to incorporate seated functional tasks involving the upper limb in strategies to reduce sedentary behaviour.

Conclusions: The novel research presented in the thesis highlights the importance of inclusion of stroke survivors with severe mobility disability in research and the need for further research to build upon the baseline provided by the thesis in order to inform future interventions to reduce sedentary behaviour in this stroke population.

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List of Abbreviations

6MWT	6 Metre Walk Test
10MWT	10 Metre Walk Test
ADLs	Activities of Daily Living
AMED	Allied and Complementary Medicine
AUECR	Academic Unit of Elderly Care and Rehabilitation
BBS	Berg Balance Scale
CINHAL	Cumulative Index to Nursing and Allied Health Literature
CRAG	Consumer Research Advisory Group
CRD	Centre for Reviews and Dissemination
EPOC	Excess Post Oxygen Consumption
EPPI	Evidence for Policy and Practice Information and Co-ordination Centre
FAC	Functional Ambulatory Classification
FAST	Frenchay Aphasia Screening Tool
HRA	Health Research Authority
IDEEA	Intelligent Device for Energy Expenditure and Activity
IPAQ	International Physical Activity Questionnaire
ISRCTN	International Standard Randomised Controlled Trial Number Registry
ISWP	Intercollegiate Stroke Working Party
LIPA	Light Intensity Physical Activity
MET(s)	Metabolic Equivalents of Task(s)
MRC	Medical Research Council
mRS	Modified Rankin Scale
MVPA	Moderate to Vigorous Physical Activity
NEADL	Nottingham Extended Activities of Daily Living Questionnaire
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NIHR	National Institute for Health Research
PA	Physical Activity
PAS	Physical Activity Scale
PASIPD	Physical Activity Scale for Individuals with Physical Disabilities
PCA	Principal Components Analysis
RCTs	Randomised Controlled Trials
REC	Research Ethics Committee
RMR	Resting Metabolic Rate
RPE	Rating of Perceived Exertion

SAM	StepWatch Activity Monitor
SB	Sedentary Behaviour
SBRN	Sedentary Behaviour Research Network
SD	Standard Deviation
SF-36	Short Form Health Survey
SIS	Stroke Impact Scale
SSNAP	Sentinel Stroke National Audit Programme
$\dot{V}o_2$	Oxygen Uptake

Chapter 1 – Introduction

1.1. Background

The research in this thesis is concerned with investigation of sedentary behaviour in stroke survivors with severe mobility disability living at home. This first chapter provides background and context to the research topic; it firstly outlines the aetiology and epidemiology of stroke, highlighting the importance of research into the health condition. It continues to discuss the emergence of interest and research in sedentary behaviour in the general population and then more specifically in the context of the stroke population. The rationale for the research is then outlined and discussed. As the thesis specifically focuses on stroke survivors with severe mobility disabilities, the term 'disability' is explored and the definition adopted confirmed. The penultimate section provides the aims and objectives for the thesis, with the chapter concluding by providing an outline of the subsequent chapters within the thesis.

1.1.1. Stroke: Aetiology, Epidemiology and Disability

Stroke remains a major illness in the United Kingdom (UK) and worldwide with approximately 100,000 people suffering a first or recurrent stroke every year in the UK (Dworzynski et al., 2015) and almost 14 million incidences of first-time strokes worldwide (Institute for Metrics and Health Evaluation, 2016). It is the fourth largest cause of death in the UK, with one in eight strokes being fatal within the first 30 days following the stroke (Bray et al., 2016) and the second leading cause of death worldwide (World Health Organisation, 2018). Despite the high mortality rates following stroke, more patients are surviving a stroke than ever before (Stroke Association, 2018). At least 1.2 million people are living in the UK who have had a stroke, with nine out of ten stroke survivors returning home within six months of their stroke in England, Wales and Northern Ireland (Stroke Association, 2018). Approximately 25% of stroke survivors will go on to have either a recurrent stroke or a transient ischaemic attack (TIA) (Stroke Association, 2018)

Stroke is the leading cause of severe disability in the UK (Stroke Association, 2018) and the second largest cause of disability globally (Johnson et al., 2016). Due to the complex nature of stroke, the effects of the stroke depend on which parts of the brain have been affected and can include; weakness in arms and legs, problems with speech and vision, fatigue and problems with memory and thinking. Limb weakness is extremely common after stroke with almost three quarters of stroke survivors reporting leg weakness that affects both walking and balance (Stroke Association, 2018). The Sentinel Stroke National Audit Programme (SSNAP) clinical audit report for April 2017 – March 2018 reported 15.2% of patients had a Modified Rankin Scale score of 4 – indicating a moderately severe disability and 7.3% had a score of 5 – indicating a severe disability at discharge. Stroke survivors often require significant support following their stroke, with 41% requiring help with their activities of daily living when discharged (Royal College of Physicians Sentinel Stroke National Audit Programme (SSNAP), 2018).

The estimated cost of stroke to the UK society, taking into account costs to the NHS, personal social services, informal carers (i.e. family and friends) and losses in productivity, is around £26 billion a year (Patel et al., 2017), 30% of which relates to the cost to the NHS. This figure is predicted to significantly increase with the overall costs of stroke in the UK for people aged over 45 years old projected to rise to £43 billion in 2025 and £75 billion by 2035 (Patel et al., 2017). Stroke is therefore a significant current economic burden in the UK that will continue into the future with increased prevalence.

Considering the significant economic burden of stroke in the UK and the devastating effects of the health condition on both the patient and their family and friends, improving longer term health outcomes is an identified research priority.

1.1.2. Sedentary behaviour

Sedentary behaviour is the focus of increasing, clinical, policy and research interest, as evidence of its detrimental effects on health and well-being increases (de Rezende et al., 2014; Davies et al., 2011; Owen et al., 2010; The Sedentary Behaviour and Obesity Expert Working Group, 2010). Sedentary behaviour is defined as any waking behaviour, while in a sitting or reclining posture, characterised by low energy expenditure (≤1.5 metabolic equivalents of task (METs)) (Tremblay et al., 2017) as opposed to physical activity which is defined as; any bodily movement produced by skeletal muscles that results in a substantial increase of resting energy expenditure (Caspersen et al., 1985).

When discussing sedentary behaviour and physical activity it is important to understand the units of measurement that are referred to in the definitions. In order to categorise intensity of activities and ultimately the energy costs associated with the activities, metabolic equivalents of tasks (METs) are used. METs are defined as multiples of the resting metabolic rate, with one MET referring to the amount of oxygen (O_2) consumed at rest, sitting in a chair quietly. This corresponds to an energy expenditure of 1kcal per kg body mass per hour or the approximate oxygen consumption of 3.5ml O_2 per kg body mass, for an average adult (Lagerros and Lagiou, 2007; Jette et al., 1990). As presented in Figure One, sedentary behaviour and varying levels of physical activity (PA) are distributed along a continuum of energy expenditures characterised by the MET level associated for the activity.

It is suggested that sedentary behaviour and physical inactivity are two distinct constructs with different physiological responses and health outcomes that can coexist (van der Ploeg and Hillsdon, 2017; Tremblay et al., 2010). Physical inactivity refers to an insufficient amount of moderate- and vigorous-physical activity (MVPA: physical activity requiring moderate to large amounts of effort causing an increase in heart rate, using approximately greater than 3 METs) (Tremblay et al., 2017), i.e. not achieving daily/weekly targets identified in physical activity guidelines (Davies et al., 2011). Considering the two definitions of sedentary behaviour and physical inactivity, an individual may not reach the recommended levels of physical activity yet spend little time sitting, whereas others may be physically active for short bursts (i.e. running for an hour), but spend prolonged periods sitting (Dempsey et al., 2014; Owen et al., 2011). In addition only high levels of moderate intensity physical activity (i.e. >60 minutes per day) have been found to eliminate the increased mortality risk associated with high sitting time (Ekelund et al., 2016).

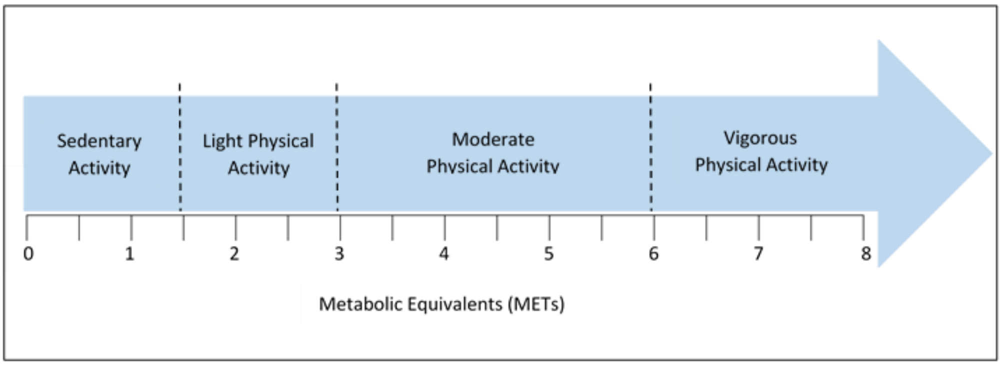


Figure 1 Energy Expenditure Continuum (Adapted from Sedentary Behaviour Research Network (2017))

For the purpose of this project, sedentary behaviour will be interpreted as sitting/lying down during waking hours without being otherwise active (Owen et al., 2011).

With the evidence (Healy et al., 2008; Matthews et al., 2008) that a significant proportion of an adult's day is spent either sedentary or in light intensity physical activity (LIPA: physical activity that requires a low amount of effort and typically uses between 1.5 - 3 METs), more recently the focus of research has concentrated on sedentary behaviour including patterns of accumulation (occurrence and durations of bouts of sedentary time), health consequences of sedentary lifestyles (Patterson et al., 2018) and interventions to reduce sedentary behaviours (Dunstan et al., 2012a).

Early work by Morris and colleagues (1958) found a higher incidence of cardiovascular disease in occupations that primarily required sitting (e.g. bus drivers and telephone operators) compared to workers who were required to be more physically active (e.g. bus conductors and postmen)(Dunstan et al., 2012a). Although early studies like this highlighted the potential role of physical activity in preventing premature mortality, the emergence of evidence reporting the deleterious health effects of sedentary behaviour has suggested that some of the associations previously found may be explained by time spent sitting rather than being less physically active (Katzmarzyk, 2010).

Prominent findings in the literature around health risks of sedentary behaviour suggest associations between sedentary time and all-cause mortality (Matthews et al., 2015; Chau et al., 2013), cardiovascular mortality (Matthews et al., 2015), metabolic risk (Healy et al., 2015; Edwardson et al., 2012; Healy et al., 2008), diabetes (Henson et al., 2016; Wilmot et al., 2012), obesity (Hu et al., 2003) and some types of cancer (Tremblay et al., 2010). Other negative impacts of sedentary behaviour have also been highlighted with indications of increased symptoms of anxiety (Teychenne et al., 2015) and depression (Teychenne et al., 2010).

Altering patterns of sedentary behaviour (number of breaks, length of break and content) is being explored. Experimental studies (primarily short-term, laboratory-based work) provide supporting evidence of the positive effect on metabolic outcomes of breaking-up sitting time (Benatti and Ried-Larsen, 2015). Short brief activity breaks throughout the day may be as effective as a continuous 30 or 60 minute bout of exercise (summarised in Dempsey et al., (2014)).

Recent work has focused on aiming to develop and evaluate interventions to reduce sedentary behaviour in different population groups, including children (Hegarty et al., 2016), adults (Gardner et al., 2016; Martin et al., 2015) and specifically occupational sedentary behaviour in adults (Shrestha et al., 2018). Although more work is required to develop, refine and evaluate, including the longer term effects of the interventions, encouraging results have been reported with some interventions demonstrating the ability to reduce sedentary behaviour.

1.1.3. Sedentary behaviour and stroke

The focus of sedentary behaviour research to date has primarily been conducted in healthy populations. However with the reported health risks of time spent sedentary, a shift to investigate sedentary behaviour in populations with health conditions or disabilities has recently been welcomed. One condition that has become a focus of sedentary behaviour research is stroke.

With stroke risk factors including high blood pressure and diabetes, targeting sedentary behaviour in stroke survivors could potentially help to reduce reoccurrence of stroke and the development of associated medical conditions. However, with stroke survivors having a greater range of disabilities than other conditions (Adamson et al., 2004), targeting sedentary behaviour in this population is challenging.

Stroke survivors spend significantly more time sedentary (English et al., 2014) and tend to have prolonged, uninterrupted periods of sedentary behaviour compared to age-matched controls (Tieges et al., 2015; Sjöholm et al., 2014). Tieges et al. (2015) conducted a longitudinal cohort study to quantify the changes in sedentary behaviour after stroke and reported that the patterns of accumulation of sedentary behaviour did not change over the first year after stroke. They also reported that higher stroke severity was associated with greater sedentary behaviour.

The need for further research relating to sedentary behaviour after stroke has been highlighted by systematic reviews (Galea et al., 2015; English et al., 2014) and reducing sedentary behaviour in stroke survivors is now recommended in national guidelines (Intercollegiate Stroke Working Party, 2016). With stroke survivors having an increased risk of poor health outcomes, focusing on reducing sedentary behaviour (time spent sitting) after stroke could be an effective way of improving health, and may also be a mechanism for empowering the stroke survivor (Morton et al., 2019).

1.2. Rationale for the research

Although increasing amounts of research is being conducted into sedentary behaviour and stroke, from an initial scoping of the literature it was apparent that stroke patients who have a severe mobility disability (i.e. impairments that affect or limit the way an individual moves or walks) are often excluded or underrepresented in research studies, especially in relation to sedentary behaviour (English et al., 2014).

Stroke patients who are severely disabled are not only neglected in research but present a significant rehabilitation challenge and may have limited access to rehabilitation. In 1998, Gladman and Sackley examined and addressed negative assertions often discussed in relation to the rehabilitation of severely disabled stroke patients and agreed that more work is needed in this patient group in order to redress the relative neglect of this group. This was supported by Finn and Horgan (2000) who agreed there is a lack of knowledge concerning severely disabled stroke patients and the effectiveness of rehabilitation. They also concluded that the process of recovery is multidimensional and characterised by individual variability and each patient should therefore be considered on an individual basis. Rodgers (2000) also agreed with the original argument proposed by Gladman and Sackley, and added that severe disability is an inappropriate reason to exclude stroke patients from clinical trials until the benefits or otherwise of rehabilitation for this patient group has been established.

Although stroke survivors who have severe mobility disability are often thought of as being more sedentary than other stroke survivors (Tieges et al., 2015), as previously discussed, they are often excluded or underrepresented in research studies, especially in relation to sedentary behaviour (English et al., 2014). The detrimental effects of sedentary behaviour on health and well-being are well documented, therefore it is not only important to determine the significance of sedentary behaviour in this population, but also to gain a better understanding of these patients' experiences and perspectives of sedentary behaviour after stroke. This will help to determine whether interventions to reduce sedentary behaviour in stroke survivors with severe mobility disabilities are required or will be accepted. It will also help to tailor possible intervention development in the future.

1.3. Models of disability

As the research aimed to explore sedentary behaviour in stroke survivors with severe mobility disability, it is important to understand and define the term 'disabled'. For the purpose of this project, the 'biopsychosocial' model of disability will be adopted as the model to characterise disability and is depicted in Figure Two. The medical model of disability frames disability as the direct result of the individual's physical impairment (World Health Organization, 2002; Johnston, 1996), the social model characterises disability as a socially created problem that is imposed onto the individual with an impairment (Barnes and Mercer, 2004; Llewellyn and Hogan, 2000), whereas the biopsychosocial model synthesises these and acknowledges disability as the interaction between heath conditions and contextual factors (environmental and personal factors)(Engel, 1977). This model forms the basis of the International Classification of Functioning, Disability and Health (ICF) and helps to understand the complex phenomenon that is disability (World Health Organization, 2002). Disability is described by the ICF as an umbrella term for impairments, activity limitations and participation restrictions, with a dysfunction being present at one or more of these levels (World Health Organization, 2002).

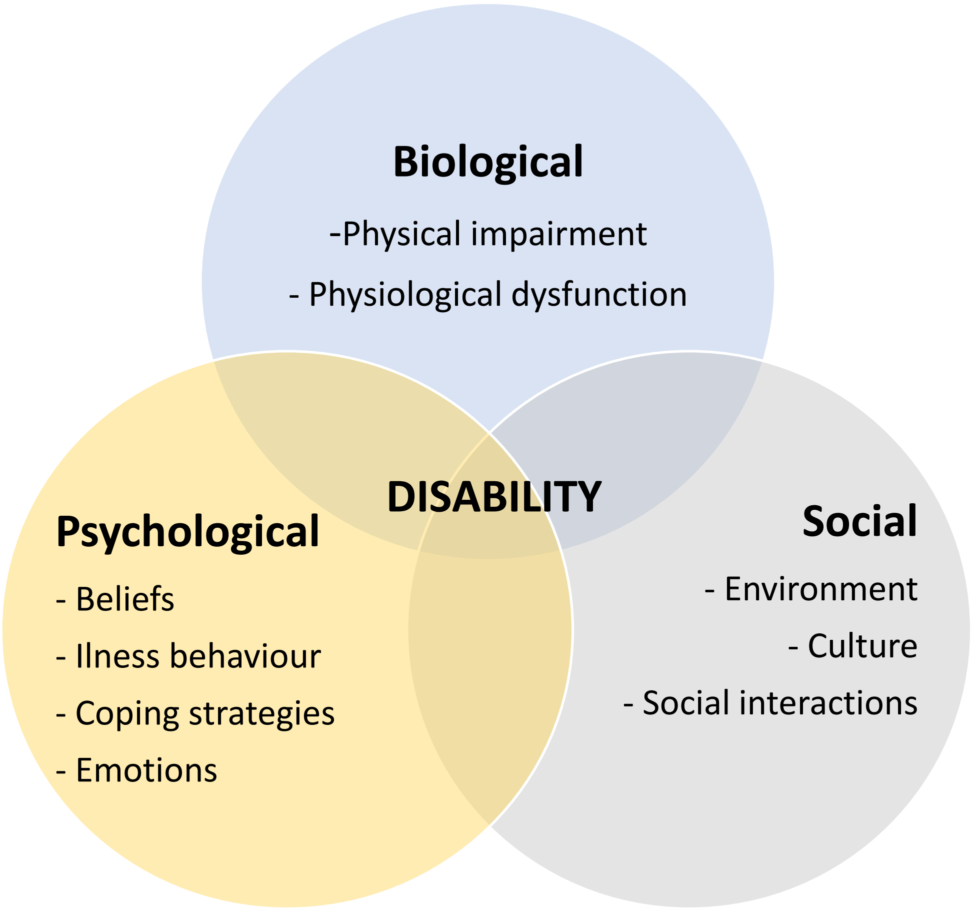
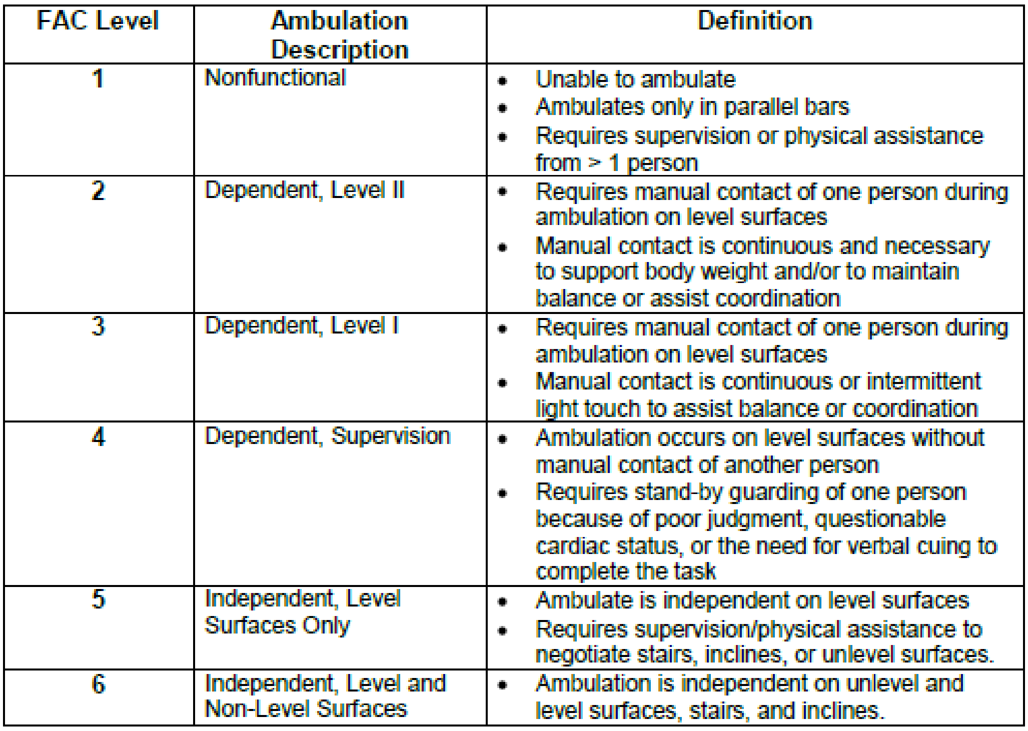


Figure 2 Biopychosocial Model of Disability

Although it is acknowledged that there is a range of severe disabilities following stroke, not all disabilities will necessarily directly impinge on sedentary behaviour, for example impairment of language. Thus, for the purpose of this project the population of focus will be stroke survivors with severe ‘mobility disabilities’, however other disabilities will be considered during the project if they emerge as an important factor. The term mobility disability, specifically refers to impairments that affect or limit the way an individual moves or walks (Manns et al., 2012). The Functional Ambulation Classification (FAC) (Holden et al., 1984) categorises patients according to basic motor skills necessary for functional ambulation and will be used in this project to identify participants with severe mobility disability (e.g. unable to stand or walk without the help of at least one person)(Figure Three).



FAC Level	Ambulation Description	Definition
1	Nonfunctional	• Unable to ambulate • Ambulates only in parallel bars • Requires supervision or physical assistance from > 1 person
2	Dependent, Level II	• Requires manual contact of one person during ambulation on level surfaces • Manual contact is continuous and necessary to support body weight and/or to maintain balance or assist coordination
3	Dependent, Level I	• Requires manual contact of one person during ambulation on level surfaces • Manual contact is continuous or intermittent light touch to assist balance or coordination
4	Dependent, Supervision	• Ambulation occurs on level surfaces without manual contact of another person • Requires stand-by guarding of one person because of poor judgment, questionable cardiac status, or the need for verbal cuing to complete the task
5	Independent, Level Surfaces Only	• Ambulate is independent on level surfaces • Requires supervision/physical assistance to negotiate stairs, inclines, or unlevel surfaces.
6	Independent, Level and Non-Level Surfaces	• Ambulation is independent on unlevel and level surfaces, stairs, and inclines.

Figure 3 Functional Ambulatory Classifications (FAC) (Holden et al., 1984)

1.4. Aims and Objectives

The overall aim of the work in this thesis was to investigate sedentary behaviour in stroke survivors who have a severe mobility disability and are living at home. The project had five sub-aims, each with objectives:

1. **To review the existing literature to assess the effectiveness, appropriateness and acceptability of interventions to reduce sedentary behaviour in people with a disability through a mixed method systematic review using the Evidence for Policy and Practice Information and Co-ordinating centre (EPPI) approach (Chapter Two).**
    a. Undertake a systematic review of qualitative 'views' studies to explore the individuals', carers' and health care professionals' perspectives and experiences of sedentary behaviour in people with a disability.
    b. Undertake a systematic review to identify, describe and assess the effectiveness of interventions aimed at reducing sedentary behaviour in people with a disability.
    c. Conduct a meta-synthesis to synthesise the findings from the two systematic reviews.

2. **To review and update the literature on sedentary behaviour in stroke survivors (Chapter Three).**
    a. Update an existing systematic review by English and colleagues (2014) to address the question; 'How active are people living in the community with stroke-related disability?' (English et al., 2014).
    b. Explore the inclusion and exclusion of stroke survivors with severe mobility disability in the included studies.

3. **To explore sedentary behaviour from the perspectives of stroke survivors with severe mobility disability, their carers and professionals involved in their care (Chapters Four and Five).**
    a. Conduct a Q-methodology study with stroke survivors with severe mobility disability, their carers and professionals involved in their care, to explore their perspectives of sedentary behaviour and assess their priorities in terms of mobility, sitting, movement and exercise.

4. **To investigate the energy requirements of activities of daily living in stroke survivors with severe mobility disability at home (Chapter Six).**
    a. Reflect upon the feasibility of taking objective measurements in a natural environment in those stroke survivors who have the most severe levels of mobility disability.
    b. Investigate the energy expenditure required when completing different activities in this group of stroke survivors with severe mobility disabilities using indirect calorimetry.
    c. Determine whether it is possible for upper extremity activity in people with stroke-related mobility impairments, to reach sufficient intensity to offset the negative effects of sedentary activity.

5. **To identify the next steps needed for research into sedentary behaviour in stroke survivors with severe mobility disabilities and develop recommendations to help reduce sedentary behaviour in this population.**
    a. Draw upon findings from aims one to four and their objectives to determine whether an intervention to reduce sedentary behaviour in stroke survivors with severe mobility disability is required, acceptable and achievable.
    b. Consider what stroke survivors with severe mobility disabilities are capable of in terms of reducing sedentary behaviour and suggest possible strategies that could be adopted in future interventions
    c. Identify future research that is required in order to help develop recommendations regarding the design and content of a possible intervention to reduce sedentary behaviour in stroke survivors with severe mobility disability.

1.5. Overview of thesis

This thesis is divided into seven chapters. The current Chapter, introduces the thesis and provides background and context to the research topic. Chapters two and three refer to the two systematic reviews conducted at the beginning of the research. The findings of which were used to inform the two empirical studies, described in Chapters four, five and six, that were completed in parallel. Finally, Chapter seven presents the combined findings and implications of the research. An overview of Chapters two - seven is provided below:

Chapter Two - The effectiveness, appropriateness and acceptability of interventions to reduce sedentary behaviour in people with disability: A mixed methods systematic review

2.1. Introduction

In order to help inform guidance for intervention development in stroke survivors with severe mobility disability to reduce sedentary behaviour, it was deemed important to draw upon the wider literature and focus on sedentary behaviour in people with a disability. This chapter presents a mixed-methods systematic review that aimed to assess the effectiveness, appropriateness and acceptability of interventions to reduce sedentary behaviour in people with disability. The rationale for the review is presented followed by a discussion of mixed-methods systematic reviews and the different approaches available for undertaking one. The methods and findings from the two sub-reviews are then presented before the planned meta-synthesis is discussed.

2.1.1. Purpose of review

Systematic reviews are important for informing healthcare decisions as they aim to provide a more accessible overview of the available evidence (Higgins and Green, 2011). They use explicit systematic methods that are pre-specified prior to initiation of the review (Higgins and Green, 2011). The strength of this approach includes using scientific methods to limit bias primarily by attempting to identify, appraise and synthesise all empirical evidence that meet defined eligibility criteria (Petticrew and Roberts, 2006). By identifying and synthesising all relevant randomised trials, systematic review methodology is particularly effective at answering specific research questions and providing reliable evaluations of intervention effectiveness (Centre for Reviews and Dissemination (CRD), 2009; Higgins and Green, 2011). It is also an effective method of identifying areas of knowledge where there is limited evidence which require more investigation (Centre for Reviews and Dissemination (CRD), 2009).

Although ‘traditional’ systematic reviews are an important method for linking research and practice by reporting effectiveness of interventions, there is growing acknowledgement that inclusion of qualitative research can add to the value of the review. Policy makers are increasingly asking for more than simply the efficacy of interventions and seek to understand the causes of variation in outcomes (Centre for Reviews and Dissemination (CRD), 2009). Specifically, understanding why and how complex interventions do and do not work in different contexts (Kavanagh et al., 2012). In order to explain and not merely describe, conclusions need to be drawn from unobservable phenomena (i.e. people's perspectives and experiences) instead of simply drawing conclusions from observationally verifiable data (e.g. randomised controlled trials (RCTs), observational studies). Mixed method review approaches, facilitate a dialogue between the observable and unobservable research data, and allow integration of 'quantitative' estimates of benefit and harm with 'qualitative' understanding from people's lives (Thomas et al., 2012).

Although more research is being conducted into sedentary behaviour and stroke, from initial scoping of the literature at the beginning of this project, it appeared that stroke survivors who have mobility disability or are severely disabled are often excluded from research studies, especially in relation to sedentary behaviour (English et al., 2014).

As little is known about sedentary behaviour in the severely disabled stroke population, it was deemed important to draw upon the wider literature and review sedentary behaviour in people with a disability. A mixed-methods systematic review was therefore proposed to review the effectiveness of interventions to reduce sedentary behaviour and explore the perspectives and experiences of people with a disability, their carers and healthcare professionals involved in their care. It was the intention of the review to identify interventions or components of interventions that could potentially translate into the stroke population and inform guidance or intervention development for stroke patients.

2.1.2. Mixed methods systematic reviews

Although various techniques and approaches to conducting a mixed-method systematic review have been developed in recent years, there is currently no consensus with regards to how 'qualitative' and 'quantitative' data should be combined in a systematic review (The Joanna Briggs Institute, 2014; Centre for Reviews and Dissemination (CRD), 2009). For the purpose of this systematic review, multiple methods were considered including; Realist Synthesis, Bayesian Methods and The Evidence for Policy and Practice Information and Co-ordinating (EPPI) Centre approach.

The focus of realist synthesis in systematic reviews is to examine the underlying theories of interventions and is therefore focused on answering the question 'what works, for whom and in what circumstances' (Pope et al., 2007). Although it is similar to the traditional Cochrane-style systematic review of effectiveness, this method specifically investigates whether and why the interventions do or do not work in different contexts and populations (Pope et al., 2007). While realist synthesis allows a large diversity of evidence, including; qualitative and quantitative data, unpublished reports and materials from media sources, to be analysed in the same review, some issues have been identified with the approach (Pope et al., 2007; The Joanna Briggs Institute, 2014). Significant bias is highly likely to occur when using realist synthesis due to the iterative nature of the search and review process which results in a continuously changing focus for the review (The Joanna Briggs Institute, 2014).

Another approach for conducting mixed-methods systematic reviews is Bayesian methods. Bayesian methods use meta-aggregation of data to create summative statements of the evidence. It involves either attributing a numerical value to all qualitative data, or attributing a qualitative thematic description to all quantitative data (Pearson et al., 2015; The Joanna Briggs Institute, 2014). This then allows a final meta-aggregation of the individual syntheses as the data has been transformed into a mutually compatible form (The Joanna Briggs Institute, 2014). Reasons for rejecting this approach are identified below.

The Evidence for Policy and Practice Information and Co-ordinating (EPPI) Centre has developed an approach which seeks to answer a broad review question through parallel systematic syntheses of quantitative and qualitative data, with each addressing sub-questions. The results are then combined in a meta-synthesis to address the broad review question (Pope et al., 2007). This approach allows in-depth analysis of the implications from the findings using a juxtaposed matrix of the individual review syntheses, and can help to identify reasons why interventions may or may not work (Kavanagh et al., 2012). One benefit of using this approach is the potential to link any number of syntheses that address individual questions relating to the effectiveness of an intervention (Centre for Reviews and Dissemination (CRD), 2009). Although one of the main limitations of using the EPPI approach is the time consuming and resource intensive nature of the methods (Kavanagh et al., 2012), it manages to preserve the integrity of the different types of studies. Unlike Bayesian methods, the EPPI approach does not convert quantitative data into words or qualitative findings into numbers (Thomas et al., 2012).

Another strength of the EPPI approach is its use of both aggregation and configuration within the cross-study synthesis. Aggregation refers to the ‘adding up’ or ‘pooling’ of results from primary quantitative studies which can be used to answer a review question and indicate the size or direction of effect (Gough et al., 2012b). Configuration allows qualitative and quantitative data from primary studies to be arranged next to each other, to identify patterns of similarities and differences caused by heterogeneity (Gough et al., 2012b). The combination of both aggregative and configuration methods used within the EPPI approach allows exploration of the research question and explanation of the differences observed, by testing the intervention and generating theories that underpin the findings (Gough et al., 2012b). Unlike the EPPI approach, Bayesian methods use only meta-aggregation.

It was therefore decided to use the EPPI approach to conduct a systematic review that would assess the effectiveness, through aggregation of quantitative RCT studies, and the appropriateness and acceptability, through configuration of both qualitative and quantitative data, of interventions aimed at reducing sedentary behaviour in people with a disability. A detailed review protocol was developed for both sub-reviews using the Centre for Reviews and Dissemination guidance for undertaking reviews in health care (2009). The stages of the EPPI approach; adapted from Oliver et al (2005) and Thomas et al (2004) for the purpose of this review, are described in Figure Four.

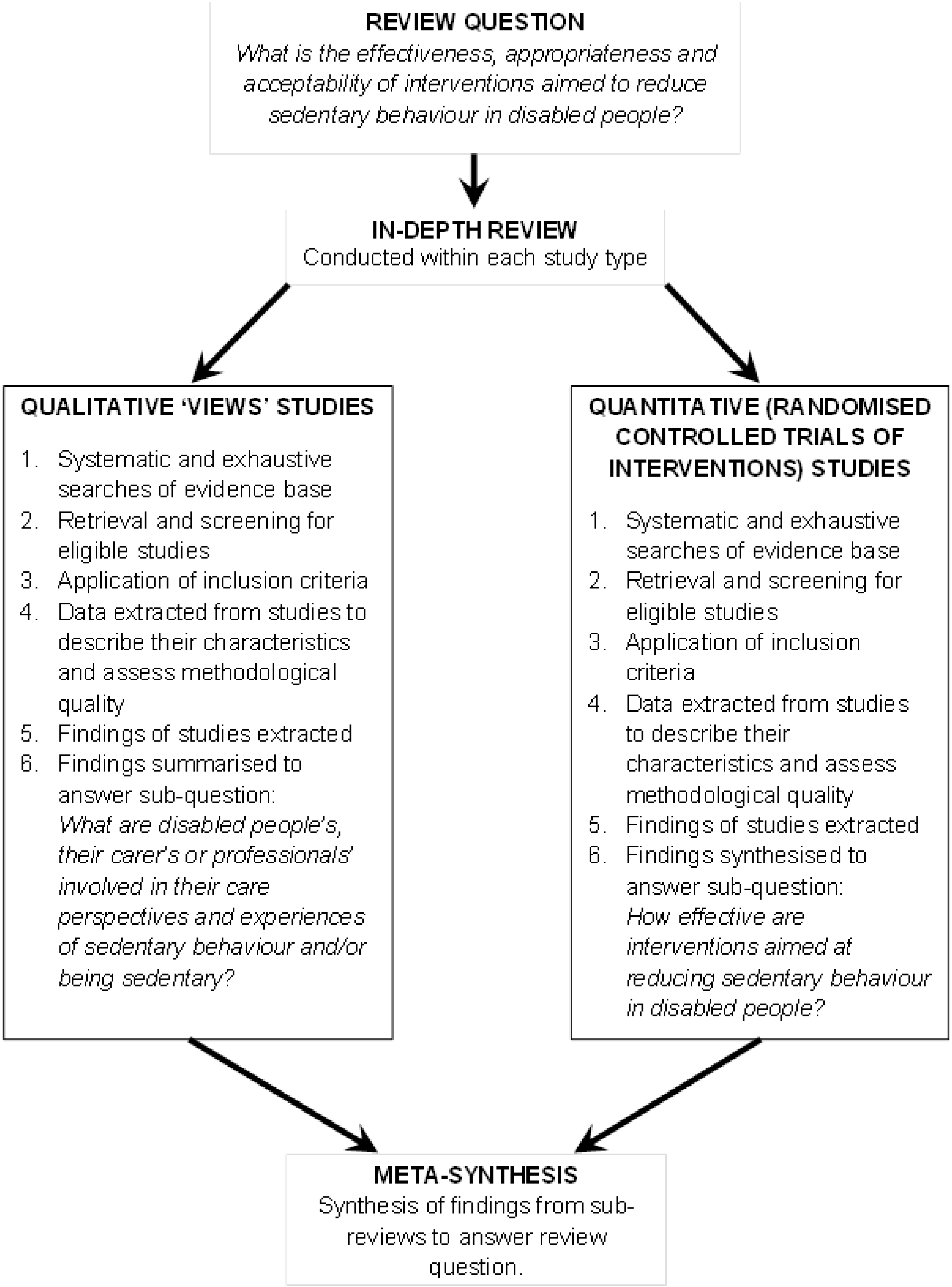


Figure 4: Stages of an EPPI centre mixed methods review (Adapted from Oliver et al (2005) and Thomas et al (2004))

2.2. Sub-review one: Synthesis of qualitative studies addressing people with disabilities’ perspectives and experiences of sedentary behaviour

2.2.1. Methods

2.2.1.1. Review question

The aim of the first sub-review was to address the question; ‘What are people with disabilities’ perspectives and experiences of sedentary behaviour and/or being sedentary?’

2.2.1.2. Eligibility criteria

2.2.1.2.1. Inclusion criteria

Studies were included if they met the following inclusion criteria:

- Used qualitative research methods (e.g. interviews and focus groups)
- Investigated perspectives and/or experiences of sedentary behaviour
- Participants of the study:
    - Have a disability and are over 18 years of age:
      Definition of disability – ‘A person has a disability if he/she has a physical or mental impairment which has a substantial and long-term effect on their ability to carry out normal day-to-day activities’ (*Equality Act 2010*)
    - Carers of people with a disability
    - Professionals who are involved in the care of patients with a disability

2.2.1.2.2. Exclusion criteria

Studies were excluded if they met the following criteria:

- Included participants under 18 years of age
- Focused on physical activity but do not address sedentary behaviour or sedentary time.

2.2.1.3. Identifying research evidence

A comprehensive search strategy was initially developed for MEDLINE with guidance from an information specialist from the University of Leeds. The review was kept as broad as possible and included all types of disability not just ‘mobility disabilities’. This was reflected in the search strategy with terms such as; ‘Disabled

Persons’, ‘Vision Disorders’ and “Mental Disorders’ being included (Appendix A). Once the MEDLINE search strategy had been developed and tested, it was then adapted for use in seven other databases. The databases of published data were selected for their relevance to the review topic and searched using the comprehensive search strategies, and included; MEDLINE, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Allied and Complimentary Medicine Database (AMED), EMBASE, the Cochrane Library, PsycINFO, Web of Science and SPORTDiscus. As the intention was to keep the review broad, language limits and date limits were kept open during the searches of the databases to allow inclusiveness. As sedentary behaviour is a relatively recent research topic it was thought that relevant studies would only be identified in a period of recent years, however the date limit was kept open to see what earlier research emerged before the term ‘sedentary’ was used.

In order to identify literature that had not been formally published in sources such as books or journal articles (i.e. theses), grey literature databases were also searched. ProQuest Dissertations and Theses database was searched using the adapted search strategy used in the Web of Science database, whilst OpenGrey, an European database containing research reports, theses, conference papers and official documents, was searched using keywords taken from the original MEDLINE search strategy. Additionally, through the Web of Science database search, the Conference Proceedings Citation Index database was also searched for grey literature.

The searches were run in all databases in April 2016 following development of the search strategies. The initial searches identified over 30,000 results and after scanning the results it was apparent that the majority of the results were not relevant to the review, specifically not qualitative studies. Following discussion with academic supervisors and the information specialist it was decided to re-run the searches with the addition of a qualitative set of search terms that would focus the search criteria and only capture studies of interest. The information specialist provided a qualitative search filter that had been developed by their team using existing filters including one produced by McMaster University’s Health Information Research Unit (Health Information Research Unit: McMaster University, 2016).

In order to try and capture all available literature, all conference abstracts identified through the searches were reviewed and checked for possibly relevant studies or any associated published papers. These were then reviewed like the other identified studies and checked for inclusion in the review. Similarly, citation searches of included studies were conducted during the study selection stage to identify additionally relevant papers that could then be checked for inclusion in the review.

2.2.1.4. Study selection

All results from the searches of databases of published data, grey literature and other sources including conference abstracts were collated and stored using Endnote, reference management software. For each study, an initial screen of the titles and abstracts against the inclusion criteria was conducted to identify potentially relevant papers.

Once the initial title and abstract screen was completed, full text articles were obtained for the potentially relevant studies. Although the majority of the articles were freely available, some had to be obtained from the authors, the University of Leeds Library and The British Library. Each article was then reviewed using a screening eligibility form framed around the eligibility criteria and research questions was used to aid decision making and also document the decisions made about each study.

The primary reviewer (NC) screened all of the results, whilst a second independent reviewer screened 20% of the results during the title and abstract review and 20% of the potentially relevant studies in the full text review. Any discrepancies between the two reviewers were initially discussed by the reviewers and resolved through the involvement of a third independent reviewer.

2.2.1.5. Data extraction

Data was extracted by the principal reviewer using a data extraction form that was developed to extract the data necessary to answer the research question and included; aims of the study, sample characteristics, details of the methodology and findings. As per the review protocol, the reviewer planned to contact study authors if any data was missing from the papers or there was additional data that was required, to request the information. However, this was not required for this sub-review as all data was available in the papers.

To reduce bias and increase accuracy during data extraction (Centre for Reviews and Dissemination (CRD), 2009; Buscemi et al., 2006) a second independent reviewer completed double data extraction of the included studies.

2.2.1.6. Quality assessment

Methodological quality of the included studies was assessed by both the primary reviewer and a second independent reviewer. For this sub-review, the NICE Quality appraisal checklist (National Institute for Clinical Excellence, 2012) was chosen to assess the quality of the included studies. This tool was deemed appropriate for use in this review as it had been designed based upon the broadly accepted principles that characterise qualitative research and ultimately those which may affect its validity (Spencer et al., 2003). The framing of the questions have also been designed to allow studies with different methods of conducting qualitative research to be assessed.

2.2.1.7. Data synthesis

Unlike data synthesis methods for systematic reviews of RCTs which are well developed and tested, methods for reviewing qualitative data in a systematic way are still emerging and being developed. Although several methods for qualitative data synthesis have recently emerged, there is no consensus on which is the best method to use within a systematic review (Thomas and Harden, 2008). There is also an ongoing debate about whether it is appropriate to combine qualitative studies, however some review teams believe that the combination of data from different types of qualitative research with different methods and theoretical assumptions strengthen the review (Centre for Reviews and Dissemination (CRD), 2009).

Thematic synthesis is a technique of synthesising qualitative research in systematic reviews, developed by Thomas and Harden (2008) of the EPPI centre. It was initially developed using a combination of methods for analysing primary qualitative research and standard systematic review methods, and later defined with the application of thematic analysis in a more explicit way (Thomas and Harden, 2008). It was developed in order to conduct systematic reviews that could address questions about the need for, appropriateness and acceptability of interventions (Barnett-Page and Thomas, 2009). The synthesis involves three stages (Thomas and Harden, 2008; Barnett-Page and Thomas, 2009).; firstly the findings of the primary studies are coded line-by-line into ‘free codes’. These ‘free codes’ are then organised into related areas to construct ‘descriptive themes’. Further interpretations of the descriptive themes are developed and worked into ‘analytical’ themes. Although the process is divided into three stages, it can often be ‘fluid; with each of the steps overlapping with one another (Thomas and Harden, 2008).

As per the review protocol, this review planned to use thematic synthesis to synthesise the data collected through data extraction, using NVivo software specifically to aid the line-by-line coding as described above.

2.2.2. Results

2.2.2.1. Description of studies

Figure Five details the study selection process, using the PRISMA flow diagram (Moher et al., 2009). The search identified 8598 potential papers, an additional five were identified through associated papers of conference abstracts and citation searching. After screening and reviewing 84 full text articles, only one study fully met the inclusion criteria.

Through the whole study selection process, the reviewers found it difficult to determine eligibility due to the discrepancies in terminology used in the papers. Often papers would refer to ‘sedentary behaviour’ when they were describing ‘physical inactivity’ (as per the definition in section 1.1.2). This has been recognised as a problem by the Sedentary Behaviour Research Network (SBRN) who have recently conducted a terminology consensus programme in order to standardise terminology and definitions in sedentary behaviour research (Tremblay et al., 2017). As a result of the ambiguity in terminology, five studies were reviewed by the third reviewer and discussed with the primary reviewer to establish if the studies were suitable for inclusion. All five studies were eventually excluded as they all explored physical activity and inactivity rather than sedentary behaviour or sedentary time.

The included study, (Thomsen et al., 2015), is a qualitative study examining sedentary behaviour in patients with rheumatoid arthritis. This study was one of the five additional studies identified through the review of conference abstracts and is associated with the conference abstracts by Esbensen (2015) titled ‘Reduction of sedentary behaviour in patients with rheumatoid arthritis – experiences from an intervention study’ and Thomsen et al (2013) titled ‘Sedentary behaviour in patients with rheumatoid arthritis: A qualitative study’.

The study aimed to examine how patients with rheumatoid arthritis describe their daily sedentary behaviour. Fifteen patients with rheumatoid arthritis from Denmark, aged between 23 to 73 years of age were interviewed using a semi-structured interview guide. The interview data were analysed using the content analysis method described by Graneheim and Lundman (2004). Of the fifteen participants, ten were female and five were male, and their disease duration ranged between 4 and 27 years. Although all participants were functionally independent, three had some disability regarding their activities of daily living. Participants self-reported between 5 and 10 hours per day spent in leisure time sedentary behaviour using the Physical Activity Scale (PAS 2.1) (Aadahl and Jørgensen, 2003).

As only one study was identified, a thematic synthesis was not appropriate to analyse the results. Instead, the findings from the study were reviewed and described narratively.

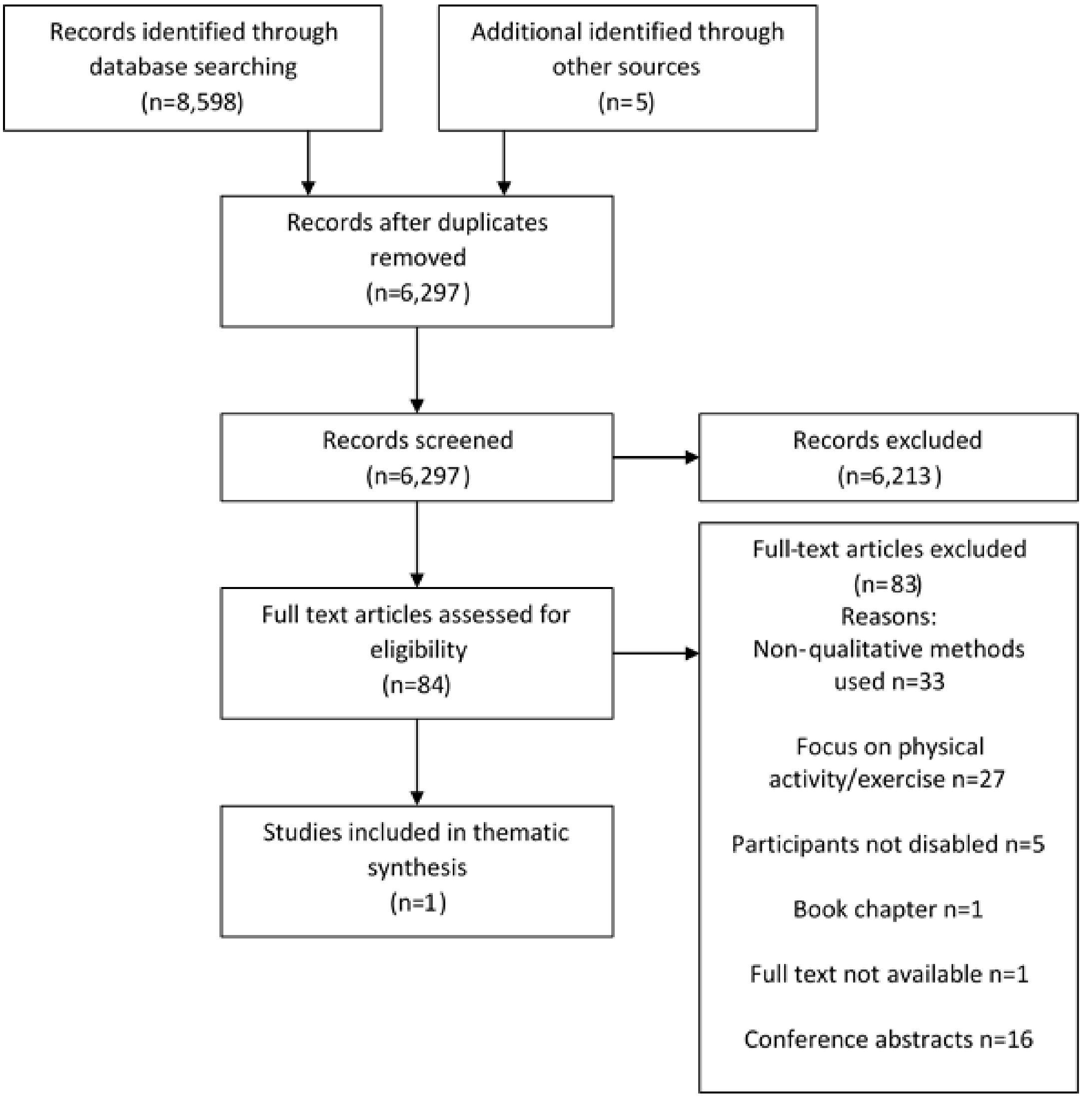


Figure 5: Sub-review one: PRISMA flow diagram of study selection (Moher et al., 2009)

2.2.2.2. Quality assessment of included studies

Overall the study was assessed as being of high quality, with the majority of the NICE quality appraisal checklist criteria (National Institute for Clinical Excellence, 2012) being fulfilled. Table One details the quality assessment scores for each of the 14 criteria. The study was very clear in describing its purpose and a clear rationale was given for the suitability and adoption of a qualitative approach. The interview process was described fully with the interview guide being piloted and presented in the paper. Overall the study is of high quality with clear justification and detail of the methods used, well-executed data collection and rich and convincing data.

Table 1 Sub-review one: Criteria scores on NICE quality appraisal checklist

Theoretical approach	
1. Is a qualitative approach appropriate?	**Appropriate** / Inappropriate / Not sure
2. Is the study clear in what it seeks to do?	**Clear** / Unclear / Mixed
Study design	
3. How defensible/rigorous is the research design/methodology?	**Defensible** / Indefensible / Not sure
Data collection	
4. How well was the data collection carried out?	**Appropriately** / Inappropriately / Not sure
Trustworthiness	
5. Is the role of the researcher clearly described?	**Clearly described** / Unclear / Not described
6. Is the context clearly described?	**Clear** / Unclear / Not sure
7. Were the methods reliable?	**Reliable** / Unreliable / Not sure
Analysis	
8. Is the data analysis sufficiently rigorous?	**Rigorous** / Not rigorous / Not sure
9. Is the data 'rich'?	**Rich** / Poor / Not sure
10. Is the analysis reliable?	**Reliable** / Unreliable / Not sure
11. Are the findings convincing?	**Convincing** / Not convincing / Not sure
12. Are the findings relevant to the aims of the study?	**Relevant** / Irrelevant / Partially relevant
13. Conclusions	**Adequate** / Inadequate / Not sure
Ethics	
14. How clear and coherent is the reporting of ethics?	**Appropriate** / Inappropriate / Not sure
Overall assessment	
As far as can be ascertained from the paper, how well was the study conducted?	**++** / + / -

2.2.2.3. Findings

From the data collected and through the method of quantitative content analysis, three categories, each with subcategories were identified by the study authors; 1) A constant battle between good and bad days, 2) Adaptation to everyday life and 3) It has nothing to do with my arthritis. The following section provides a summary of the findings as interpreted by the author (NC) using the categories and sub-categories identified by the study authors and the quotations provided in the paper (Thomsen et al., 2015).

1) A constant battle between good and bad days

Being dependent on efficient medical treatment

Patients described the fluctuation in disease symptoms as a constant battle within their bodies between good and bad days. They also perceived the constant battle between disease symptoms and effective medical treatment as a battle for control of their body. Their dependence on medical treatment and it's effectiveness at reducing symptoms was vital for them to regain control of their body. It is on bad days, whereby they feel they have lost control, resulting in an increased dependence on family and a limitation of daily activities. This ultimately increases their periods of inactivity and sitting, as this participant indicated:

> *"On bad days, the arthritis still breaks out and takes over my body. It is in all my joints and it hurts all over. Then I sit and do whatever, e.g., my crosswords or reading a book."*
>
> (P 2, Thomsen et al. (2015), P.5).

When symptoms dominate

Although the majority of patients generally felt that their disease symptoms were well controlled by their prescribed medication and treatment, all patients described days whereby the disease dominated and caused severe fatigue and pain.   Often these days resulted in severe exhaustion with participation in activities of daily living only causing greater exhaustion and reduced movement. Patients would avoid tasks that involved standing or walking as a method of controlling their fatigue levels, but this ultimately limited their engagement in activities of daily living and increased their levels of sedentary behaviour. Energy levels appeared to be most diminished in evenings as a result of using all of their energy to get through the day. As a consequence, evening activities were often given up on and replaced with periods of rest and sedentary behaviour, as described by participant P15:

> *"I am extremely tired. Some evenings when I return from work and sit on the couch and turn on the TV I simply pass out. It is like I use all my strength at work. All energy is gone...I use more efforts during the day, which you compensate for at night."*
>
> (P 15, Thomsen et al. (2015), P.5).

During bad days when patients' experienced extreme pain and fatigue, physical activity levels would be minimal with their time regularly spent doing activities that were highly sedentary e.g. watching TV, reading or needlework. These days would come without warning and therefore restrict patients in making plans for the future. This also made organising social events very difficult, often with plans having to be cancelled at the last minute due to flare-ups of their disease symptoms. The inability to plan events affected patients psychologically; with feelings of irritation and frustrations when pain and fatigue stopped them doing things that they knew they were perfectly capable of doing at other times. Patients also described their bad days as particularly isolating either because they were forced to stay in the house and rest or due to a lack of motivation to do anything for fear of inducing pain and increasing their fatigue. Lack of motivation is often seen as a barrier to physical activity and is therefore a precursor to increased levels of sedentary behaviour. Participant P1 highlighted how lack of motivation often affects how much they do throughout the day and how it often causes them to remain in their house and not venture out:

> *"I try to protect myself and hide at home, because I am so tired all the time. And I cannot motivate myself to do anything. So actually my home base is my own personal hell some days."*
>
> (P 1, Thomsen et al. (2015), P5).

2) Adaptation to everyday life

The body signals a need for sitting time

Patients were regularly forced to take more breaks, in particular sitting breaks during and between their day-to-day activities as a result of their condition. Greater levels of pain and stiffness were observed during mornings, causing routines to be adapted to include a rest period in the morning to allow their bodies to ‘wake-up’ and prepare themselves for the day ahead. Although these planned breaks were a necessity on bad days, patients described how these planned periods of rest had become part of their daily routine and continued even on days when they did not have pain or stiffness.

Protection of joints is essential

Daily routines were also constructed by the patients with protection of their joints in mind. Strategies implemented daily to reduce strain on their joints, for example, always to go by car, never walk upstairs and not to take longer walks then necessary, mainly reduced their movement in order to limit pain. These strategies, although beneficial to reducing pain and helping to alleviate symptoms onset, also increased their periods of sitting and sedentary behaviour as evidenced by P11:

> *“My girlfriend and I have put a barstool in the kitchen. That way it is possible for me to sit while cooking. I want to protect myself. By doing all these little things in everyday life I believe it will help me in the long term.”*
> (P 11, Thomsen et al. (2015) , P6).

As with the regular morning breaks, the strategies implemented to reduce strain on their joints are not always required, for example on good days, but have become incorporated into their daily routines. These preventative methods result in continued reduced movement even on good days.

A dependence on others developed during particularly bad periods in the early stages of their disease trajectory had often forced patients to change how they carried out activities. Being accustomed to taking precautions has lead to maintained practice even when symptoms are absent. This was described by participant P11 who often continued the restricted or adapted movements in order to prevent or reduce the severity of future flare-ups:

> *"Even though the medicine really has improved my everyday life, some days I don't even notice I suffer from RA, I still want to protect myself and not strain my joints".*
>
> (P 11, Thomsen et al. (2015), P6).

Awareness of rest, movement and sitting time

The patients' awareness of having their condition and the requirement for protecting their joints and energy was reflected in the way they utilised activity pacing and energy conservation during domestic activities. This involved breaking activities, including; laundry, cooking and cleaning, into smaller steps to make them more manageable. During the rest periods, patients did not need to sleep but instead sit and participate in sedentary activities, for example, reading a newspaper or looking at something on the internet.

Essential planned rest days became routine for the patients, often scheduled after a busy day. These days often involved not leaving the house and spending the majority of the day on the sofa with minimal movement watching TV or reading. Patients described how these rest days had become part of their lives and without them many felt "punished" with severe fatigue, as this participant indicated:

> *"I allow myself a weekly day of rest when I have been working a lot. On these days nothing is going on besides TV-watching, eating and maybe reading a book. I do not even shower".*
>
> (P 14, Thomsen et al. (2015) , P6).

3) It has nothing to do with my arthritis

Co-morbidities are influencing sitting time

Some patients described the effects of their co-morbidities as being more limiting compared with rheumatoid arthritis. Other existing diseases, including osteoporosis and cardiovascular diseases often limited their physical activity and led to increased sitting time. Participant P5 strongly believed that their arthritis was not the main factor affecting their movement, but instead problems with their heart:

> *"It is not the arthritis that prevents me from mowing our lawn, but my heart does not work properly. Sometimes even the stairs feel overwhelming. Also, the time with the slipped disk was awful. The arthritis was nothing compared to that. I could not do anything."*
>
> (P 5, Thomsen et al. (2015) , P6).

Simply a way of living

Sedentary behaviour was also described as simply a way of living. Laziness or a lack of interest in moving too much was regularly described by the patients as reasons for increased periods of sitting time and sedentary behaviour. Sitting was often expressed as generally being more comfortable not only in relation to their disease symptoms but generally, for example, even on good days when their pain, stiffness and fatigue levels were low.

Although sedentary behaviours were essential for these patients, offering them time to rest and giving them a period of relief from their disease symptoms, they also formed a major part of their leisure time. A lot of leisure time activities and hobbies often involve sitting and sedentary behaviour including; watching TV, reading, crafts and using a computer, and this was no different for these patients. They relished their time spent sitting as it often involved hobbies and activities that they enjoyed doing. In this respect, the time that they spent sedentary was not always as a result of their condition but because it brought enjoyment and happiness and was seen as an important aspect of their life, as described by participant P9:

> *"I have never been interested in sports. It has always been reading, reading, reading. As soon as there was Windows 3.11 on the computer I plunged into that. Even now, I always sit at the computer. Love my games. I'm lazy. Why go out for a walk if you can sit and play a computer game? Life is about to do what you want to, not to live as long as possible."*
>
> (P9, Thomsen et al. (2015), P6-7).

Social relations contribute to increased and decreased sitting time

Social interaction, although important to the patients for improved quality of life, also involved increased episodes of sitting. Social events with friends often involved meeting for coffee or going out for meals resulting in periods of sitting. Even social interactions with family would often involve sedentary activities including lazy evenings on the sofa watching TV or movies with family members. Although these social relations ultimately increased the patients' levels of sedentary behaviour, they were important as they allowed them to have a break from the controlling nature of their condition on them and their engagement in activities, and ultimately improved their quality of life through having fun and socialising.

Alternatively social interactions also increased the patients' physical activity levels resulting in a reduction of sedentary behaviour. Family responsibilities commonly involved looking after children or grandchildren, for example, spending a day looking after and playing with grandchildren or taking their children and picking them up from school. These activities, although seen as a necessary part of their routines were important to keep the patients' active and reduce the time they spent in sedentary behaviours.

2.2.3. Discussion

The single included study was, to the best of the authors' knowledge, the first study to report sedentary behaviour from the perspective of rheumatoid arthritis patients. A significant finding from the study was the distinction between disease-specific and disease-independent reasons for reduced physical activity and increased sedentary behaviour. Although sedentary behaviour was often a consequence of disease flare-ups or as a means of managing everyday life with a health condition, it was also established that much of their sedentary behaviour was not related to their disease but instead a way of living. This finding is synonymous with the general population who spend the majority of their free-time in sedentary behaviour out of choice and enjoyment.

After a brief scoping of the literature during the early stages of the PhD project, a limited amount of results pertaining to sedentary behaviour after stroke and none specifically relating to patient experiences of sedentary behaviour were identified. This led to the current review, more specifically the review question, to be designed to draw upon the wider literature and examine the literature around sedentary behaviour and disability. The review was kept as broad as possible and included all types of disability not just 'mobility disabilities'. This was reflected in the search strategy with terms such as; 'Disabled Persons', 'Vision Disorders' and "Mental Disorders' being included (See Appendix A). The hope with widening the search criteria was to ultimately identify more studies to allow comparisons across different disability causing conditions. The generalised results would then have been compared with the results from the Q-methodology study (Chapters Four and Five) to examine the similarities and differences of the stroke patients' perspectives with those of other people with disabilities. They would also be used in a meta-synthesis with the findings from sub-review two to answer the overall research question; ‘What is the effectiveness, appropriateness and acceptability of interventions aimed to reduce sedentary behaviour in disabled people?’ As only one qualitative study was identified within this sub-review, a meta-synthesis of the findings from the two sub-reviews was not feasible. This is discussed further in section 2.4. The results were though, as planned, reviewed and included in the development process of the Q-sort in the Q-methodological study (Chapters Four and Five).

Although only one study matched the inclusion criteria, the broad search strategy initially identified over 8500 results with 84 results suitable for full text review. Five studies did not meet the inclusion criteria as their participants were not disabled but instead older adults, for example, a study by Chastin et al (2014). The majority of the papers that were excluded used non-qualitative methods to collect data. Questionnaires using closed, fixed item response type questions were often used to explore attitudes and barriers to or measure levels of physical activity, and included the Short Form Health Survey (SF-36) (Ware and Sherbourne, 1992) and the Physical Activity Scale for Individuals with Physical Disabilities (PASIPD) (Washburn et al., 2002). Apart from a small number of studies that used questionnaires that measured sedentary behaviour, for example the International Physical Activity Questionnaire (IPAQ) (Craig et al., 2003) , which has been recognised as a sedentary behaviour questionnaire by the SBRN (Sedentary Behaviour Research Network, 2013), the majority of measures used focused on physical activity and exercise. A proportion of the studies excluded for using non qualitative methods were initially misidentified as qualitative. Although the abstracts stated that interviews were used to collect data, upon reading the full text article it became apparent that although interviews were used, the participants were asked fixed response or closed ended questionnaire items by the interviewer, with the data then being statistically analysed.

Another reason for a large proportion of the studies to be excluded was the focus on physical activity and exercise rather than sedentary behaviour. Studies often explored barriers and motivators to physical activity using questionnaires or through qualitative techniques. An issue that was highlighted through this review is the lack of precision in terminology in relation to physical activity and sedentary behaviour used in health science.

While the one included study was of high quality, not enough data was available to draw any meaningful conclusions about experiences of sedentary behaviour in people with disabilities. Although more studies would be beneficial in order to draw better conclusions and make comparisons between different conditions causing disability, the lack of available studies only highlights the absence of published research exploring sedentary behaviour from the patients' perspective. There should therefore be an acknowledgement of the need for further research into patients' perspectives of sedentary behaviour in order to develop tailored interventions to reduce sedentary behaviour in this population. Although 16 conference abstracts were included in the full text review stage of the study selection process, potentially suggesting an increase of emerging studies, only three studies investigated sedentary behaviour. Of the three conference abstracts, two were related to the included study (Esbensen, 2015; Thomsen et al., 2013) and one used non-qualitative methods (Loeppenthin et al., 2013). This ultimately provides support for the requirement of the Q-methodological study conducted as part of this PhD project as it will add to the body of literature on sedentary behaviour in stroke specifically but also sedentary behaviour in people with disabilities.

Since the search was conducted in April 2016, more studies exploring patients' views of sedentary behaviour have emerged including some specific to stroke (Hall et al., 2019; Ezeugwu et al., 2017; Nicholson et al., 2016). These additional studies are discussed is more detail in Chapter Four. However, for the purpose of this project the search was deemed suitable and not requiring updating as it highlighted and supported the need for an exploratory study to examine stroke patients' perspectives of sedentary behaviour and also contributed to the Q-sort development process.

2.3. Sub-review two: Synthesis of trial studies to address the effectiveness of interventions

2.3.1. Methods

2.3.1.1. Review question

The aim of the second sub-review was to address the question; 'What is the effectiveness of interventions aimed at reducing sedentary behaviour in people with disabilities?'

2.3.1.2. Eligibility criteria

2.3.1.2.1. Inclusion criteria

Studies were included if they met the following inclusion criteria:

- Randomised controlled trials of non-pharmacological interventions aimed at reducing sedentary behaviour.
    - Any trials regardless of who provided the intervention, type of intervention or the amount of intervention delivered.
- Trials with participants that have a disability:
    - Definition of disability – 'A person has a disability if he/she has a physical or mental impairment which has a substantial and long-term effect on their ability to carry out normal day-to-day activities' (*Equality Act 2010*).

2.3.1.2.2. Exclusion criteria

Studies were excluded if they met the following criteria:

- Trials including participants under 18 years of age.
- Trials of interventions that focus on increasing physical activity but do not address sedentary behaviour.

2.3.1.3. Identifying research evidence

A comprehensive search strategy for sub-review two was simultaneously developed with the search strategy for sub-review one (Appendix B). Similar to the first sub-review, the search strategy was initially developed for MEDLINE and then adapted for use in the same seven databases of published data (MEDLINE, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Allied and Complimentary Medicine Database (AMED), EMBASE, the Cochrane Library, PsycINFO, Web of

Science and SPORTDiscus). As the focus of this sub-review was to identify RCTs aiming to reduce sedentary behaviour, the qualitative search filter was replaced with a RCT search filter specifically developed to focus the search and identify RCTs. With the intention to keep the review broad, language limits and date limits were kept open during the searches of the databases to allow inclusiveness.

Like sub-review one, grey literature databases (ProQuest Dissertations and Theses, OpenGrey) were also searched in order to identify literature that had not been formally published in sources such as books or journal articles (i.e. theses). Additionally, through the Web of Science database search, the Conference Proceedings Citation Index database was also searched for grey literature.

In order to try and capture all available literature, all conference abstracts identified through the searches were reviewed and checked for possibly relevant studies or any associated published papers. Like the other identified studies, these were then reviewed and checked for inclusion in the review. Similarly, citation searches of included studies were conducted during the study selection stage to identify additionally relevant papers that could then be checked for inclusion in the review.

2.3.1.4. Study selection

As per sub-review one, the primary reviewer (NC) screened all of the results, whilst a second independent reviewer screened 20% of the results in stage one and 20% of the potentially relevant studies in the full text review during stage two. Any discrepancies between the two reviewers were initially discussed by the reviewers and resolved through the involvement of a third independent reviewer.

2.3.1.5. Data extraction

Data was extracted electronically by the principal reviewer using a data extraction form that was developed in order to collate the data necessary to answer the research question and included; aims of the study, sample characteristics, details of the methodology and results. As per the review protocol, the reviewer planned to contact study authors if any data was missing from the papers or there was additional data that was required, to request the information. However, this was not required for this sub-review as all data was available in the papers.

To reduce bias and increase accuracy during data extraction (Centre for Reviews and Dissemination (CRD), 2009; Buscemi et al., 2006) a second independent reviewer completed double data extraction of all the included studies.

2.3.1.6. Quality assessment

It is important when reviewing RCTs, to assess the risk of bias of a study rather than the 'methodological quality', as a study may have been executed to the highest possible standards but also have a high risk of bias (Higgins and Green, 2011). For this sub-review, the Cochrane Risk of Bias Tool (Higgins and Green, 2011) was used by two independent reviewers (primary reviewer and second independent reviewer) to assess the risk of bias of each of the eligible papers.

The Cochrane Risk of Bias Tool is a domain-based evaluation, where critical assessments are made on seven different domains including; random sequence generation, allocation concealment, blinding of participants and personnel, blinding of outcome assessment, incomplete outcome data, selective reporting and other bias. A judgement of 'low risk', 'high risk' or 'unclear risk' of bias is assigned by the reviewer to each of the domains (Higgins and Green, 2011).

2.3.1.7. Data synthesis

The most commonly used method to synthesise quantitative data in a systematic review is a traditional meta-analysis (Higgins and Green, 2011). It is a statistical technique that pools the results from similar quantitative studies to summarise effect size. Pooling of data enhances the statistical power of the analysis and allows a more precise estimate of intervention effectiveness (Higgins and Green, 2011; Pope et al., 2007).

Typically meta-analyses are based upon one of two statistical models, the fixed effects model or the random-effects model. The fixed effects model assumes that there is one true effect size which underlies all the studies in the analysis and that all differences in observed effects are due to sampling error (Borenstein et al., 2009, p.63). Alternatively, the random effects model accounts for between-study differences by relaxing the fixed effects assumption that they are all estimating the same 'true' effect and instead assumes that each study is representative of its own population of studies. The effect that is being estimated in the random effects model is therefore assumed to be the mean of all these different populations of studies (Gough et al., 2012a, pp.211-212).

A meta-analysis is deemed appropriate if the included studies are assumed to be similar enough to suggest a synthesis of the data. However it is often not possible to assume that the studies are identical, i.e. the true effect size is exactly the same in all of the included studies. As this sub-review is including studies with variation in the study populations (e.g. different disabilities), and implementation and design of interventions, there may be different effect sizes underlying the different studies. The random-effects model was therefore chosen as the statistical model to be used in this meta-analysis. The sub-review also aims to draw more general inferences about the treatments, settings and outcomes, rather than drawing specific inferences about the specific studies included (Cooper et al., 2009). This therefore also supports the decision to use a random-effects model.

As it was anticipated that there would be variety in the interventions including length of intervention and timings of outcome measurements, it was decided to use the first time point of outcome measurement following intervention completion to include in the synthesis. The data extracted for this sub-review was entered into RevMan 5 software and a meta-analysis was used to synthesise the data.

Although the assumption that the studies to be included would be similar enough to combine in a meta-analysis, heterogeneity statistics were reviewed to check the suitability of a meta-analysis. As per the review protocol, if statistical analysis was not possible due to the studies being too diverse; either methodological or clinically, a narrative synthesis would be undertaken to summarise the data (Centre for Reviews and Dissemination (CRD), 2009).

2.3.2. Results

2.3.2.1. Description of studies

The study selection process is summarised in Figure Six using the PRISMA flow diagram (Moher et al., 2009). 16,417 studies were initially identified, with 101 studies suitable for full text review. A total of six randomised controlled studies fully met the inclusion criteria and were included in the review. Table Two provides details on the study characteristics for the six included randomised controlled trials.

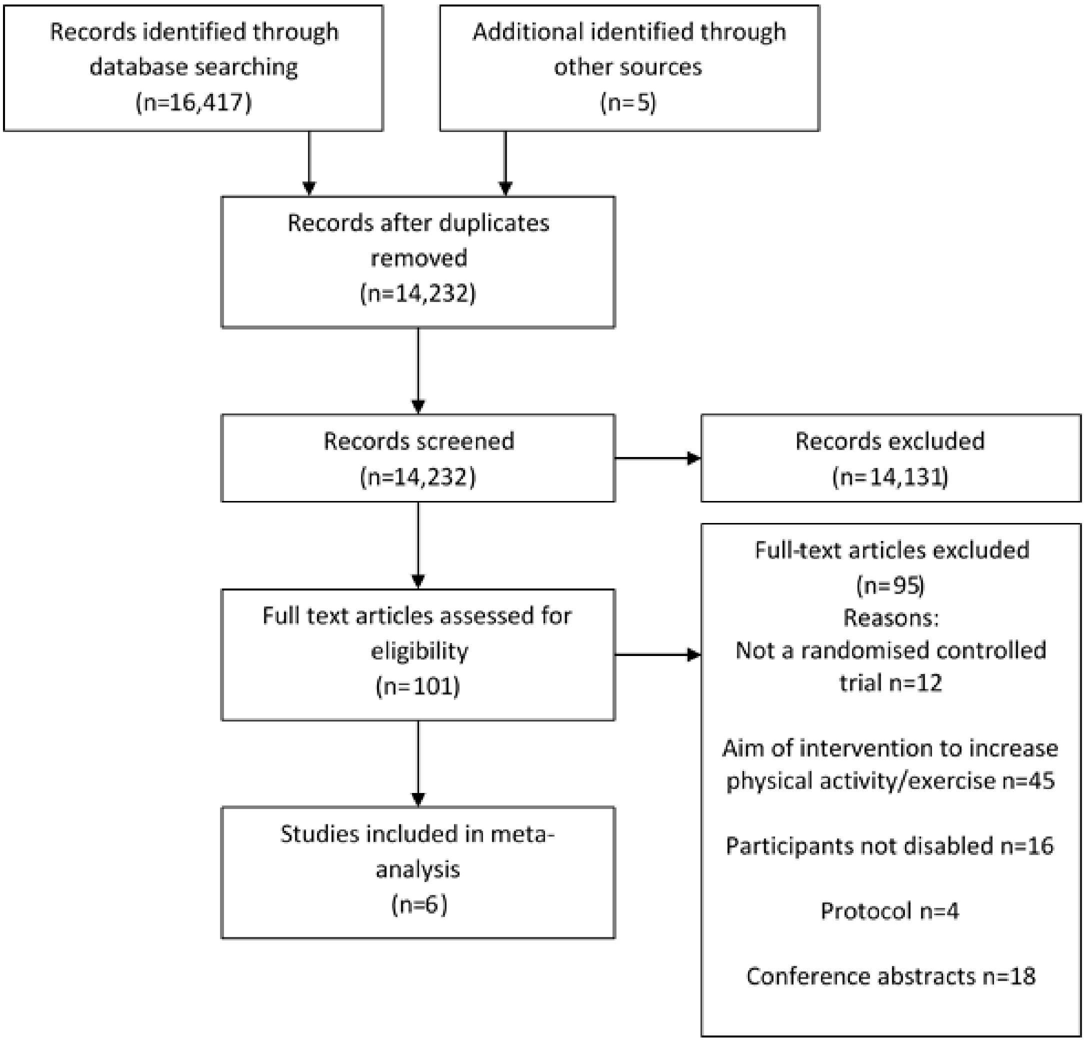


Figure 6 Sub-review two: PRISMA flow diagram of study selection (Moher et al., 2009)

The included trials were conducted in five different countries and included five different patient groups with disabilities; Cerebral Palsy (Bania et al., 2016; Slaman et al., 2015), Multiple sclerosis (McAuley et al., 2015), Intellectual disabilities (Melville et al., 2015), Spinal cord injury (Nooijen et al., 2016) and Rheumatoid arthritis (Thomsen et al., 2016). Two randomised controlled trials with patients with cerebral palsy (Bania et al., 2016; Slaman et al., 2015) had the lowest average ages of the six trials, with 18.4 years and 20 years respectively. Although the review excluded trials including participants under the age of 18 years of age, following a discussion with academic supervisors, it was decided to include the two trials in cerebral palsy patients as the average age of all participants was above 18 years of age.

A range of interventions were tested in the trials and were composed of specified exercise training interventions , behaviour change interventions or a combination of both. Similarly, duration of the intervention varied across the trials ranging from 12 weeks up to 8 months. The majority of the interventions focused on increasing physical activity and therefore reducing sitting or sedentary time as a result (Bania et al., 2016; Nooijen et al., 2016; McAuley et al., 2015; Melville et al., 2015). Only one trial (Thomsen et al., 2016) investigated the effect of an intervention aimed solely at reducing daily sitting time in patients. None of the studies reported adverse effects of the interventions.

Five trials (Bania et al., 2016; Melville et al., 2015; Nooijen et al., 2016; Slaman et al., 2015; Thomsen et al., 2016) objectively measured sedentary behaviour using accelerometers (e.g. ActivPAL 3TM, Actigraph GT3X), with the remaining trial (McAuley et al., 2015) using the Marshall Sitting Time Questionnaire (Marshall et al., 2010), a self-report questionnaire that assesses time spent sitting on weekdays and weekend days. Two studies (Melville et al., 2015; Slaman et al., 2015) reported sedentary behaviour as a percentage of the time awake in the day. In order to conform to the majority of the data that presented the results as hours per day spent sedentary and to allow inclusion in the meta-analysis, the study authors were contacted first to try and obtain the raw data and to check the measurement period and the length of time considered as ‘waking hours’ within a 24 hour period. As this was not available, the data was converted into hours per day by the primary reviewer and checked by an independent reviewer. Waking hours was estimated to be 16 hours per day, as the average duration of sleep is between 7 and 9 hours (Hirshkowitz et al., 2015). Another study (McAuley et al., 2015) reported sedentary behaviour as total minutes per day and was therefore also converted into hours per day to allow inclusion in the meta-analysis.

As previously described, although it was assumed that included studies would be similar enough to be suitable for a meta-analysis, heterogeneity statistics were reviewed to check for appropriateness. The Chi^2 statistic is a heterogeneity statistic that assesses how heterogeneous the effect sizes in the analysis are (Gough et al., 2012a, p.210). As the Chi^2 statistical test is often underpowered in a meta-analysis with small number of studies, i.e. it will fail to detect heterogeneity in many situations where results are actually heterogeneous, it was also important to consider the I^2 statistic (Borenstein et al., 2009, p.113). The I^2 statistic is another statistical test which describes the percentage of variation that is due to heterogeneity rather than chance across the studies. Both statistical assessments showed that the included studies had little to no heterogeneity, with a non-significant Chi^2 statistic of 4.58 (df = 5, p=0.47) indicating homogeneity of the data and an I^2 of 0% indicating that no heterogeneity was observed (Figure Nine).

It is often noted that it is important not to solely rely on statistical tests of heterogeneity but to also review the studies to assess if it is appropriate to combine the study results statistically (Boland et al., 2014, p.118). This was completed by a visual check of the included studies' confidence intervals and effects sizes. The confidence intervals were shown to overlap and the effects sizes were in close alignment, indicating little heterogeneity as shown by the two statistical tests.

Although both Chi^2 and I^2 statistical assessments showed low to no heterogeneity across the trials, examination of the intervention and study characteristics showed that heterogeneity was present. Differences were observed through disabilities (intellectual and physical); varied intervention content (exercise, behaviour change and a combination); length of interventions and outcome measurement time points. This therefore supports the decision to use the random effects model for this meta-analysis. However, it is important to note that the meta-analysis was run for both fixed- and random-effects models and the results produced were exactly the same. It can be assumed that this result is probably due to the heterogeneity statistics, specifically I^2 being 0%, i.e. none of the variation seen across the studies was due to heterogeneity, but instead chance.

Table 2 Sub-review two: Characteristics of included randomised controlled trials studies

Author, Year & Country	Disability	Sample size n (% male)	Age (y) $\overline{X}$ (SD)	Intervention details					Sedentary behaviour outcome measure	Time points measured
				Type of intervention	Control condition	Mode of delivery / Facilitators	Location of intervention	Duration of intervention		
Bania et al., 2016 Australia	Cerebral Palsy	48 (54%)	18.4y (2.4)	Progressive resistance training	Usual care: usual recreation and physiotherapy	Face-to-face (individually or in pairs) Physiotherapists	Community gymnasiums	12 weeks	ActivPAL activity monitor: Time spent in sitting and lying	Baseline 12 weeks 24 weeks
McAuley et al., 2015 USA	Multiple Sclerosis	48 (25%)	59.7y (5.5)	FlexToBa: DVD exercise intervention	Healthy ageing DVD	DVD Exercises modelled by trained exercise leader	Home based	6 months	Sitting time questionnaire (Marshall et al., 2010)	Baseline 6 months
Melville et al., 2015 Scotland, UK	Intellectual Disabilities	102 (56%)	46.2y (13)	Walk well: Behaviour change intervention and Individualised structured walking programme	Waiting list control	Face-to-face meetings Walking advisors	Community	12 weeks	Actigraph GT3X accelerometer: Percentage time per day sedentary	Baseline 12 weeks 24 weeks

Author, Year & Country	Disability	Sample size n (% male)	Age (y) $\bar{X}$ (SD)	Intervention details					Sedentary behaviour outcome measure	Time points measured
				Type of intervention	Control condition	Mode of delivery / Facilitators	Location of intervention	Duration of intervention		
Nooijen et al., 2016 The Netherlands	Spinal cord injury	45 (85%)	44y (14.8)	Act-Active: Usual care (Handcycle training programme) plus behavioural intervention	Usual care (Handcycle training programme)	Face-to-face Usual staff at the specialised rehabilitation centres and a physiotherapist or occupational therapist trained in motivational interviewing	Specialised rehabilitation centres, outpatient rehab centres and participant's home	2 months before discharge and 6 months following discharge from inpatient rehab centres	Ambulatory monitoring system with body-fixed three-axis accelerometer: Sedentary daytime (min/day)	Baseline (0 months) Discharge(2 months) 6 months 12 months
Slaman et al., 2015 The Netherlands	Cerebral Palsy	57 (47%)	20 (3)	Active Lifestyle and Sports Participation (ALSP): Lifestyle intervention consisting of fitness training and counselling on physical behaviour and sports participation	Usual care (e.g. physical therapy)	Face-to-face Physical therapist / movement therapist	Community – Both centre based and home based	6 months	VitaMove system (body-fixed accelerometers): Sedentary time (% part of wakening part of the day)	Baseline 6 months 12 months
Thomsen et al., 2016 Denmark	Rheumatoid Arthritis	20 (40%)	59.3 (12.5)	Motivational counselling and SMS-reminders	Usual lifestyle	Face-to-face and SMS reminders Project staff trained in motivational interviewing	Outpatient clinic or research unit and participants' homes	16 weeks	ActivPAL 3TM Activity monitor: Daily sitting time (hours/day)	Baseline 16 weeks

2.3.2.2. Risk of bias in included studies

Risk of bias judgments for the six included studies are presented in Figures Seven and Eight. No study was judged to have low risk of bias across all categories, with Melville et al (2015) being scored the lowest risk of bias with five out of the seven categories deemed low risk and the remaining two an unclear risk of bias. Both McAuley et al (2015) and Nooijen et al (2016) were judged joint second lowest in relation to risk of bias, each with one high risk of bias, two unclear risk of bias and four deemed low risk of bias (See Figure Eight for judgements about each risk of bias item for each included study).

No studies were deemed low risk for the ‘blinding of participants and personnel’ (performance bias) item. Blinding of participants and personnel (i.e. delivery) in rehabilitation interventions studies is often very difficult due to the observable nature of activity components, specific training requirement for delivery personnel and obvious controls. Five of the studies were judged to be at high risk of performance bias, with one of the studies (Thomsen et al., 2016), specifically asking participants to evaluate the intervention, proving un-blinding and a high risk of performance bias. Although the study by Melville et al (2015) described the allocation sequence process that concealed the next allocation in the sequence from both the researcher and participants, there was insufficient reporting of blinding therefore deeming the study at an unclear risk of performance bias. By contrast all six studies were judged to have adequately blinded the outcome assessment process and therefore scored low risk of detection bias.

A consistent lack of information provided by the studies caused them to be assessed as unclear risk of bias. This is especially true for allocation concealment which was not well reported by the studies resulting in four out of the six studies being judged as unclear risk of selection bias. Overall the six randomised controlled trials studies were assessed to be moderate to low risk of bias, with five out of the seven criteria scoring 50% or more low risk of bias.

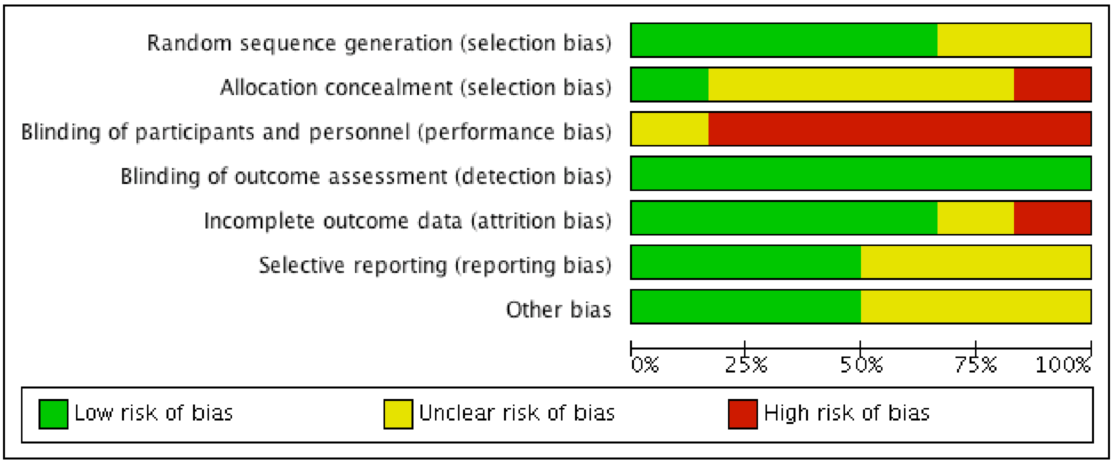
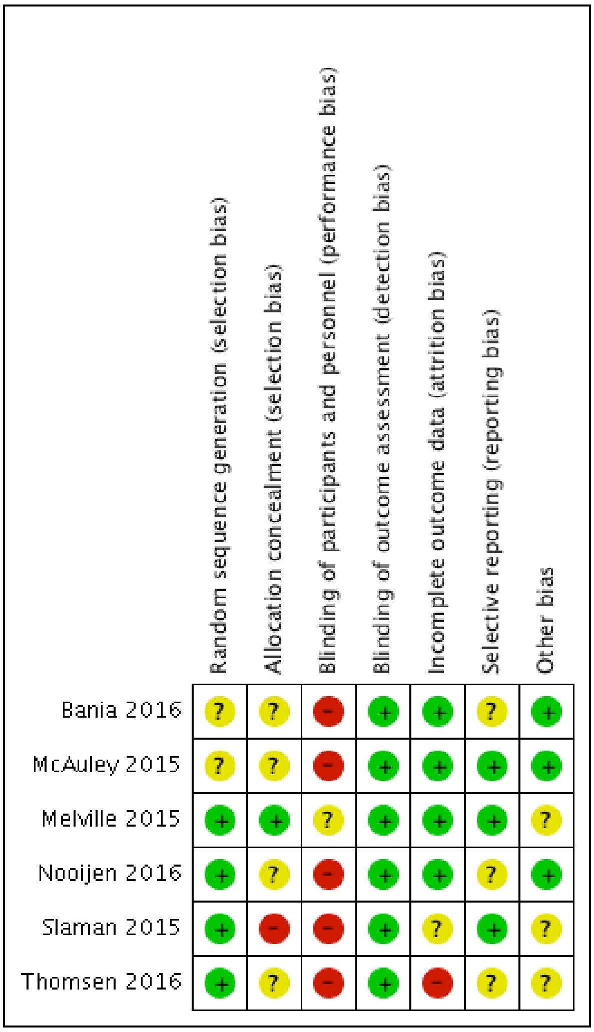


Figure 7 Risk of bias graph: Judgements about each risk of bias item presented as percentages across all included studies



	Random sequence generation (selection bias)	Allocation concealment (selection bias)	Blinding of participants and personnel (performance bias)	Blinding of outcome assessment (detection bias)	Incomplete outcome data (attrition bias)	Selective reporting (reporting bias)	Other bias
Bania 2016	?	?	−	+	+	?	+
McAuley 2015	?	?	−	+	+	+	+
Melville 2015	+	+	?	+	+	+	?
Nooijen 2016	+	?	−	+	+	?	+
Slaman 2015	+	−	−	+	?	+	?
Thomsen 2016	+	?	−	+	−	?	?

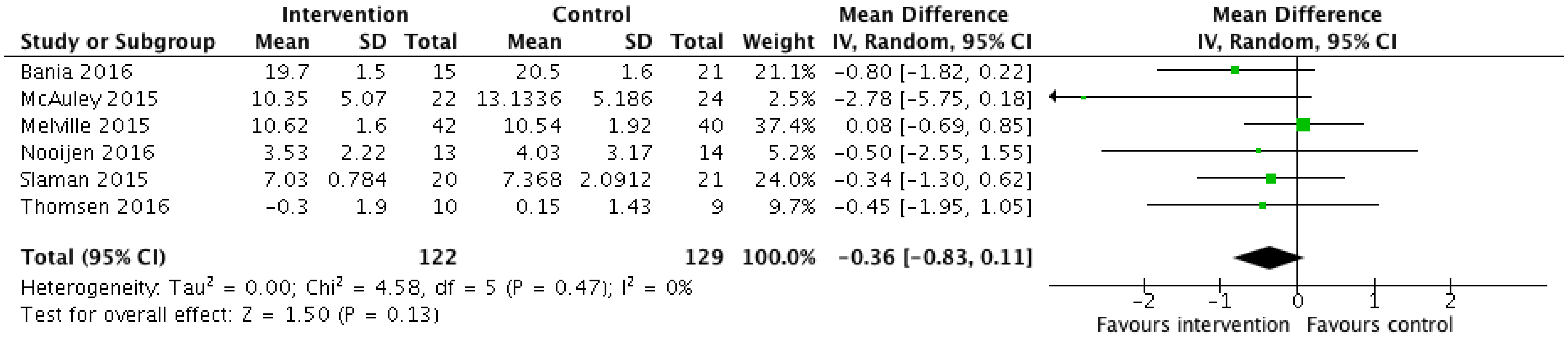
Figure 8 Risk of bias summary; Judgements about each risk of bias item for each included study

2.3.2.3. Measures of treatment effects

All six identified randomised controlled trial studies were suitable for inclusion in the meta-analysis. As all of the studies either originally reported or were converted to report sedentary behaviour as hours per day, the mean differences were used in the meta-analysis.

The overall treatment effect was shown to be non-significant (P = 0.13), with the total mean difference showing small effects favouring the intervention (MD= -0.36 (-0.83,0.11)). Figure Nine shows the meta-analysis results and forest plots for effect of intervention to reduce sedentary behaviour. Although, all studies apart from Melville et al (2015) showed effects in favour of the intervention with the effect sizes to left of the vertical axis, wide confidence intervals for each of these studies suggests greater uncertainty of where the true effect lies. As the 95% confidence intervals cross the vertical axis we cannot be certain that the effects are in favour of the interventions, suggesting that further information is needed before conclusions can be made. The large confidence intervals seen for the five studies (Bania 2016, McAuley 2015, Nooijen 2016, Slaman 2015 and Thomsen 2016) could be related to their sample sizes, with smaller sample sizes tending to provide less-precise estimates of effects (Higgins and Green, 2011). In the trial by Melville et al (2015), a mean difference of 0.08 (-0.69, 0.85) was observed, indicating a lack of intervention effect. This study had the largest number of participants and was also given the largest weighting (37.4%) out of the six studies.

Although all studies reported sedentary time, only McAuley et al (2015) used a self-report questionnaire with the other five studies using objective measurements recorded by an accelerometer. As the protocol stated that any outcome measure of physical activity, including instruments and self-report would be included if they measured sedentary behaviour, all six studies were included in the meta-analysis. However it was decided, a posteriori, that a sensitivity analysis should be conducted to assess whether only objective outcome measurements would affect the results. Figure Ten shows the sensitivity analysis for effect of intervention to reduce sedentary behaviour in studies using objective outcome data from accelerometers only. The removal of McAuley et al (2015) reduced the mean difference from -0.36 (-0.83, 0.11) to -0.30 (-0.77, 0.18) and made the overall treatment effect less significant (P = 0.22). The result of the sensitivity analysis confirms the acceptability of combining both objective measures and self-report measures in the meta-analysis. Whilst the sensitivity analysis indicated that combining the studies with different outcome measures was acceptable, it is important to consider the validity of self-report measures to accurately measure treatment effects. This will be discussed in more detail in the discussion.

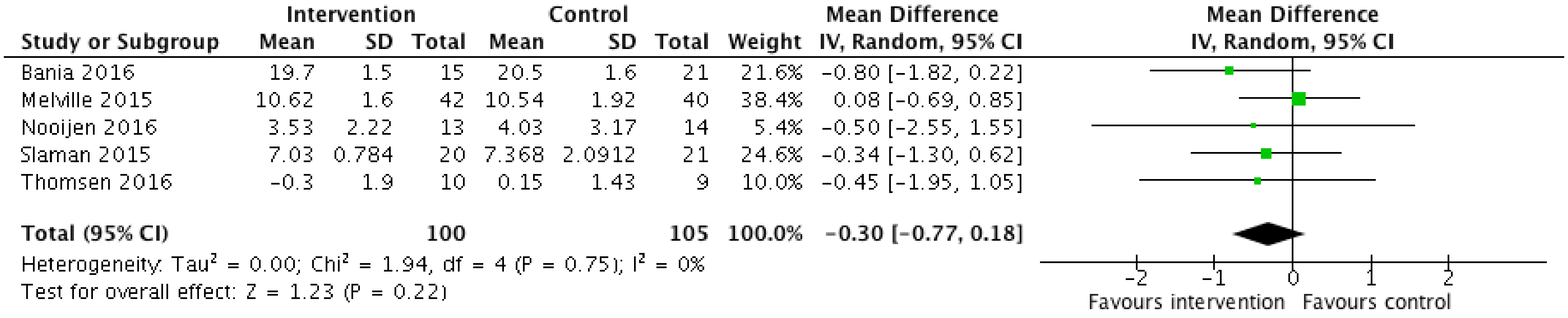


Study or Subgroup	Intervention Mean	Intervention SD	Intervention Total	Control Mean	Control SD	Control Total	Weight	Mean Difference IV, Random, 95% CI
Bania 2016	19.7	1.5	15	20.5	1.6	21	21.1%	-0.80 [-1.82, 0.22]
McAuley 2015	10.35	5.07	22	13.1336	5.186	24	2.5%	-2.78 [-5.75, 0.18]
Melville 2015	10.62	1.6	42	10.54	1.92	40	37.4%	0.08 [-0.69, 0.85]
Nooijen 2016	3.53	2.22	13	4.03	3.17	14	5.2%	-0.50 [-2.55, 1.55]
Slaman 2015	7.03	0.784	20	7.368	2.0912	21	24.0%	-0.34 [-1.30, 0.62]
Thomsen 2016	-0.3	1.9	10	0.15	1.43	9	9.7%	-0.45 [-1.95, 1.05]
Total (95% CI)			**122**			**129**	**100.0%**	**-0.36 [-0.83, 0.11]**

Heterogeneity: $\text{Tau}^2 = 0.00$; $\text{Chi}^2 = 4.58$, df = 5 ($P = 0.47$); $I^2 = 0\%$

Test for overall effect: $Z = 1.50$ ($P = 0.13$)

Figure 9 Effect of interventions to reduce sedentary behaviour in people with disabilities



Study or Subgroup	Intervention Mean	Intervention SD	Intervention Total	Control Mean	Control SD	Control Total	Weight	Mean Difference IV, Random, 95% CI
Bania 2016	19.7	1.5	15	20.5	1.6	21	21.6%	-0.80 [-1.82, 0.22]
Melville 2015	10.62	1.6	42	10.54	1.92	40	38.4%	0.08 [-0.69, 0.85]
Nooijen 2016	3.53	2.22	13	4.03	3.17	14	5.4%	-0.50 [-2.55, 1.55]
Slaman 2015	7.03	0.784	20	7.368	2.0912	21	24.6%	-0.34 [-1.30, 0.62]
Thomsen 2016	-0.3	1.9	10	0.15	1.43	9	10.0%	-0.45 [-1.95, 1.05]
Total (95% CI)			**100**			**105**	**100.0%**	**-0.30 [-0.77, 0.18]**

Heterogeneity: $\text{Tau}^2 = 0.00$; $\text{Chi}^2 = 1.94$, df = 4 ($P = 0.75$); $I^2 = 0\%$

Test for overall effect: $Z = 1.23$ ($P = 0.22$)

Figure 10 Sensitivity analysis for effect of intervention to reduce sedentary behaviour in studies using objective outcome data from accelerometers only

2.3.3. Discussion

The main findings from this sub-review showed that current interventions to reduce sedentary behaviour in people with disability do not have a statistically significant effect in favour of the interventions. The present meta-analysis is conservative with only six randomised controlled trials and 251 participants in total (intervention and control) and may explain the non-significance of the results.

As no statistical heterogeneity was observed it was deemed appropriate to combine the six studies in the meta-analysis. However it is important to give consideration to the variation observed across the studies in relation to the intervention delivered including content and duration. Four of the six interventions included a behavioural component with the other two being focused on exercise and resistance training, indicating different targets of the interventions. Additionally, five interventions were delivered face-to-face with only one intervention being delivered through a DVD. Intervention duration varied between twelve weeks and 8 months, possibly suggesting different intensities in the interventions. Although on initial thought it is believed to be useful to combine the individual studies to assess the overall effectiveness of interventions to reduce sedentary behaviour, upon reflection, the variability across studies makes this more difficult. The results of the meta-analysis are difficult to interpret as it is not fully known what components of the included interventions are effective i.e. duration and content. Future reviews should be mindful when considering what studies to include in a meta-analysis and combine the heterogeneity statistics with an examination of the studies to ensure that only similar studies are combined in the analysis to produce meaningful and useful results. If future reviews combine studies that exhibit variation like the present review, it would be important for sub-group analyses to be run with similar studies being combined to ensure useful results and understanding of the effectiveness of similar intervention types.

Melville et al (2015) evaluated the effectiveness of a walking programme to support adults with intellectual disabilities to increase physical activity. This is the only study with patients that have an intellectual disability, with the other five trials investigating interventions in patients with physical disabilities, for example, Cerebral Palsy, Multiple Sclerosis, Spinal cord injury and rheumatoid arthritis. As this is the most obvious difference between the studies, it may be that interventions to increase physical activity and reduce sedentary behaviour may, in individuals with intellectual disabilities, require different components than interventions for individuals with physical disabilities. This is supported by two studies which found that the parent walking programme that was adapted for use in the current intervention, to be effective in adults (Baker, et al., 2008) and adults older than 65 years (Mutrie et al., 2012). The study authors also acknowledged that the lack of effect may be partially explained by the challenges in adapting complex behaviour change interventions for adults with intellectual disabilities. It is therefore important to consider when undertaking future systematic reviews or updates of the present sub-review, whether it is sufficient to include both physical and intellectual disabilities in a meta-analysis or whether the types of interventions are too heterogeneous to group together.

None of the studies reported significant differences between the intervention and control conditions in relation to reducing sedentary behaviour. Thomsen et al (2016) saw a mean reduction in daily sitting time of 0.30 (SD 1.90) hours per day in the intervention group versus an increase of 0.15 (SD 1.43) hours per day in the control group. However, as the study was a randomised controlled feasibility study with a small sample size (10 in each condition), conclusions on within- and between-group changes could not be determined.

The results of the sensitivity analysis demonstrated that both objective measures and self-report questionnaires of sedentary behaviour can be combined in a meta-analysis. Although, statistically it was acceptable to combine the two different forms of sedentary behaviour measurement, it is important to consider the validity of the measures to ensure that accurate measurements of sedentary behaviour are included in the meta-analyses. Self-report questionnaires are often comprised of questions assessing both total sedentary behaviour and specific sub-domains and modes of sedentary behaviour (e.g. tv viewing, screen time, stationary transportation). As questionnaires are tested for validity against objective measurement tools (e.g. inclinometers and accelerometers), only questions that are aimed at estimating total sedentary time can be validated. A review of sedentary behaviour measurements in population health surveys (Prince et al., 2017) found poor validity in total sedentary behaviour when various self-report questionnaires were assessed against objective measures, including the Marshall Sitting Time Questionnaire used in McAuley et al. (2015) in the present review. It would therefore be important when considering future reviews or updates of the present sub-review to consider the acceptability of combining different forms of sedentary behaviour measurements i.e. objective and self-report and to assess the validity of the measures used. If it is decided to combine the different measurement methods it would also be important to plan to conduct sub-group analyses, to determine the effect of the different types of outcomes separately.

Despite the broad search strategy initially identifying over 16,400 studies and 101 results suitable for full text review, only 6 studies fully matched the inclusion criteria. Twelve studies did not meet the inclusion criteria as they were not randomised controlled trials, four studies were protocol papers and sixteen studies were excluded as their participants were not disabled (e.g. older adults, overweight, risk of Type II diabetes). The majority of the studies excluded (45) investigated interventions that focused on increasing physical activity and exercise with no consideration of sedentary behaviour or did not include a measure of sedentary time. Not only did a large proportion of the excluded interventions focus on increasing exercise levels, but similarly to sub-review one, confusion of terminology in relation to physical activity and sedentary behaviour made it difficult to determine eligibility of the studies. As per sub-review one, studies often referred to ‘sedentary behaviour’ when they were describing ‘physical inactivity’. One of the included studies (Thomsen et al., 2016), was identified whilst looking for associated studies of the sixteen excluded conference abstracts. The study is associated with the conference abstract by Esbensen (2015) and was conducted by the same research team that conducted the qualitative study included in sub-review one (Thomsen et al., 2015).

It was also noted that the majority of the six interventions focused on increasing physical activity and therefore reducing sitting or sedentary time as a result (Bania et al., 2016; Nooijen et al., 2016; McAuley et al., 2015; Melville et al., 2015), with only one intervention (Thomsen et al., 2016) aimed solely at reducing daily sitting time in patients.

The results of this review are supported by a recently published review by Prince (2018), exploring interventions directed at reducing sedentary behaviour in persons with pre-existing disease or disability. The review only identified nine interventions, including one included in the present sub-review (Thomsen et al., 2016). Five of the interventions included in Prince’s review (2018), targeted individuals with long-term conditions such as Type 2 Diabetes and Hypertension, which were not suitable for inclusion in the present sub-review as they did not fit the inclusion criteria. One of the interventions was excluded from the present sub-review as it was not a randomised controlled trial, whilst another was excluded as the reported data focused on physical activity levels and not sedentary behaviour. The final intervention targeting stroke survivors by English et al. (English et al., 2016c) was published after the searches were run for this sub-review and therefore was not able to be included, but would be included if the searches were to be updated in the future.

Although the review protocol stated that any outcome measure of physical activity, including instrument and self-report would be extracted for inclusion in the summary of findings (e.g. accelerometers, pedometers and sedentary behaviour questionnaires as outlined by The Sedentary Behaviour Research Network (2013)), future reviews should be more prescriptive to what outcomes are suitable to be included. This is due to the capacity of instruments to accurately measure sedentary behaviour. Not all activity monitors (e.g. Actigraph GT3X) can accurately measure sedentary behaviour as they do not measure posture or postural changes, only acceleration, which is key to measuring sedentary behaviour (i.e. sitting and lying) (Sanders et al., 2016; Atkin et al., 2012). In this sub-review, one study (McAuley et al., 2015) used a sitting time questionnaire that is approved by The Sedentary Behaviour Research Network (Sedentary Behaviour Research Network, 2013) for measuring sedentary behaviour. Four of the studies (Bania et al., 2016; Nooijen et al., 2016; Slaman et al., 2015; Thomsen et al., 2016) used activity monitors that measured acceleration and posture and therefore accurately measured sedentary time. The final study included in the review by Melville et al. (2015) used the Actigraph GT3X accelerometer to measure number of steps, total physical activity , moderate-vigorous intensity physical activity and sedentary behaviours. Although Actigraph GT3X uses a tri-axial accelerometer to measure physical activity and Melville and colleagues used cut-offs from a previous intellectual disabilities weight loss study (Melville et al., 2011) to categorise accelerometer data as sedentary behaviour (0-499 counts per minute), without a measure of posture, the sedentary time measurement cannot be as accurate as other instruments (Prince, 2018). Future reviews should take this into account when reviewing interventions that have measured sedentary behaviour and try to only include studies that have used instruments that have the capacity to measure acceleration, posture and postural changes.

The present systematic sub-review highlights the need for further intervention development aimed at specifically reducing sedentary behaviour in individuals with disabilities. Although the six included trials show promise for future interventions, consideration needs to be given to how complex interventions are developed for different types of disability (e.g. physical, intellectual). Increased number of randomised controlled trials, each with larger sample sizes, would allow conclusions to be determined with regards to the effectiveness of interventions aimed at reducing sedentary behaviour.

2.4. Meta-synthesis: The effectiveness, appropriateness and acceptability of interventions to reduce sedentary behaviour in people with disabilities

2.4.1. Methods

To address the overall broader review question; ‘What is the effectiveness, appropriateness and acceptability of interventions aimed to reduce sedentary behaviour in people with disabilities?’ it was planned to aggregate the findings of each single-method parallel synthesis through a meta-synthesis. This involves juxtaposing the findings from the two parallel syntheses using a matrix. The matrix would enable the qualitative findings relating to the views of disabled people, their carers and professionals involved in their care to be compared and contrasted against the interventions evaluated in the quantitative synthesis (Centre for Reviews and Dissemination (CRD), 2009; Thomas et al., 2004).

It was hoped that the meta-synthesis would investigate which of the interventions tested matched the general findings derived from the views of disabled people, their carers and professionals involved in their care. It would also identify whether these interventions demonstrate larger effects. Gaps identified from the synthesis would then be used to recommend what kinds of interventions or components of interventions, to reduce sedentary behaviour in patients with disability, need to be developed and tested in the future.

2.4.2. Results

As only one qualitative study was identified for inclusion in sub-review one, the meta-synthesis planned and outlined in the protocol was not feasible. The meta-synthesis, if feasible, would have been valuable to explain what aspects of the interventions were effective at reducing sedentary behaviour in individuals with disability and which aspects were not. It may have also helped to explain why the interventions did not show significant changes in sedentary time and maybe recognise what important aspects if any, as identified by the views of disabled people, their carers and professionals, were in fact missing from the interventions. This would have ultimately helped to identify what intervention components from each of the interventions would be essential to build an intervention that specifically aims to reduce sedentary behaviour in disabled individuals.

2.5. Discussion

The overall aim of this systematic review was to answer the question 'What is the effectiveness, appropriateness and acceptability of interventions aimed to reduce sedentary behaviour in people with disabilities?' Unfortunately due to a lack of available studies, this question could not be answered fully. Although a small number of studies were identified and included in the sub-reviews, one in sub-review one and six in sub-review two, the main finding from the review was the need for more research into sedentary behaviour and disabilities. While more interventions aimed at reducing sedentary behaviour are required to be designed and tested in individuals with disabilities, there is a greater need for more qualitative studies to be undertaken in order to explore the disabled population's perspectives and experiences of sedentary behaviour. This is important in order to synthesise the findings and develop tailored interventions that take into account the views and ideas of the target intervention population. This would hopefully produce an intervention that would be more effective, evidenced by randomised controlled trials, at reducing sedentary behaviour as it would hopefully be deemed acceptable to the target population.

Since the search was conducted in April 2016, more studies exploring sedentary behaviour in the disabled population have been published. Studies exploring patient's views of sedentary behaviour have emerged including some specific to stroke (Hall et al., 2019; Ezeugwu et al., 2017; Nicholson et al., 2016). Similarly, more randomised controlled trial studies are expected to have been published, with four papers excluded during the screening process being protocols for randomised controlled trials, indicating an increase in intervention development and testing. This is supported by review of the International Standard Randomised Controlled Trial Number registry (ISRCTN), revealing a number of trials set to examine the effects of interventions targeting the reduction of sedentary behaviours in disabled population including, but not limited to; multiple sclerosis, Parkinson's disease and intellectual disabilities. Although an update of the searches would produce more results, for the purpose of this project the reviews were not required to be updated as they highlighted the lack of research into sedentary behaviour and disability and evidenced the need for an exploratory study to examine stroke patients' perspectives of sedentary behaviour.

Although research into sedentary behaviour is increasing, it was noted during the study selection process that the majority of studies still had a focus on physical activity levels and exercise rather than sedentary behaviour. This ultimately resulted in a large proportion of the studies identified through the searches to be excluded. Studies in sub-review one often explored barriers and motivators to physical activity using questionnaires or through qualitative techniques, whereas sub-review two excluded a large proportion of studies that focused on increasing physical activity and exercise with no consideration of sedentary behaviour or did not include a measure of sedentary time. An issue that was highlighted through this review, and was noted in both sub-review one and two, is the lack of precision in terminology in relation to physical activity and sedentary behaviour in health science.

Another consideration for future research studies aiming to assess the effectiveness of interventions, is the measure used to record physical activity or sedentary behaviour. Self-report questionnaires rely on the participants' recall ability and often result in overestimation of physical activity levels (Limb et al., 2019). Validity of both physical activity questionnaires (Helmerhorst et al., 2012) and sedentary behaviour questionnaires (Prince et al., 2017) remain low. This reduced precision observed when using self-report measures compared to objective measures of physical activity and sedentary behaviour has resulted in a preference for objective measures, specifically accelerometry, to be used. Objective measures minimise bias and improve precision when assessing effects of a physical activity or sedentary behaviour intervention (Limb et al., 2019). It would also be important for future systematic reviewers to give consideration of the outcome measures used to measure treatment effects and assess whether these studies are suitable to include in a meta-analysis.

Although the overall research question could not be answered as not enough data was available to draw any meaningful conclusions about experiences of sedentary behaviour or effectiveness of interventions to reduce sedentary behaviour in people with disabilities, it is important to note that sedentary behaviour levels are affected by both condition- specific and condition-independent reasons. Although sedentary behaviour was often a consequence of disease flare-ups or as a means of managing everyday life with a health condition, it was also established that much of their sedentary behaviour was not related to their disease but instead a way of living. As observed in sub-review two, interventions to reduce sedentary behaviour must take into account the different factors affecting physical activity and sedentary behaviour levels, with the resulting intervention having to be complex and tailored in order to be effective.

2.6. Conclusion

Prior to conducting the mixed methods systematic review presented in this chapter, it was believed that there was limited available evidence in relation to sedentary behaviour and stroke survivors with severe mobility disability. This chapter has supported this belief and has also highlighted the limited research available in the topic of sedentary behaviour in people with a disability generally. It is therefore important for more research to be conducted into sedentary behaviour in people with a disability. This chapter provides support for the rationale for the Q-methodological study presented in Chapters four and five, in order to understand what sedentary behaviour means to stroke survivors with severe mobility disability. It also provides support for the work presented in Chapter six, as there is a need to identify possible strategies for intervention development given the lack of available research and evidence. The following chapter will present a second systematic review aimed at investigating the physical activity and sedentary behaviour levels of stroke survivors, and exploring the inclusion and exclusion of sedentary behaviour with severe mobility disability.

Chapter 3 - A systematic review of physical activity and sedentary behaviours in people with stroke living in the community

3.1. Introduction

Given the significant increase in research into physical activity and sedentary behaviour in stroke survivors and a commensurate increase in published research, it was deemed timely to update a systematic review by English et al. (2014) to address the question; 'How active are people living in the community with stroke-related disability?'. The systematic review also aimed to explore the inclusion and exclusion of stroke survivors with severe mobility disability in the included studies. This chapter presents the rationale for the systematic review before detailing the methods used for conducting the review. The findings are then provided before a discussion of the findings, including implications for future research, is presented.

3.2. Background

It is well documented that physical activity is important to maintain a healthy lifestyle. Physical inactivity is associated with many chronic conditions including coronary heart disease, type 2 diabetes, stroke and some types of cancer (Knight, 2012). Even small amounts of regular activity have been associated with some protection against chronic diseases and improved quality of life (Davies et al., 2011). Physical activity guidelines for healthy adults, including over 65 year olds, recommends 30 minutes of moderate intensity activity five times a week (Davies et al., 2011). In addition, older adults (65+ years) are also advised to undertake physical activity to improve muscle strength (e.g. body weight or resistance exercises) on at least two days a week, and to also incorporate physical activity to improve balance and co-ordination (e.g. tai chi and yoga) on at least two days a week. The importance of physical activity after stroke is also well established; with physical activity and exercise recommendations having a prominent position in the National Clinical Guideline for Stroke (Intercollegiate Stroke Working Party, 2016). Similar to the general guidance, stroke survivors are recommended to perform aerobic activity (e.g. walking) for 20 to 60 minutes three to five days per week. Additionally, it is recommended that they should also include two to three days per week whereby they perform strength (e.g. resistance training), neuromuscular (e.g. balance and coordination) and flexibility (e.g. stretches) exercises (Billinger et al., 2014). Physical activity following stroke is not only important to improve fitness and muscle strength, but also to provide optimal metabolic health and prevention of chronic diseases, including reoccurrence of stroke (English et al., 2014). As well as a focus on physical activity, the health consequences of sedentary behaviour have, over the past few years, also become the focus of considerable clinical, policy and research interest. (de Rezende et al., 2014; Davies et al., 2011; Owen et al., 2010; The Sedentary Behaviour and Obesity Expert Working Group, 2010). It is suggested that sedentary behaviour and physical activity are two distinct constructs with different physiological responses and health outcomes that can co-exist (van der Ploeg and Hillsdon, 2017; Tremblay et al., 2010). As discussed in Chapter One, with the growing body of literature around the detrimental health effects of sedentary behaviour; the reduction of daily sitting time is now included in general population guidance (The Sedentary Behaviour and Obesity Expert Working Group, 2010) and also outlined in stroke specific guidelines (Intercollegiate Stroke Working Party, 2016).

English and colleagues conducted a systematic review in 2014 with the intention to document the current knowledge about both physical activity levels and patterns of sedentary behaviour in community living stroke survivors and investigate the factors associated with physical activity levels in the stroke population. The review included 26 studies with the majority reporting mainly number of steps per day. Although the review also aimed to review sedentary behaviour, only four studies reported on sedentary time and none reported on the patterns and accumulation of sedentary behaviour. Although the review was published in 2014, the principal searches were conducted in June and July 2012, with a final search for new articles conducted on 7th November 2012. Along with the significant increase in interest in sedentary behaviour, significant increases in the number of studies and journal articles into sedentary behaviour have been published in the past few years. It was therefore deemed important to update the original review (English et al., 2014) to make the results current and relevant in order to update the knowledge base and to help inform the research questions and design the empirical research work.

3.3. Methods

3.3.1. Review question

As per the original systematic review (English et al., 2014), the aim of the current review was to address the overall question; ‘How active are people living in the community with stroke-related disability?’

The overarching question was answered through four sub-questions:
1. How much time per day do people with stroke spend sedentary?
2. How much time per day do people with stroke spend engaged in light, moderate and vigorous physical activity?
3. What is the pattern of accumulation of sedentary time and physical activity?
4. What factors influence physical activity levels in people with stroke?

The review also aimed to explore the inclusion and exclusion of stroke survivors with severe mobility disability in the included studies.

3.3.2. Eligibility criteria

3.3.2.1. Inclusion criteria

Studies were included if they met the following inclusion criteria:

- Report new, original data
- Include adults (>18 years of age) who had experienced a stroke
- Include at least one objective measurement of free-living physical activity or exercise (e.g. accelerometry)
- The objective measurements of physical activity must have been taken in a free-living situation (i.e. while undertaking their usual daily activities in the community and not in a hospital, residential care facility, or laboratory) and over at least two days
- Full text available in English.

3.3.2.2. Exclusion criteria

- Conference abstracts
- Does not include an objective measure of physical activity
- Less than two days of objective measurements of physical activity recorded

3.3.3. Identifying research evidence

The lead author of the original review (English et al., 2014) was contacted to request a copy of the search strategy used in the original review. Following a review of the original search strategy it was noted that non-stroke specific terms (e.g. Parkinson disease, multiple sclerosis and spinal cord injuries) were included. As the purpose of the current review was to explore activity levels and sedentary behaviour in stroke survivors it was decided to refine the original search strategy to focus the search and minimise the number of non-relevant results. With guidance from an information specialist from the University of Leeds and in consultation with the original author (CE), the original search strategy was amended, with terms relating to health conditions other than stroke being removed and additional terms pertaining to sedentary behaviour being added, to create a comprehensive search strategy initially for MEDLINE (Appendices C and D). Once the MEDLINE search strategy had been developed and tested, it was then adapted for use in seven other databases. The databases were selected for their relevance to the review topic and searched using the comprehensive search strategies, and included five used in the original review; MEDLINE, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Allied and Complimentary Medicine Database (AMED), EMBASE, the Cochrane Library, and three additional databases; PsycINFO, Web of Science and SPORTDiscus.

In order to identify literature that had not been formally published, grey literature databases were also searched. ProQuest Dissertations and Theses database was searched using the adapted search strategy used in the Web of Science database, whilst OpenGrey, an European database containing research reports, theses, conference papers and official documents, was searched using keywords taken from the MEDLINE search strategy. Additionally, through the Web of Science database search, the Conference Proceedings Citation Index database was also searched for grey literature.

The searches for the original review were conducted in June and July 2012, with a final search for new articles conducted on 7th November 2012. As the current review aimed to update the previous search, ordinarily the date limits for the search would start just before the date of the original searches (i.e. November 2012). However, due to the search strategy being refined for use in the current review it was decided to check the results produced for the same time period. Over 500 additional results were identified by the new search strategy and it was therefore decided to open the date limits to run the search from all time periods, including the time covered by the original search. Databases were therefore searched for research published between database inceptions to the search date.

Principal searches were run in all databases in September 2016 following development of the search strategies. In October 2017, a final search for new articles published since September 2016 was conducted. In order to try and capture all available literature, all conference abstracts identified through the searches were reviewed and checked for possibly relevant studies or any associated published papers. These were then reviewed like the other identified studies and checked for inclusion in the review.

3.3.4. Study selection

The study selection process was conducted in two stages. All results from the searches of databases of published data, grey literature and other sources including conference abstracts were collated and stored using Endnote, reference management software. For each study, an initial screen of the titles and abstracts against the inclusion criteria was conducted to identify potentially relevant papers. Once the initial title and abstract screen was completed, full text articles were obtained for the potentially relevant studies. Although the majority of the articles were freely available, some had to be obtained from the authors and the University of Leeds Library. Each article was then reviewed using a screening eligibility form framed around the eligibility criteria and research questions, on which decisions made about each study were documented.

Two reviewers were involved in study selection process to assess the papers for eligibility. The primary reviewer (NC) screened all of the results, whilst a second independent reviewer screened 20% of the results in stage one and 20% of the potentially relevant studies in the full text review during stage two. Any discrepancies between the two reviewers were initially discussed by the reviewers and resolved through the involvement of a third independent reviewer.

3.3.5. Data extraction

Data was extracted electronically by the principal reviewer using a data extraction form that was developed to extract the data necessary to answer the research questions and included; aims of the study, sample characteristics, details of the methodology (e.g. physical activity outcome measurements) and results (e.g. steps per day, amount of sedentary behaviour and predictors of physical activity). To reduce bias and increase accuracy during data extraction (Centre for Reviews and Dissemination (CRD), 2009; Buscemi et al., 2006) a second independent reviewer completed double data extraction of the included studies.

Where data was collected before and after an intervention, only whole group baseline data was included. Similarly, where data was collected from the same participants at different time points, only data from the last recorded time point post-stroke was included. If it was unclear whether articles were reporting original data or were additional reports using the same study data, the study authors were contacted for clarification. The reviewer also planned to contact study authors if any data was missing from the papers or there was additional data that was required, to request the information. However this was not required as all data was available in the papers.

3.3.6. Critical Appraisal

Risk of bias of the included studies was assessed by both the primary reviewer and a second independent reviewer. The critical appraisal tool used in the original review was sought from the lead author for use in the current review. The tool was based on a tool developed for use in case-control observation studies (Scottish Intercollegiate Guidelines Network) that had been through a process of robust development (Sanderson et al., 2007) and that has been found to have good validity (Hootman et al., 2011). Despite its validity, the same study found poor inter-rater reliability for the SIGN tool, with the authors suggesting the six response options for each item causing more subjectivity in choosing between the response options. As the studies in the original review were not all case-control studies, the original review authors adapted the tool to be appropriate for use in a wider range of research designs. As part of the refinements, they also changed the judgement options for each of the items to reflect the Cochrane Collaboration guidance of low, high and unclear risk of bias options, potentially addressing the reliability issues with the original SIGN tool. Although it is unknown whether the adapted tool by English et al. (2014) was validated, all of the adaptations were made in reference to and in accordance with the Cochrane Collaboration guides for assessing risk of bias (Higgins and Green, 2011; Higgins et al., 2011). This tool was deemed appropriate for use in the current review as similarly to the original review, it included studies with a range of research designs.

The tool included detailed instructions on how to score each of nine criteria assessed over four categories: selection of subjects, assessments, confounders and statistical analysis. Each criterion is scored either high risk of bias, low risk of bias, unclear or not applicable. The first criterion, ‘Comparable Groups’ referred to the two groups being studied (if applicable) being selected from source populations that are comparable, with a low risk of bias being scored if groups are at least matched by age and gender. The second criterion, ‘Eligibility Criteria’ scored a low risk of bias if clearly defined eligibility criteria are presented, for example; level of walking ability, time since stroke, other measures of disability. ‘Numbers screened and recruited’ criterion refers to an indication of how many of the people asked to take part did so, in each of the groups being studied. If the study authors do not report recruitment strategies, the criterion is scored a high risk of bias. The last criterion within the ‘Selection of Participants’ category is ‘Drop outs reported’. In order to score a low risk of bias, authors should report the number of participants included and the number with complete outcome measures. If data are missing, authors should report how these missing data were dealt with.

The second category in the critical appraisal tool is ‘Assessment’ and is comprised of three criteria. ‘Clear primary outcome and valid assessment tool’ scored a low risk of bias if both the reliability and validity of the primary outcome are justified either from the data generated from the study itself, or by quoting other studies in the same population (e.g. stroke). In order to score a low risk of bias for the criterion ‘Blind Assessment of Prognostic Factors’, the assessment of prognostic factors must have been made without knowledge of measures of energy expenditure or physical activity. All key prognostic factors had to be clearly defined and measured using a valid and reliable tool in order to score a low risk of bias for ‘Clearly Defined Prognostic Factors’ criterion.

The last two criteria refer to confounding and analyses. The main potential confounders must have been identified and taken into account in the design and analysis. In order to score a low risk of bias for ‘Confounders considered’, measurement of physical activity must have been over at least a 5 days period, and if he study had more than one group of participants they must have been matched for both age and sex. A high risk of bias was scored for ‘Selective reporting’ if not all outcomes are reported or are only partially reported in the article.

3.3.7. Data synthesis

As with the original review, the purpose of the current review was to provide a descriptive overview of all available studies measuring physical activity and sedentary behaviours in community living stroke survivors. Given the heterogeneous nature of the studies, a descriptive summary of the findings was deemed a suitable method of synthesis for the review, as used by English et al. (2014) in the original review.

With the systematic review aiming to answer the overall question; 'How active are people living in the community with stroke-related disability', the findings were synthesised to reflect and answer the four sub-questions. As per the original review, findings are presented in five sections; Sedentary time, Time spent in light-intensity activity (Standing and walking), Time spent in moderate-to-vigorous physical activity, Patterns of activity and inactivity and Factors influencing free-living physical activity.

3.4. Results

3.4.1. Description of studies

Figure Eleven summarises the study selection process, using the PRISMA flow diagram (Moher et al., 2009). 14,385 articles were initially identified, with 84 articles suitable for full text review. A total of 52 papers fully met the inclusion criteria and were included in the review. Six study authors were contacted to determine if 17 papers were either linked or reporting independent study data. Responses were received from three study authors who confirmed that six studies were independent (Danks et al., 2016a; Danks et al., 2016b; Danks et al., 2014; Mudge and Stott, 2009; Mudge et al., 2009; Mudge and Stott, 2008) and four were linked and reporting the same study data (English et al., 2016a; English et al., 2016b; English et al., 2016c; Lewis et al., 2016). For the seven remaining papers, where no response was received from the study authors (Mahendran et al., 2016a; Mahendran et al., 2016b; Michael et al., 2009; Michael and Macko, 2007; Michael et al., 2006; Michael et al., 2005; Haeuber et al., 2004), the primary reviewer (NC) reviewed the papers using the Cochrane Handbook's guidance on identifying multiple reports from the same study (Higgins and Green, 2011, Section 7.2.2) and consulted with the original review author (CE). As five of the papers were included in the original review (English et al., 2014) as individual studies, it was decided to present them in the current review as separate studies. Following a review of the two remaining papers it was determined, to the best of the reviewer's knowledge, that they were reporting findings from the same study and were therefore treated as one study.

Following review of the 52 papers and contacting study authors to check originality of data, 44 individual studies were identified. The original review published by English and colleagues in 2014 identified 26 studies reported in 30 articles. The current review identified one additional study for inclusion (Mudge and Stott, 2008) that was published during the search period of the original review. Three studies that were included in the original review were excluded from the current review. Two of the studies did not have objective measurements taken over at least two days (Janssen. et al., 2010; Sakamoto et al., 2008). The third excluded study (Shaughnessy et al., 2005) did not report the amount of measurement time. After discussing these with the lead author of the original review (English et al., 2014), an agreement was made to exclude all three studies. Twenty-four articles, reporting on 20 studies were published since the original paper (English et al., 2014).

Studies were published between 1998 and 2017 with a combined total sample of 1966 participants. Sample sizes of the studies ranged from 9 (Touillet et al., 2010) to 262 (Butler and Evenson, 2014) participants. The majority of studies included participants at least six months after stroke who were living in the community and able to walk short distances independently. One study published by Jones et al. (2016) assessed the feasibility and acceptability of a self-management program for increasing physical activity in adults with acquired brain injury. Although this study had a mixed patient group with data unable to be separated for the two groups, the majority of participants were stroke survivors (83%). As per the protocol, studies with mixed participant groups would be included if the majority of participants were stroke survivors, therefore it was decided to include Jones et al. (2016) in the review.

Characteristics of the included 44 studies, including details on the measurement tools used, are shown in Table Four. Physical activity data, sedentary behaviour data and predictors of physical activity are summarised in Table Five.

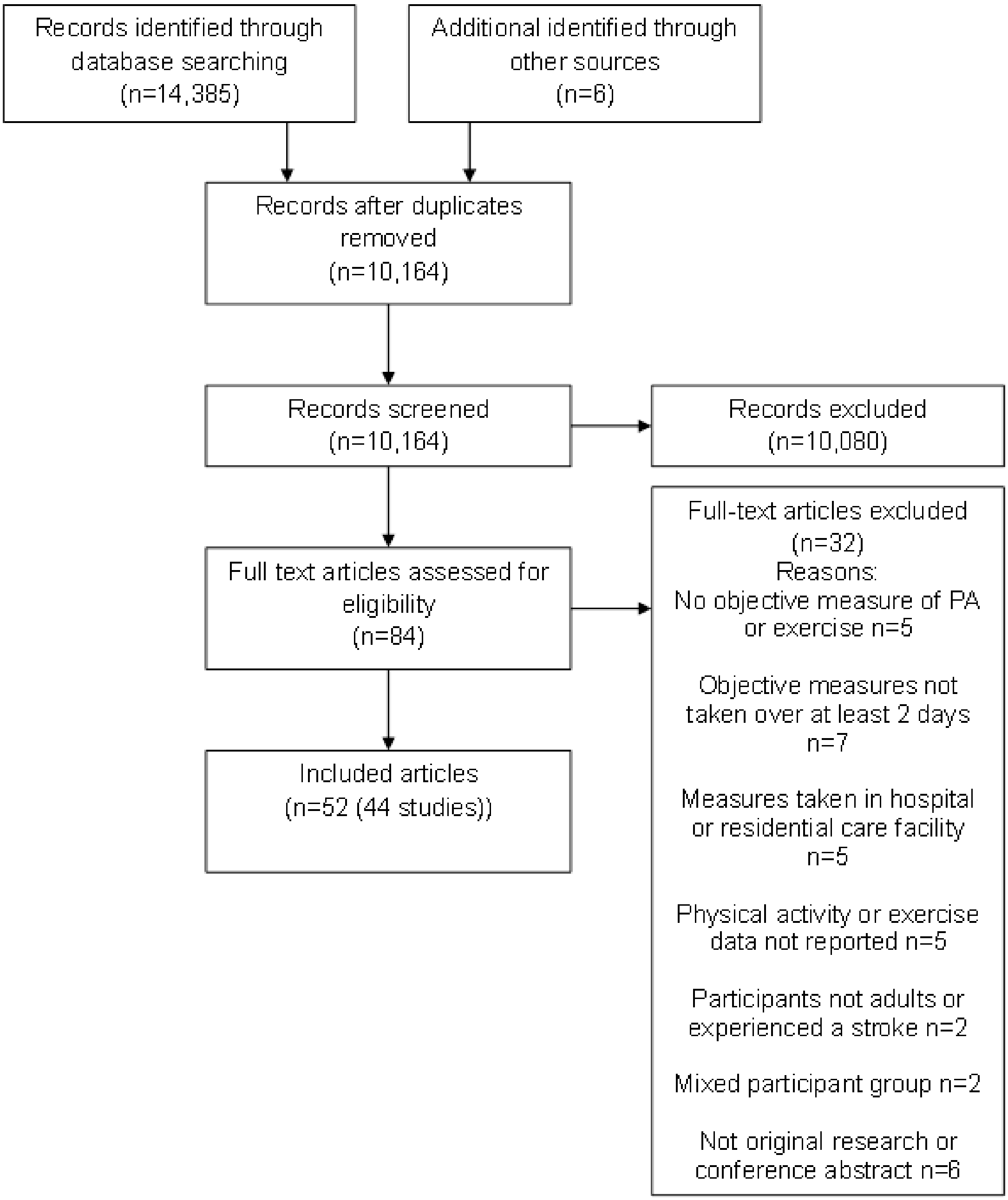


Figure 11 PRISMA flow diagram of study selection (Moher et al., 2009)

3.4.2. Critical appraisal of included studies

The results of the critical appraisal for each individual paper are presented in Table Three. Overall, the methodological quality of included papers was good with the majority of the articles (50 out of 52) scoring a low risk of bias (or not applicable) on at least five out of the nine criteria. Two articles scored an overall high risk of bias with five out of nine (Kerr et al., 2016) and six out of nine (Loprinzi and Addoh, 2017) criteria scoring high of risk of bias. Seven papers were of extremely high quality, scoring a low risk of bias (or not applicable) on all nine criteria (Ezeugwu et al., 2017; Preston et al., 2017; English et al., 2016c; Jones et al., 2016; Tieges et al., 2015; Moore et al., 2013; Moore et al., 2010).

In 44 of the 52 articles included in the review, inclusion and exclusion criteria were clearly stated. However, the number of potential participants who were screened for inclusion was reported in only 22 (42%) of the 52 studies. The number of drop outs and details of how missing data was dealt with was adequately reported in 51 of the 52 articles. The majority of studies used a valid and reliable method of measuring physical activity and/or sedentary behaviour. A primary outcome of interest was clearly defined and the reliability and validity of the measure used was presented in over 82% of the articles (43 of the 52 included articles). Overall, the included studies were good at reporting the findings of the studies with 51 out of the 52 included papers reporting the findings of all outcomes, therefore scoring a low risk of bias for this criteria.

Table 3 Critical Appraisal Score

Study	Selection of Participants				Assessment			Confounding / Analyses	
	Comparable Groups	Eligibility Criteria	Numbers Screened and Recruited	Dropouts Reported	Clear Primary Outcome and Valid Assessment Tool	Blind Assessment of Prognostic Factors	Clearly Defined Prognostic Factors	Confounders Considered	Selective Reporting
Alzahrani et al,2009	-	✓	X	✓	✓	✓	✓	X	✓
Alzahrani et al, 2011	X	✓	X	✓	✓	-	-	X	✓
Alzahrani et al, 2012	-	✓	X	✓	✓	✓	✓	X	✓
Askim et al, 2013	-	✓	X	✓	✓	X	✓	X	✓
Baert et al, 2012	-	X	X	✓	X	X	✓	✓	✓
Bowden et al, 2008	-	✓	X	✓	✓	X	✓	✓	✓
Butler and Evenson, 2014	✓	X	✓	✓	✓	X	✓	✓	✓
Danks et al, 2014	-	✓	X	✓	✓	-	-	✓	✓
Danks et al. 2016a	-	✓	✓	✓	✓	X	✓	✓	✓
Danks et al, 2016b	-	✓	X	✓	✓	✓	✓	✓	✓
English et al, 2016a	✓	✓	X	✓	✓	✓	✓	✓	✓
English et al, 2016b	-	✓	X	✓	✓	✓	✓	✓	✓
English et al, 2016c	✓	✓	✓	✓	✓	✓	✓	✓	✓
Ersöz Hüseyinsinoğlu et al, 2017	X	✓	✓	X	✓	✓	✓	X	✓
Ezeugwu & Manns, 2017	-	✓	✓	✓	✓	✓	✓	✓	✓
Frazer et al, 2013	-	✓	X	✓	X	-	-	✓	✓

X = criteria not met, high risk of bias; ✓ = criteria met, low risk of bias; - = not applicable. Highlighting serves to make the clear criteria for which a low risk of bias was determined

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Study	Selection of Participants				Assessment			Confounding / Analyses	
	Comparable Groups	Eligibility Criteria	Numbers Screened and Recruited	Dropouts Reported	Clear Primary Outcome and Valid Assessment Tool	Blind Assessment of Prognostic Factors	Clearly Defined Prognostic Factors	Confounders Considered	Selective Reporting
Fulk et al, 2010	X	✓	X	✓	✓	✓	✓	✓	✓
Hachisuka et al, 1998	✓	✓	X	✓	X	✓	✓	✓	✓
Haeuber et al, 2004	-	✓	X	✓	✓	✓	✓	X	✓
Hale et al, 2008	X	✓	X	✓	✓	✓	X	X	✓
Jones et al, 2016	-	✓	✓	✓	✓	-	-	✓	✓
Joseph et al, 2017	-	✓	X	✓	✓	✓	✓	X	✓
Katoh et al 2002	-	X	X	✓	X	X	✓	✓	✓
Kerr et al, 2016	-	X	✓	✓	X	X	X	X	✓
Lewis et al, 2016	✓	✓	X	✓	✓	✓	✓	✓	✓
Loprinzi & Addoh, 2017	-	X	X	✓	X	X	X	X	✓
Mahendran et al, 2016a	-	✓	✓	✓	✓	-	X	X	✓
Mahendran et al, 2016b	-	✓	✓	✓	✓	✓	✓	X	✓
Manns et al, 2009	✓	✓	X	✓	✓	✓	✓	X	✓
Manns et al, 2010	✓	X	X	✓	✓	X	✓	X	✓
Manns and Baldwin, 2009	-	✓	X	✓	✓	✓	✓	X	✓
Mansfield et al, 2016	X	X	✓	✓	✓	✓	✓	✓	✓
Michael et al, 2005	-	✓	✓	✓	✓	✓	✓	X	✓
Michael et al, 2006	-	✓	✓	✓	✓	✓	✓	X	✓

Study	Selection of Participants				Assessment			Confounding / Analyses	
	Comparable Groups	Eligibility Criteria	Numbers Screened and Recruited	Dropouts Reported	Clear Primary Outcome and Valid Assessment Tool	Blind Assessment of Prognostic Factors	Clearly Defined Prognostic Factors	Confounders Considered	Selective Reporting
Michael and Macko, 2007	-	✓	✓	✓	✓	✓	✓	X	✓
Michael et al, 2009	-	✓	X	✓	✓	✓	✓	✓	✓
Moore et al, 2010	-	✓	✓	✓	✓	-	-	✓	✓
Moore et al, 2013	✓	✓	✓	✓	✓	✓	✓	✓	✓
Mudge and Stott, 2008	-	✓	X	✓	✓	-	-	X	✓
Mudge and Stott, 2009	-	✓	X	✓	✓	✓	✓	X	✓
Mudge et al, 2009	✓	✓	✓	✓	✓	✓	✓	X	✓
Paul et al, 2016	✓	✓	X	✓	✓	✓	✓	✓	✓
Preston et al, 2017	-	✓	✓	✓	✓	-	-	✓	✓
Rand et al, 2009	-	✓	X	✓	✓	✓	✓	X	✓
Rand et al, 2010	-	✓	X	✓	✓	✓	✓	X	✓
Robinson et al, 2011	-	✓	✓	✓	X	✓	✓	✓	✓
Roos et al, 2012	X	✓	✓	✓	✓	-	-	X	✓
Tiedemann et al, 2012	-	✓	✓	✓	X	✓	✓	✓	✓
Tieges et al, 2015	-	✓	✓	✓	✓	✓	✓	✓	✓
Touillet et al, 2010	-	✓	X	✓	X	X	✓	✓	X
Vanroy et al, 2016	✓	✓	✓	✓	✓	-	-	X	✓
Zalewski and Dvorak, 2011	X	X	X	✓	✓	✓	✓	X	✓

3.4.3. Findings

3.4.3.1. Sedentary time

Unlike the study by English et al. (2014) in which no studies specifically measured sedentary behaviour, 16 of the included studies of this review reported sedentary behaviour, using the similar definition of sitting or lying down with low energy expenditures. Amount of sedentary behaviour in minutes and hours per day was reported in 11 studies (Ezeugwu et al., 2017; Joseph et al., 2017; English et al., 2016a; Jones et al., 2016; Kerr et al., 2016; Mahendran et al., 2016b; Paul et al., 2016; Tieges et al., 2015; Butler and Evenson, 2014; Frazer et al., 2013; Moore et al., 2013). Time spent sedentary ranged from 9.3 hours/day (SD=1.5) (Joseph et al., 2017) to 11.3 hours/day (Ezeugwu et al., 2017) when measured over waking hours. When sedentary behaviour was measured over a 24 hour period, time spent sedentary ranged from 19.6 hours/day (SD=1.9) (Jones et al., 2016) up to 23 hours/day (SD=0.7) (Moore et al., 2013). Compared to age-matched controls, who accumulated between 8.2 hours/day (SD=2) (English et al., 2016a) and 9.2 hours/day (SE= 0.1) (Butler and Evenson, 2014) measured over waking hours, and between 17.4 hours/day (SD=3.8) (Paul et al., 2016) and 22.8 hours/day (SD= 4.5) (Moore et al., 2013) when measured over a 24 hour period, stroke survivors spent at least one hour more in sedentary behaviour.

Four studies used a measurement protocol that allowed reporting of time not on feet (i.e. sitting or lying down) (Alzahrani et al., 2011; Rand et al., 2010; Mudge et al., 2009; Mudge and Stott, 2009). Alzahrani et al. (2011) reported people with stroke spent on average almost 7 hours (SD= 1.7) not on their feet (65% of the average 10.8 hour monitoring period.). This study also reported comparison values for healthy controls, with healthy controls spending around 7.5 hours/day (SD = 1.6) not on their feet, however the measurement period was longer for healthy controls (12.7 hours) compared with people with stroke (10.8 hours). After adjusting the observation period to 12 hours, no significant difference was observed between the two groups. Interestingly, stroke survivors made significantly less transitions (i.e. lie to sit, sit to lie, recline to sit, sit to recline, recline to stand, stand to recline, sit to stand, stand to sit) during the day compared to healthy controls, with healthy controls almost having double the number of transitions throughout the day (57 (SD = 43) compared to 109 (SD= 91)). A study by Mudge and Stott (2009) observed 83% of stroke survivors' waking hours were spent without steps. Similarly two studies by Rand et al. (2010) and Mudge et al. (2009), reported 86% and 83%, respectively, of the waking day spent inactive.

Four longitudinal studies measured sedentary behaviour over a range of times post-stroke. A study by Askim et al. (2013) observed a non-significant increase in length of time spent lying down in patients, one month, three months and six months after stroke (12.5 hours, 12.7 hours, 13.1 hours, respectively). Mahendran et al. (2016b) found that amounts of sedentary behaviour per day remained constant over one month (19.8 hours), three months (19.7 hours) and six months (19.8 hours). Similarly, a study by Moore et al. (2013) found no significant difference in amount of sedentary time per day at one week (23 hours), three months (22.5 hours) and six months (22.5 hours) after stroke. However Tieges et al. (2015) reported a non-significant drop in sedentary time from one month post-stroke (19.9 hours/day) to six (19.1 hours/day) and twelve months (19.3 hours/day) post-stroke.

Six of the 16 studies used an *activ*PAL to record levels of sedentary behaviour. This is a small activity monitor that includes both a triaxial accelerometer and inclinometer and is capable of measuring sitting, standing and stepping. The *activ*PAL measures posture and has 100% accuracy in classifying sitting and standing positions in older people and stroke compared to direct observational techniques (Taraldsen et al., 2011). Of the remaining ten studies, two used an ActiGraph accelerometer, two used a StepWatch Activity Monitor (SAM) to infer time without steps and periods of inactivity and one used the Intelligent Device for Energy Expenditure and Activity (IDEEA).

3.4.3.2. Time spent in light-intensity activity (Standing and walking)

Steps per day were reported in 37 of the 44 studies, with 18 using the StepWatch Activity Monitor to record the activity, six using pedometers, eight using accelerometers, four using an *activ*PAL and one using the IDEEA. Average number of steps per day ranged from 1193 (Range 512 – 2856) (Kerr et al., 2016) to 7379 (SD=3107) (Manns et al., 2009). Healthy control data was measured in nine studies, with average steps per day ranging from 5313 (SD= 2100) (English et al., 2016a) to 14,730 (SD=4522) (Manns et al., 2009).

Light intensity physical activity (LIPA) was reported in four studies, with stroke survivors spending between 1.8 hours/day (SD= 0.8) (Joseph et al., 2017) and 3.5 hours/day (SE=6) (Butler and Evenson, 2014) in LIPA. Only two of the studies also measured healthy control levels of LIPA. Butler and Evenson (2014) observed almost 4 hours/day of physical activity classified as light intensity whereas English and colleagues reported age-matched controls spending on average 6 hours/day in

LIPA. Butler and Evenson (2014) utilised cut-points previously defined by Matthews et al. (2008, 2005), with the light activity intensity threshold using the ActiGraph accelerometer, being defined as 101 to 759 counts/minute. Both English et al. (2016a) and Joseph et al. (2014) also used the ActiGraph accelerometer to measure physical activity, with English using cut-off points based on Freedson and colleagues' (1998) categorisation of LIPA (100-1951 counts/minute) and Joseph using cut-offs of 100-1041 counts/minute indicating LIPA (Copeland and Esliger, 2009).

The intensity of walking activity based on step cadence was reported in three studies. Manns and Baldwin (2009) and Michael and Macko (2007) both categorised low intensity bouts as those with less than 15 and less than 16 steps per minute, respectively. In these studies, 68% (Manns and Baldwin, 2009) and 45% (Michael and Macko, 2007) of total activity recorded was at light intensity. Mahendran et al. (2016b) defined low-intensity bouts as cadence less than 30 steps per minute and showed no difference in amount of LIPA at one (1.4 hours/day (SD=0.7)) and three months (1.4 hours/day (SD= 0.5)) post-stroke and a non-significant drop of around ten minutes per day of light activity at six months post-stroke (1.2 hours/day (SD=0.6)).

Six studies monitored time spent standing during the day, with two following people with stroke over three time points (Mahendran et al., 2016b; Askim et al., 2013). Average time spent standing in stroke survivors ranged from 1.7 hours/day (7% of the day) (Kerr et al., 2016) to 2.7 hours/day (17.9% of waking hours) (Ezeugwu et al., 2017). English et al. (2016a) also reported comparative data with healthy controls spending on average 5.2 hours/day standing (SD=1.7). The longitudinal study conducted by Askim et al. (2013) noticed no significant difference in time spent standing at one, three or six months post-stroke (2.4hours/day at all three time points). Mahendran et al. (2016b) also observed no significant difference in hours per day spent standing across one month (3.1 hours/day), three months (3.2 hours/day) and six months post-stroke (3.1 hours/day).

Time spent walking per day was measured in seven studies, with stroke survivors walking for an average of between 26 minutes per day (1.8% of the day) (Kerr et al., 2016) and 1.8 hours per day (Danks et al., 2014), which compared to 2.2 hours per day that healthy controls spent walking each day. Again, Mahendran et al.'s (2016b) longitudinal study showed no significant difference in walking time over the first six months post-stroke (approximately 1 hour/day at one, three and six months).

One additional study (Alzahrani et al., 2011) monitored time spent on feet, i.e. standing and walking, using the IDEEA. They observed 3.8 hours of a stroke survivors' day spent on their feet compared to 5.1 hours per day for healthy controls.

3.4.3.3. Time spent in moderate-to-vigorous physical activity

Fewer studies reported on time spent specifically in moderate to vigorous physical activity (MVPA). Five of the included studies, observed minutes per day spent in MVPA in the stroke population. Baert et al. (2012) utilised heart rate data and The American College of Sports Medicine (ACSM) guidelines (2013) to define activity level cut-offs. They found that stroke survivors one year after stroke spent on average 44 minutes per day in MVPA. A study by Preston et al. (2017) used the Sensewear armband and utilised energy expenditure to define activity levels, with MVPA being defined by energy expenditure greater than 3.3 Metabolic Equivalents. The study found, similar to Baert et al. (2012), that stroke survivors spent around 47 minutes per day in MVPA. Three additional studies reported daily levels of MVPA using Actigraph accelerometers. Butler et al. (2014) and English et al. (2016a) both used cut-off points around 2000 counts/minute for MVPA (Butler and Evenson (2014) >2020 counts/minute and English et al. (2016a) ≥1952 counts/minute). The amount of MVPA was on average 10 minutes/day in the study by Butler and Evenson (2014) and 4.9 minutes/day in English et al.'s study (2016a). These two studies were the only ones that also measured and provided healthy control data and found 13 minutes per/day (Butler and Evenson, 2014) and 38 minutes/day (English et al., 2016a) spent in MVPA. Joseph et al. (2017) also used the Actigraph accelerometer as the measurement tool, but used different cut-off points, with >1042 counts/minute indicating MVPA. They found that people with stroke spent on average 37 minutes/day (5% of waking hours) in MVPA. The higher number of minutes recorded in this study may be explained by the lower cut-off point applied to the activity count data therefore categorising more activity as MVPA compared with the cut-off points used by Butler and Evenson (2014) and English et al. (2016a).

In four studies, the intensity of activity and categorisation of activity into MVPA was based on step cadence. Mahendran et al. (2016b) defined moderate activity as 30-

80 steps/minute and observed a significant effect of time post-stroke on minutes per day spent in MVPA, with time in MVPA recorded as 58.9 minutes/day, 64.7 minutes/day and 63.2 minutes/day at one month, three months and six months respectively. High intensity activity was defined by >80 steps/minute and again reported 3.6 minutes/day, 3.2 minutes/day and 4.1 minutes/day at one month, three months and six months respectively. A study by Manns and Baldwin (2009) also recorded measurements over three time points post-stroke. Moderate intensity, defined by 15-39 strides/minute accounted for 31.2% of absolute activity at pre-discharge, 24.7% of absolute activity at 2 weeks post-discharge and 26.2% of absolute activity at 6 weeks post-discharge (no significant difference over the three timepoints). Greater than and equal to 40 strides per minute were defined as high intensity and stroke survivors demonstrated high intensity activity in 6.2% of absolute activity at pre-discharge, 7.3% of absolute activity at 2 weeks post-discharge and 5.4% of absolute activity at 6 weeks post-stroke (no significant difference over the three timepoints). Another study reported 46% of total activity during the day categorised as moderate intensity (≥16 and <30 steps/minute) and 6% of the day being spent in high intensity activity (≥30 steps/minute) (Michael and Macko, 2007). Paul and colleagues (2016) categorised MVPA as any activity with a cadence of >100 steps/minute and reported stroke survivors spending 12 minutes/day compared to 36 minutes/day by healthy controls.

3.4.3.4. Patterns of activity and inactivity

Similar to reports of MVPA, a limited number of studies measured and reported patterns and accumulation of activity and inactivity. Five studies in total reported number of bouts of physical activity during the day, with one showing patterns across the day (Frazer et al., 2013) and two longitudinal studies reporting over three time periods post-stroke (Mahendran et al., 2016b; Manns and Baldwin, 2009). In a study conducted by Danks et al. (2014), a bout began when a participant took 2 strides in a 10 second interval and ended when no strides were taken in a 10 second interval. They reported 134 bouts/day (SD= 64) with a median number of steps per bout of 22.8 (SD= 6.3). Manns et al. (2010) observed an average 64 activity bouts per day (bout defined as >1 stride/minute) with a mean duration of 4.1 minutes/bout. In comparison, healthy controls accumulated 74.2 bouts/day with an average duration of 5.6 minutes. Frazer et al. (2013) recorded 197 bouts/day of activity, when categorised as periods of activity that were at least 4 seconds in duration. Stroke survivors typically had more periods of ambulatory activity during the afternoon and evening compared to morning (Morning: 3.18

hours (SD=1), Afternoon: 4.85 hours (SD= 0.19), Evening: 4.9 hours (SD= 1)). The average duration of activity bout was recorded as 16 seconds/bout.

The longitudinal study by Mahendran et al. (2016b) defined a bout of activity whereby at least two steps were taken in a 15s period. Number of ambulation bouts were recorded as 142 bouts/day (SD=65.1) at one month post-stroke, 151.4 bouts/day (SD= 151.4) at three months post-stroke and 141.6 bouts/day (SD=60.8) at six months post-stroke. Although number of ambulation bouts did not significantly change over the three time points, the results indicate a trend towards time having an overall effect on change in activity when adjusted. Similarly Manns and Baldwin (2009) also tracked number of bouts (defined as >1 stride/minute) at multiple time points but over a shorter period post stroke. At pre-discharge stroke survivors had 57.6 bouts/day at an average duration of 3.3 minutes/bout. This was similar at two weeks post-discharge with stroke survivors accumulating 57.2 bouts at an average duration of 3.6 minutes/bout. At the third time point (6 weeks post-discharge), stroke survivors showed a slight increase in the number of activity bouts (61.5 bouts/day) with average bout duration of 3.8 minutes/ bout. Although the number of activity bouts were not significantly different across the three time periods, length of activity bouts were significantly longer at 6 weeks post-discharge compared to time point one (pre-discharge).

With regards to patterns of accumulation and breaks in sedentary behaviour, only three studies specifically examined it. English et al. (2016a) observed 7.4 hours of a stroke survivors' day was spent in bouts of 30 minutes or greater of sitting. This equated to 51.6% of waking hours being spent in bouts of sedentary behaviour lasting 30 minutes or longer. In comparison, healthy controls were found to spend 3.7 hours/day in bouts of sedentary behaviour lasting 30 minutes or more (24 % of waking hours). A study conducted by Moore et al. (2013) observed the absolute number of breaks in sedentary time. Stroke survivors significantly increased their number of breaks throughout the day from one week post-stroke (252 breaks) to three months post-stroke (291 breaks) and six months post-stroke (282 breaks). They also measured healthy controls and found that on average 341 breaks in sedentary time were taken during the day. Finally, a longitudinal study conducted by Tieges et al. (2015) measured the average sedentary bout duration. At one month post-stroke, sedentary behaviour bouts lasted around 1.7 hours and this remained the same at six months (1.7 hours) and twelve months (1.7 hours).

3.4.3.5. Factors influencing free-living physical activity

In 13 studies, the influence of walking ability on free-living physical activity was examined (Ersoz Huseyinsinoglu et al., 2017; Ezeugwu and Manns, 2017; Danks et al., 2016b; Baert et al., 2012; Roos et al., 2012; Tiedemann et al., 2012; Zalewski and Dvorak, 2011; Fulk et al., 2010; Rand et al., 2010; Alzahrani et al., 2009; Mudge et al., 2009; Bowden et al., 2008; Michael et al., 2005). Seven studies found significant moderate strength associations between performance on Six Metre Walking Test (6MWT)/ Ten Metre Walking Test (10MWT) and total accelerometer activity counts/day (Rand et al., 2010 (r=0.67, p<0.000); Alzahrani et al., 2009 (r=0.66, p<0.001)) total steps/day (Baert et al., 2012 (r=0.56, p<0.05); Tiedemann et al., 2012 (p<0.001); Zalewski and Dvorak, 2011 (r=0.55, p<0.05),; Fulk et al., 2010 (r=0.68, p=0.001); Mudge and Stott, 2009 (r=0.55-0.67, p=0.01)) and time on feet during the day (Alzahrani et al., 2009 (r=0.60, p<0.001)). Gait speed was also identified as a significant predictor of total steps/day in six studies (Ezeugwu and Manns, 2017 (r=0.61, p<0.01); Roos et al., 2012 (p<0.05); Tiedemann et al., 2012 (p<0.001); Zalewski and Dvorak, 2011 (r=0.588-0.67, p<0.05); Bowden et al., 2008 (r=0.67, p<0.001)). Although an increase in gait speed was associated with an increase in total steps/day, a study by Fulk et al. (2010) found that gait speed was not a significant predictor of steps/day.

Significant correlations between balance (Berg Balance Scale (BBS), standing balance and modified leg stance) and physical activity levels were reported in five studies. Three observed significant associations between balance and total number of steps/day (Tiedemann et al., 2012 (p<0.001-0.02); Michael et al., 2006 (r^2=0.161, p=0.02); Michael et al., 2005 (r=0.58, p<0.01)), one noted that better performance on the BBS was significantly associated with more time spent in an upright position (i.e. standing and walking) (Askim et al., 2013 (p<0.001)) and another observed significantly greater numbers of accelerometer activity counts per day with increased performance on the modified leg stance test (Alzahrani et al., 2012 (r=0.54, p<0.001)).

A study by Butler and Evenson (2014) found an inverse relationship between time since stroke and physical activity levels, with participants within one year post-stroke having the greatest volume of moderate to vigorous, lower to moderate and light activity. This was the only study to report a significant association between time since stroke and physical activity. Although Ezeugwu and Manns (2017) also investigated the effect of time since stroke on physical activity levels, they found no significant associations between time post-stroke and volume of activity throughout the day (r=-0.22, p>0.05).

Eight studies investigated the role of age and gender on physical activity levels in community-living stroke survivors, with the majority finding no significant relationship for both age (Ezeugwu and Manns, 2017 (r=0.18, p>0.05); Baert et al., 2012 (r=-0.47, p>0.05); Tiedemann et al., 2012 (p=0.42); Robinson et al., 2011 (r=-0.21, p=0.17); Fulk et al., 2010 (r=-0.43, p=0.063)) or gender (Joseph et al., 2017 (p=0.96); Baert et al., 2012 (r=0.14, p>0.05); Tiedemann et al., 2012 (p=0.53)). Two studies however, did find significant associations between physical activity levels and age (Joseph et al., 2017 (p=0.62); Mudge and Stott, 2009 (r=-0.29, p+0.05)) and one other study by Ersoz Hüseyinsinoğlu et al. (2017) found increased levels of self-reported physical activity in males compared to female stroke survivors (p=0.03).

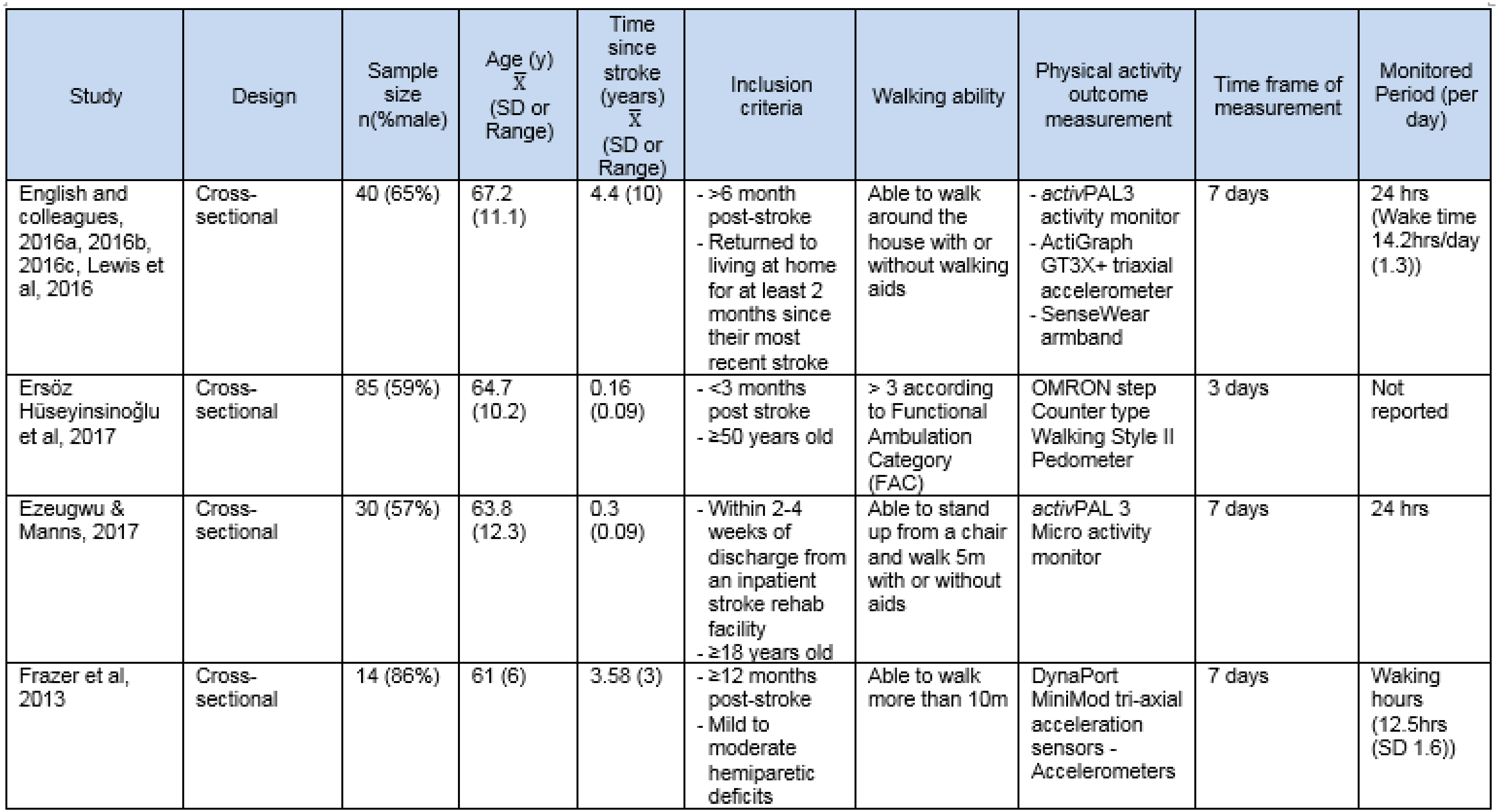
Three studies found significant correlations between cardiovascular fitness, measured by $\dot{V}o_2$ peak, and physical activity. Participants with higher $\dot{V}o_2$ peak values were likely to take more steps per day (Baert et al., 2012(r=0.73, p<0.05); Michael and Macko, 2007 (r=0.316, p=0.05); Katoh et al., 2002 (r=0.61, p<0.01)) and a higher proportion of those steps would be at a higher intensity (Michael and Macko, 2007 (r=0.61, p<0.01)). However, in contrast, a study conducted in 2005 found no such relationship between fitness ($\dot{V}o_2$ peak) and steps/day (r=0.058, p>0.05) (Michael et al., 2005).

Factors associated with sedentary behaviour were investigated in four studies. Stroke severity was found to be significantly correlated with sitting time in three studies (Joseph et al., 2017 (p=0.05); English et al., 2016b (r=-0.345, p=0.02); Tieges et al., 2015 (β=0.11, SE=0.05, p=0.02). English et al. (2016b) also observed higher levels of sitting time and more time in prolonged bouts of sitting in participants who self-reported higher levels of disability (Stroke Impact Scale, SIS) (r=-0.5, p=0.001) and had slower walking speeds (r=-0.454, p=0.001). Similarly, Joseph et al. (2017) found that slower gait speeds (p<0.01) and the use of a walking aid (p=0.02) were significantly associated with higher levels of sedentary activity. The fourth study to investigate factors associated with sedentary behaviour observed a relationship between time post-stroke and levels of sedentary behaviour. Average daily hours of sedentary behaviour increased as time post-stroke also increased (Butler and Evenson, 2014).

Table 4 Characteristics of Included Studies

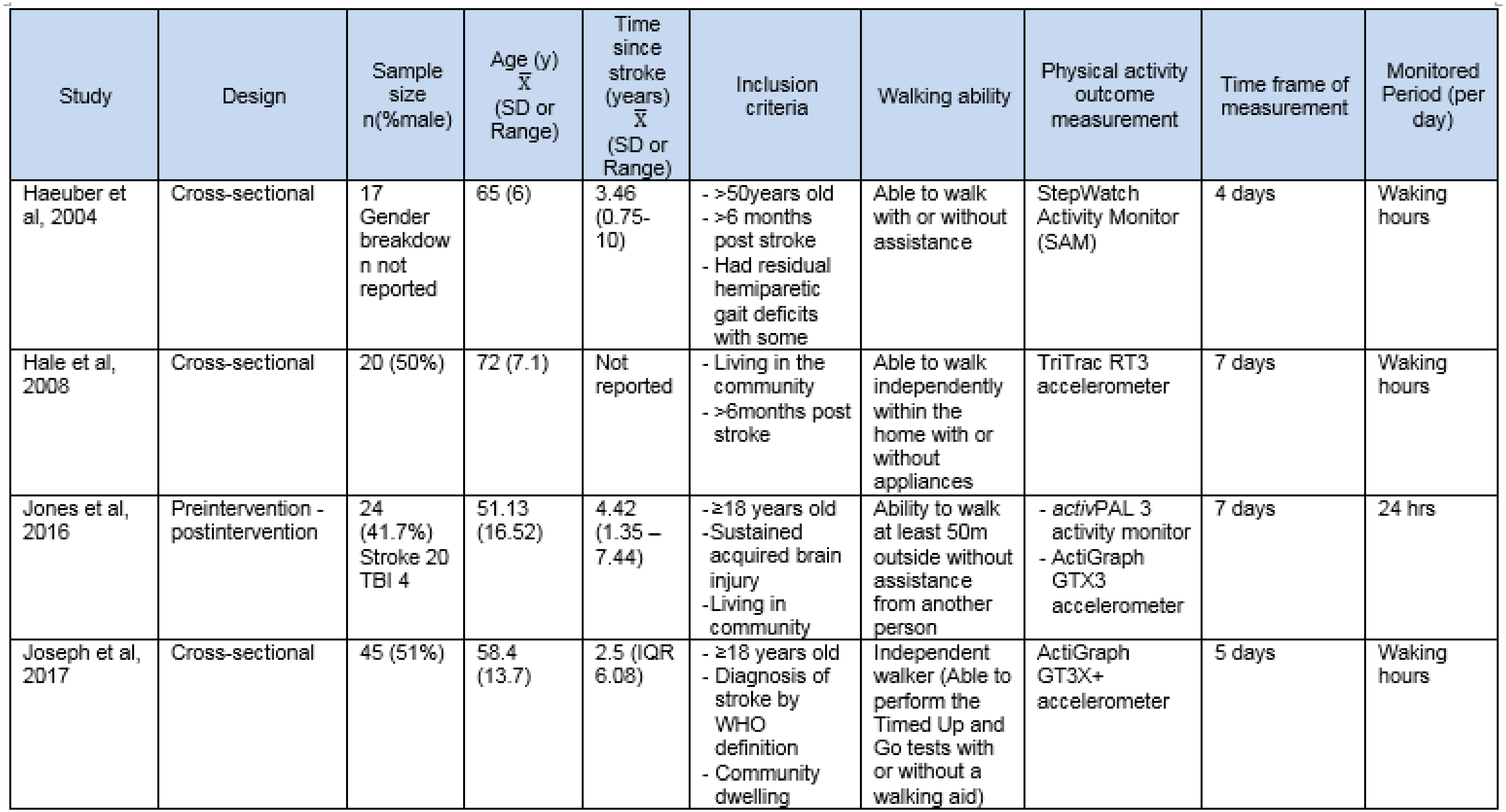
Study	Design	Sample size n(%male)	Age (y) $\overline{X}$ (SD or Range)	Time since stroke (years) $\overline{X}$ (SD or Range)	Inclusion criteria	Walking ability	Physical activity outcome measurement	Time frame of measurement	Monitored Period (per day)
Alzahrani and colleagues, 2009, 2011 and 2012	Cross-sectional	42 (69%)	70 (10)	2.8 (1.4)	- >50 years old - Within 1-5 years of their first stroke	Able to walk 10m independently without aids or orthoses	Intelligent Device for Energy Expenditure and Activity (IDEEA)	2 days	10.8 hrs
Askim et al, 2013	Longitudinal	44 (54%)	78.7 (8.7)	0.02 (0.009)	- Stroke < 14 days ago	Not reported	PAL2 Single axis accelerometer	3 days	24 hrs
Baert et al, 2012	Cross-sectional	16 (75%)	61.9 (11.9)	1	- First ever stroke - Age <75 years	Not reported	- Polar RS-400 HR monitor - Yamax SW-200 pedometer	5 days	Waking hours
Bowden et al, 2008	Cross-sectional	59 (81%)	61.9 (10.8)	4.05 (3.72)	- History of unilateral stroke	Ambulatory without contact assistance	StepWatch Activity Monitor (SAM)	5 days	Waking hours
Butler and Evenson, 2014	Cross-sectional	262 (53%)	20-59: 50 60-69: 74 70-79: 67 ≥80: 71	≤1 yr: 51 2-5 yrs: 89 >5 yrs: 116 Missing: 6	- ≥ 20years old - Previously experienced stroke	Ambulatory	ActiGraph Accelerometer	7 days	12 hrs (waking hours)

Study	Design	Sample size n(%male)	Age (y) $\overline{X}$ (SD or Range)	Time since stroke (years) $\overline{X}$ (SD or Range)	Inclusion criteria	Walking ability	Physical activity outcome measurement	Time frame of measurement	Monitored Period (per day)
Danks et al, 2014	Preintervention-postintervention	16 (81%)	66.08 (10.95)	4.13 (0.91)	- 55-80 years old having sustained stroke	Able to walk with or without assistance	StepWatch Activity Monitor (SAM)	6 days	Waking hours
Danks et al, 2016a	Randomised controlled trial	27 (56%)	58.6 (10.58)	3.4 (3.0)	- >6 months post-stroke - Able to walk outside the home before stroke - Currently walking less than 10,000 steps/day	Able to walk without assistance (orthotic or assistive devices allowed)	StepWatch Activity Monitor (SAM)	7 days	Waking hours
Danks et al, 2016b	Cross-sectional	55 (33%)	54 (11)	3.9 (0.3-30.5)	- >6 months post-stroke - Able to walk outside the home before stroke - Currently walking less than 10,000 steps/day	Able to walk (5mins) without assistance (orthotic or assistive devices allowed)	StepWatch Activity Monitor (SAM)	7 days	Waking hours



Study	Design	Sample size n(%male)	Age (y) $\overline{X}$ (SD or Range)	Time since stroke (years) $\overline{X}$ (SD or Range)	Inclusion criteria	Walking ability	Physical activity outcome measurement	Time frame of measurement	Monitored Period (per day)
English and colleagues, 2016a, 2016b, 2016c, Lewis et al, 2016	Cross-sectional	40 (65%)	67.2 (11.1)	4.4 (10)	- >6 month post-stroke - Returned to living at home for at least 2 months since their most recent stroke	Able to walk around the house with or without walking aids	- *activ*PAL3 activity monitor - ActiGraph GT3X+ triaxial accelerometer - SenseWear armband	7 days	24 hrs (Wake time 14.2hrs/day (1.3))
Ersöz Hüseyinsinoğlu et al, 2017	Cross-sectional	85 (59%)	64.7 (10.2)	0.16 (0.09)	- <3 months post stroke - ≥50 years old	> 3 according to Functional Ambulation Category (FAC)	OMRON step Counter type Walking Style II Pedometer	3 days	Not reported
Ezeugwu & Manns, 2017	Cross-sectional	30 (57%)	63.8 (12.3)	0.3 (0.09)	- Within 2-4 weeks of discharge from an inpatient stroke rehab facility - ≥18 years old	Able to stand up from a chair and walk 5m with or without aids	*activ*PAL 3 Micro activity monitor	7 days	24 hrs
Frazer et al, 2013	Cross-sectional	14 (86%)	61 (6)	3.58 (3)	- ≥12 months post-stroke - Mild to moderate hemiparetic deficits	Able to walk more than 10m	DynaPort MiniMod tri-axial acceleration sensors - Accelerometers	7 days	Waking hours (12.5hrs (SD 1.6))

Study	Design	Sample size n(%male)	Age (y) $\bar{X}$ (SD or Range)	Time since stroke (years) $\bar{X}$ (SD or Range)	Inclusion criteria	Walking ability	Physical activity outcome measurement	Time frame of measurement	Monitored Period (per day)
Fulk et al, 2010	Cross-sectional	19 Gender breakdown not reported	65.7 (11.9)	3.5 (3)	- Community dwelling - Self-selected gait speed faster than 0.40m/s	Score of 4 or 5 on the FAC, (Able to ambulate on level surfaces independently with or without an assistive device)	StepWatch Activity Monitor (SAM)	7 days	Waking hours
Hachisuka et al, 1998	Cross-sectional	102 (67%)	64.6 (5)	7 (4.6)	- Chronic stage of stroke >1year post stroke - >54 years old and <75 years old - Living at home with a spouse or other family members - Self-rating Barthel Index score of 70 or above	Not reported	Pedometer	7 days	Waking hours



Study	Design	Sample size n(%male)	Age (y) $\bar{x}$ (SD or Range)	Time since stroke (years) $\bar{x}$ (SD or Range)	Inclusion criteria	Walking ability	Physical activity outcome measurement	Time frame of measurement	Monitored Period (per day)
Haeuber et al, 2004	Cross-sectional	17 Gender breakdown not reported	65 (6)	3.46 (0.75-10)	- >50years old - >6 months post stroke - Had residual hemiparetic gait deficits with some	Able to walk with or without assistance	StepWatch Activity Monitor (SAM)	4 days	Waking hours
Hale et al, 2008	Cross-sectional	20 (50%)	72 (7.1)	Not reported	- Living in the community - >6months post stroke	Able to walk independently within the home with or without appliances	TriTrac RT3 accelerometer	7 days	Waking hours
Jones et al, 2016	Preintervention - postintervention	24 (41.7%) Stroke 20 TBI 4	51.13 (16.52)	4.42 (1.35 – 7.44)	-≥18 years old -Sustained acquired brain injury -Living in community	Ability to walk at least 50m outside without assistance from another person	- *activ*PAL 3 activity monitor - ActiGraph GTX3 accelerometer	7 days	24 hrs
Joseph et al, 2017	Cross-sectional	45 (51%)	58.4 (13.7)	2.5 (IQR 6.08)	- ≥18 years old - Diagnosis of stroke by WHO definition - Community dwelling	Independent walker (Able to perform the Timed Up and Go tests with or without a walking aid)	ActiGraph GT3X+ accelerometer	5 days	Waking hours

Study	Design	Sample size n(%male)	Age (y) $\overline{X}$ (SD or Range)	Time since stroke (years) $\overline{X}$ (SD or Range)	Inclusion criteria	Walking ability	Physical activity outcome measurement	Time frame of measurement	Monitored Period (per day)
Katoh et al, 2002	Cross-sectional	20 (80%)	64 (9)	1.83 (1)	- Mild to moderate hemiparesis, including both upper and lower limb	Independent in indoor and/or outdoor gait with prosthesis	Accelerometer	12 days (SD=4)	14 hrs (7:30-21:00)
Kerr et al, 2016	Cohort study	41 (46%)	69 (11)	Not reported	-Clinical diagnosis of stroke -Referred for ESD	Modified Rivermead Mobility Index 33.5 (Range 9-40)	Single tri-axial accelerometer	2 days	24 hrs
Loprinzi & Addoh, 2016	Prospective	131 (49%)	65.6 (95% CI 63.2-67.9)	Not reported	- Self-reported stroke diagnosis - 26-85 years of age	Not reported	ActiGraph accelerometer	≥4 days	≥10 hrs/day
Mahendran et al, 2016a	Prospective	34 (71%)	71.6 (13.8)	Not reported	- <4 months post-stroke - >18 years old - Community dwelling	Able to walk indoors 10m	*activ*PAL accelerometer	4 days	24 hrs
Mahendran et al, 2016b	Prospective longitudinal	36 (70%)	71.0 (13.7)	Not reported	- <4 months post-stroke - >18 years old - Community dwelling	Not reported	*activ*PAL accelerometer	4 days	24 hrs

Study	Design	Sample size n(%male)	Age (y) $\overline{X}$ (SD or Range)	Time since stroke (years) $\overline{X}$ (SD or Range)	Inclusion criteria	Walking ability	Physical activity outcome measurement	Time frame of measurement	Monitored Period (per day)
Manns and colleagues 2009 and 2010	Case control	10 (40%)	54 (10)	7.5 (8.3)	- >6 months post-stroke	Able to walk >10m with or without a walking aid	Step Activity Monitor (SAM)	4 days	24 hrs
Mann and Baldwin, 2009	Longitudinal	10 (60%)	66.3 (15)	0.2 (0.09)	- 1st incident cerebrovascular accident - discharged home	Able to walk >10m with or without a walking aid	Step Activity Monitor (SAM)	2 or 3 days T1 (predischarge) : 2 days T3 (2 weeks postdischarge) : 3 days T3 (6 weeks postdischarge) : 3 days	Waking hours Average time monitored per time period: T1: 12.9 hrs T2: 13.3 hrs T3: 15.14 hrs
Mansfield et al, 2016	Feasibility intervention study – Control data	15 (40%)	67.1 (13.4)	0.25 (0.07)	- Diagnosed stroke - No musculoskeletal impairments or pain that would limit ability to exercise	Not reported	ActiGraph accelerometer	6 weeks	Waking hours

Study	Design	Sample size n(%male)	Age (y) $\overline{X}$ (SD or Range)	Time since stroke (years) $\overline{X}$ (SD or Range)	Inclusion criteria	Walking ability	Physical activity outcome measurement	Time frame of measurement	Monitored Period (per day)
Michael et al, 2005	Cross-sectional	50 (56%)	65 (45-84)	0.86 (0.5-13.83)	- Community dwelling - >45 years old - Mild to moderate hemiparetic gait deficits after ischemic stroke	Ambulate for a sufficient duration to allow treadmill testing as 0.2mph minimal speed (With or without assistive devices)	Step Activity Monitor (SAM)	2 days	Waking hours
Michael et al, 2006	Cross-sectional	53 (59%)	66 (45-84)	0.86 (0.5-13.83)	- Community dwelling - 45-84 years of age - Mild to moderate hemiparetic gait deficits after ischemic stroke - ≥6 months post-stroke	Ambulate for a sufficient duration to allow treadmill testing as 0.2mph minimal speed	Step Activity Monitor (SAM)	2 days	Waking hours

Study	Design	Sample size n(%male)	Age (y) $\overline{X}$ (SD or Range)	Time since stroke (years) $\overline{X}$ (SD or Range)	Inclusion criteria	Walking ability	Physical activity outcome measurement	Time frame of measurement	Monitored Period (per day)
Michael and Macko, 2007	Cross-sectional	79 (53%)	65 (45-84)	0.86 (0.5-13.83)	- Community dwelling - 45-84 years of age - Mild to moderate hemiparetic gait deficits after ischemic stroke - ≥6 months post-stroke	Ambulate for a sufficient duration to allow treadmill testing as 0.2mph minimal speed	Step Activity Monitor (SAM)	2 days	Waking hours
Michael et al, 2009	Pre-post intervention	10 (70%)	71 (61-79)	7.5 (4-22)	- Community dwelling - Mild to moderate hemiparetic gait deficits after ischemic stroke	Ambulate for a sufficient duration to allow treadmill testing as 0.2mph minimal speed	StepWatch Activity Monitor (SAM)	5 days	24 hrs
Moore et al, 2010	Randomised crossover trial	20 (70%)	50 (15)	1.1 (0.6)	- Hemiparesis of >6 months duration	Able to walk >10m without physical assistance	StepWatch Activity Monitor (SAM)	≥5 days	Waking hours

Study	Design	Sample size n(%male)	Age (y) $\overline{X}$ (SD or Range)	Time since stroke (years) $\overline{X}$ (SD or Range)	Inclusion criteria	Walking ability	Physical activity outcome measurement	Time frame of measurement	Monitored Period (per day)
Paul et al, 2016	Cross-sectional	22 (45%)	55.9 (9.9)	4.2 (4)	- Single unilateral stroke - Discharged from rehabilitation - Aged over 18 years old	Able to walk independently, with or without using an aid or orthosis	*activ*PAL activity monitor	7 days	24 hrs
Preston et al, 2017	Pre-post intervention	20 (65%)	68 (12)	0.04 (0.02)	- Discharge directly home from an acute stroke unit	Able to walk 10m across flat ground without any aids	Bodymedia Sensewear armband	7 days	Waking hours
Rand and colleagues, 2009 and 2010	Cross-sectional	40 (68%)	66.5 (9.6)	2.9 (2.4)	- ≥6 months post-stroke - Living in the community	Able to walk independently (with or without a walking aid)	2 x Acticals (triaxial accelerometer)	3 days	Waking hours
Robinson et al, 2011	Cross-sectional	50 (54%)	65 (8.4)	7.1 (7.5)	- ≥6 months post-stroke - Lived in the community or assisted-living centre	Able to walk without physical assistance ≥10ft with or without an assistive device	Pedometer (VKRFitness Twin Step)	7 days	Waking hours

Study	Design	Sample size n(%male)	Age (y) $\overline{X}$ (SD or Range)	Time since stroke (years) $\overline{X}$ (SD or Range)	Inclusion criteria	Walking ability	Physical activity outcome measurement	Time frame of measurement	Monitored Period (per day)
Roos et al, 2012	Cross-sectional	51 (not reported)	63.7 (10.4)	3.4 (3.1)	- Living in the community - ≥18 years old	Able to walk without assistance of another person (orthotics and assistive devices allowed)	StepWatch Activity Monitor (SAM)	3 days	Waking hours
Tiedemann et al, 2012	Secondary analysis of randomised controlled trial	76 (50%)	66.7 (14.3)	6.7 (6.7)	- Suffered at least one stroke	Able to walk 10m independently with or without a mobility aid	Digimax pedometer	7 days	Waking hours
Tieges et al, 2015	Longitudinal cohort	96 (60%)	72.2 (64-80)	0.08	- Recent stroke	Not reported	activPAL activity monitor	7 days	24 hrs
Touillet et al, 2010	Prospective pilot study	9 (70%)	45 (IQR= 43-47)	0.46 (IQR=0. 38-0.75)	- At least 3 months post-stroke	Able to walk on their own	activPAL activity monitor	7 days	24 hrs
Vanroy et al, 2016	Observational	15 (60%)	62.5 (10.4)	7.34 (5.15)	- 1st stroke - ≥6 months post-stroke	Able to move independently (with or without a walking aid)	- Sense Wear Pro 2 Armband accelerometer - Knee-worn pedometer (Yamax Digi Walker SW 200)	3 days 3 days	24 hrs Waking hours

Study	Design	Sample size n(%male)	Age (y) $\overline{X}$ (SD or Range)	Time since stroke (years) $\overline{X}$ (SD or Range)	Inclusion criteria	Walking ability	Physical activity outcome measurement	Time frame of measurement	Monitored Period (per day)
Zalewski and Dvorak, 2011	Cross-sectional	17 (82%)	71.3 (935)	2.2 (0.6-7.2)	- Stroke survivors and care partners - Not actively engaged in rehabilitation	Able to ambulate independently	StepWatch 2 Activity Monitor (SAM)	3 days	24 hrs

Table 5 Physical activity and sedentary behaviour data

Study	Steps per day $\overline{X}$ (SD)	Sedentary behaviour $\overline{X}$ (SD)	Other physical activity data $\overline{X}$ (SD)	Age-matched control data	Significant Predictors of Physical Activity	Factors Not Predictive of Physical Activity
Alzahrani and colleagues, 2009, 2011, 2012	5475 (3999)	Time not on feet: 418 (101) min/day	-Time on feet: 230 (115) min/day -Transitions: 57 (43)	- Time on feet: 309 (103) min/day - Time not on feet: 454 (96) min/day - Transitions: 109 (91) - Steps/day: 10,964 (3,804)	- Mobility (Walking speed (10m-Walk Test), 6MWT, Timed stair climb) - Balance (Modified single leg stance) - Mood (SDHS)	
Askim et al, 2013		Lying down in min/day median (IQR): 1 month: 755 (656 – 910) 3 month: 760 (663 – 877) 6 month: 786 (655 – 919)	Standing in min/day median (IQR): 1 month: 146 (29 – 141) 3 month: 144 (31 – 248) 6 month: 144 (66 – 232)		- Activities of daily living (Barthel Index) - Balance (BBS)	
Baert et al, 2012	6428 (4117)		HR derived: -Light- intensity activity: 149 (107) min/day -Moderate-intensity activity: 44 (39) min/day		- Mood (BDI-II) - Participation (SIS) - Functional mobility (RMA-GF, 10m Walk) - Fitness (VO_2 peak)	- Age - Sex - Daylight hours

Study	Steps per day $\overline{X}$ (SD)	Sedentary behaviour $\overline{X}$ (SD)	Other physical activity data $\overline{X}$ (SD)	Age-matched control data	Significant Predictors of Physical Activity	Factors Not Predictive of Physical Activity
Bowden et al, 2008	2777 (1483)				- Gait speed categories	
Butler and Evenson, 2014		10 (SE 0.2) hrs/day	-Vigorous intensity activity: 0.9 (SE 0.9) min/day -Moderate intensity activity: 10 (SE 2.4) min/day -Moderate to vigorous intensity activity: 10.9min/day (SE 3.2) -Low moderate intensity activity: 46 (SE 3.7) min/day -Light intensity activity: 212 min/day (SE 6.0)	- Sedentary behaviour (hr/day): 9.2 (SE 0.1) - Vigorous intensity activity (min/day): 0.2 (SE 0.1) - Moderate intensity activity (min/day): 12.8 (SE 1.0) - Moderate to vigorous intensity activity (min/day): 13 (SE 1.0) - Low moderate intensity activity (min/day): 61.4 (SE 2.4) - Light intensity activity (min/day): 237.2 (SE 3.6)	- Time since diagnosis (-ve association with PA)	

Study	Steps per day $\overline{X}$ (SD)	Sedentary behaviour $\overline{X}$ (SD)	Other physical activity data $\overline{X}$ (SD)	Age-matched control data	Significant Predictors of Physical Activity	Factors Not Predictive of Physical Activity
Danks et al, 2014	5205 (2571)		-No. of bouts per day: 134 (64) -Median steps per bout: 22.8 (6.3) -Total time walking: 1.80 hours (0.73) -No. of short bouts (≤40 steps): 92 (49) -No. of medium bouts (41-500 steps): 41 (18) -No. of long bouts (>500 steps): 0.45 (0.41)			
Danks et al, 2016a	5149 (2918)					
Danks et al, 2016b	5816 (3293)				- Self-efficacy (Walk 12) - Co-morbidity burden (MCIR) - Walking capacity (FGA)	

Study	Steps per day $\bar{X}$ (SD)	Sedentary behaviour $\bar{X}$ (SD)	Other physical activity data $\bar{X}$ (SD)	Age-matched control data	Significant Predictors of Physical Activity	Factors Not Predictive of Physical Activity
English and colleagues, 2016a, 2016b, 2016c, Lewis et al, 2016	2411 (1835)	- Total sitting time: 10.9 (2) hr/day - Sitting time accumulated in bouts ≥30 min: 7.4 (2.8) hr/day - % wake hours sitting: 74.8% (13.3) - % waking hours sitting in bouts ≥30min: 51.6% (18.3)	-Standing time: 2.6 (1.5) hr/day -Stepping time: 1.1 (0.8) hr/day -Sit-to-stand transition: 41.2 (18.1) -Light intensity physical activity (LPA): 206 (93.8) min/day -% waking hours in LPA: 23.4% (11.2) -Moderate to vigorous intensity physical activity (MVPA): 4.9 (5.8) min/day -% waking hours in MVPA: 0.52% (0.65) -Total daily energy expenditure: 7,210 kj/day (2,399)	- Steps/day: 5314 (2100) - Total sitting time: 8.2 (2) hr/day - Sitting time accumulated in bouts ≥30 min: 3.7 (1.7) hr/day - % wake hours sitting: 52.8% (12.3) - % waking hours sitting in bouts ≥30min: 24% (10.9) - Standing time: 5.2 (1.7) hr/day - Stepping time: 2.2 (0.8) hr/day - Sit-to-stand transition: 47.8 (15.6) - Light intensity physical activity (LPA): 361.5 (86.8) min/day - % waking hours in LPA: 39.1% (9.4) - Moderate to vigorous intensity physical activity (MVPA): - 38.0 (31.0)min/day - % waking hours in MVPA: 4.2% (3.5) - Total daily energy expenditure: 8,315 (1,677) kj/day	- Self-reported physical disability (SIS) - Stroke severity (NIHSS) - Slower walking speed (-ve association with total sitting time and prolonged sitting time, and +ve association with MVPA).	

Study	Steps per day $\bar{X}$ (SD)	Sedentary behaviour $\bar{X}$ (SD)	Other physical activity data $\bar{X}$ (SD)	Age-matched control data	Significant Predictors of Physical Activity	Factors Not Predictive of Physical Activity
Ersöz Hüseyinsinoğlu et al, 2017	2646.5 (1235.6)			Steps/day: 6136.2 (5220.8)	- Gender (Male) - Ability to walk independently (FAC)	- Apathy (Apathy Evaluation Scale) - Cognition (MMSE) - Depression (GDS)
Ezeugwu & Manns, 2017	Males: 4127 (2233-5995) Female: 2373 (1874-3649)	11.3 hours (74.8% of waking hours) Males: 674.4 min/day (102.5) Females: 678.3 min/day (95.7)	- Standing time ▪ *Average:* 2.7 hrs (17.9% of waking hours) ▪ *Males:* 167.1 (64.6) min/day ▪ *Females:* 162.9 (94.0) min/day - Stepping time ▪ *Average:* 1.1hrs (7.3% or waking hours) ▪ *Males:* 78.3 (56.8) min/day ▪ *Females:* 56.1 (50.5) min/day - Sit-to-stand transitions: ▪ *Males:* 46/day (40-56) ▪ *Females:* 39/day (33-46) - Stepping Intensity, median (IQR) ▪ *Sporadic steps:* 4.7 (2.8-7.3) min/day ▪ *Purposeful steps:* 8.8 (6.1-15.4) min/day ▪ *Slow steps:* 13 (7.6-29.6) min/day ▪ *Medium steps:* 11.9 (5.8-27.4) min/day ▪ *Brisk steps:* 1.2 (0.2-5.6) min/day ▪ *Fastest steps:* 0.2 (0.1-0.5) min/day		- Gait speed - Higher self-reported mobility score	- Age - Time since stroke - Cognition (MoCA)

Study	Steps per day $\overline{X}$ (SD)	Sedentary behaviour $\overline{X}$ (SD)	Other physical activity data $\overline{X}$ (SD)	Age-matched control data	Significant Predictors of Physical Activity	Factors Not Predictive of Physical Activity

Frazer et al, 2013		589 min/day sitting	- Standing time: 115 (61) min/day
			- Activity time (Total min of activity per day): 54 (33) min/day
			- No. of transitions: 29-95
			- No. of activity bouts (counts of periods of activity of at least 4s): 197/day (109)
			- Length of activity bouts (Duration of activity bouts in S): 16s (5) per bout/day
			- Daily pattern of ambulatory activity:
			  - *Morning:* 3.18 hours (1.03)
			  - *Afternoon:* 4.85 hours (0.19)
			  - *Evening:* 4.90 hours (1)			

Study	Steps per day $\bar{X}$ (SD)	Sedentary behaviour $\bar{X}$ (SD)	Other physical activity data $\bar{X}$ (SD)	Age-matched control data	Significant Predictors of Physical Activity	Factors Not Predictive of Physical Activity
Fulk et al, 2010	3838 (1964)			Steps/day: 6294 (1768)	- Mobility (6MWT)	- Mobility (Gait speed) - Impairment (BBS, FMA LE) - Participation (SIS) - Age
Hachisuka et al, 1998	3315 (1929)					
Haeuber et al, 2004	3035 (1944)		Mean estimated activity energy expenditure: 321 (187) kcal/day		Energy expenditure and steps per day	
Hale et al, 2008			Accelerometer derived “activity units”/day: 673,920 (379,495)			
Jones et al, 2016	5598 (2722)	19.6 (1.9) hrs/day	Time spent in MVPA: 41 (31) min/day			
Joseph et al, 2017	3491 (4040)	560 min/day (92) 80% of wear time (11%)	- Light intensity physical activity: 106 (48) min/day 15% of wear time (6%) - Moderate to vigorous physical activity: 37 (42) min/day 5% of wear time (6%)		- Age - Use of walking aid - Receiving outpatient rehab - Stroke severity (NIHSS) - Independence (Barthel Index) - Function/Mobility (TUG, Gait speed, Mini BESTest, FES-I)	- Gender - Comorbidities - BMI - Anxiety or depression (HADS)

Study	Steps per day $\bar{X}$ (SD)	Sedentary behaviour $\bar{X}$ (SD)	Other physical activity data $\bar{X}$ (SD)	Age-matched control data	Significant Predictors of Physical Activity	Factors Not Predictive of Physical Activity
Katoh et el, 2002	4346 (2933)		Accelerometer derived energy expenditure: 112 (82) kcal/day		- Fitness (VO2 peak, Maximal work load) (Oxygen uptake kinetics -ve correlation)	
Kerr et al, 2016	1193 (Range 512-2856)	1349 (Range 1256 - 1402) min/day	- Standing time: 100 (Range 51-178) min/day (7.0% of day) - Stepping time: 26 (Range 13-42) min/day (1.8% of day)			
Loprinzi & Addoh, 2017			Total physical activity: 295.2 (276.0-314.3) min/day		- PA inversely associated with all-cause mortality	

Study	Steps per day $\bar{X}$ (SD)	Sedentary behaviour $\bar{X}$ (SD)	Other physical activity data $\bar{X}$ (SD)	Age-matched control data	Significant Predictors of Physical Activity	Factors Not Predictive of Physical Activity
Mahendran et al, 2016b (linked to Mahendran et al, 2016a)	1 month: 4592 (3411) 3 months: 4623 (2735) 6 months: 4946 (3732)	1 month: 1188.9 (115) min/day 3 months: 1184.5 (90) min/day 6 months: 1188.1 (92) min/day	- Time spent standing min/day ▪ 1 month: 188.1 (94) ▪ 3 month: 191.9 (72) ▪ 6 months: 188.5 (68) - Time spent walking min/day ▪ 1 month: 61.5 (37) ▪ 3 month: 63.4 (33) ▪ 6 months: 63.4 (42) - Time spent upright min/day ▪ 1 month: 249.7 (114.1) ▪ 3 month: 255.2 (90.8) ▪ 6 months: 251.9 (92.4) - No. of ambulation bouts/day ▪ 1 month: 142.0 (65.1) ▪ 3 month: 151.4 (59.6) ▪ 6 months: 141.6 (60.8) - Low-intensity bouts (cadence <30steps/min) min/day ▪ 1 month: 83.8 (40) ▪ 3 month: 83.4 (31) ▪ 6 months: 74.3 (33) - Moderate-intensity bouts (cadence 30-80 steps/min) min/day ▪ 1 month: 58.9 (33) ▪ 3 month: 64.7 (33) ▪ 6 months: 63.2 (35) - High-intensity bouts (cadence >80 steps/min) min/day ▪ 1 month: 3.6 (3) ▪ 3 month: 3.2 (3) ▪ 6 months: 4.1 (4)			

Study	Steps per day $\bar{X}$ (SD)	Sedentary behaviour $\bar{X}$ (SD)	Other physical activity data $\bar{X}$ (SD)	Age-matched control data	Significant Predictors of Physical Activity	Factors Not Predictive of Physical Activity
Manns and colleagues, 2009, 2010	7379 (3107)		- No.of daily activity bouts: 64 (19) - Mean length of activity bouts 4.1 min (0.7)	- Steps/day: 14730 (4522) - No. of daily activity bouts: 74.2 (10.4) - Mean length of activity bouts: 5.6 (1.6) min		
Manns and Baldwin, 2009	**T1** (predischarge) : 5541.4 (1845.8) **T2** (2 weeks postdischarge) : 5506.2 (2196.6) **T3** (6 weeks postdischarge) : 6195 (2068)		**T1** - Absolute activity min/day: 182.6 (38.5) - No. of activity bouts: 57.6 (15.9) - Intensity of activity: ▪ Low (<15 strides/min): 62.6% (8.6) ▪ Moderate (15-39 strides/min): 31.2% (6.2) ▪ High (≥40 strides/min): 6.2% (5) - Length of activity bouts: 3.3 mins (0.5) **T2** - Absolute activity min/day: 198.5 (69) - No. of activity bouts: 57.2 (21.4) - Intensity of activity: ▪ Low (<15 strides/min): 68% (12.5) ▪ Moderate (15-39 strides/min): 24.7% (7.3) ▪ High (≥40 strides/min): 7.3% (10.7) - Length of activity bouts: 3.6 mins (0.8)			

Study	Steps per day $\overline{X}$ (SD)	Sedentary behaviour $\overline{X}$ (SD)	Other physical activity data $\overline{X}$ (SD)	Age-matched control data	Significant Predictors of Physical Activity	Factors Not Predictive of Physical Activity
Manns and Baldwin, 2009 (Cont.)			**T3** - Absolute activity min/day: 228.8 (65.4) - No. of activity bouts: 61.5 (17.9) - Intensity of activity: ▪ Low (<15 strides/min): 68.5% (8.4) ▪ Moderate (15-39 strides/min): 26.2% (5.4) ▪ High (≥40 strides/min): 5.4% (5.8) - Length of activity bouts: 3.8 mins (0.7)			

Study	Steps per day $\bar{X}$ (SD)	Sedentary behaviour $\bar{X}$ (SD)	Other physical activity data $\bar{X}$ (SD)	Age-matched control data	Significant Predictors of Physical Activity	Factors Not Predictive of Physical Activity
Mansfield et al, 2016	2519 (2133)				- Lack of willpower as a barrier to PA (BBAQ)	
Michael et al, 2005	2837 (1503)				- Mobility (gait speed, SSFWV) - Impairment - balance (BBS)	- Fitness (VO_2 peak, economy of gait)
Michael et al, 2006	2821 (1527)				- Impairment – balance (BBS)	- Fatigue (FSS)
Michael and Macko, 2007	1389 (798)		Activity Intensity Patterns: - Low intensity (<16 steps/min): 624 (289) 45% of total a.a - Medium intensity (≥16 and <30 steps/min): 640 36) 46% of total a.a - High intensity (≥30 steps/min): 83 (168) 6% of total a.a.		- Fitness (VO_2 peak)	- Fatigue (FSS)
Michael et al, 2009	2608 (1563)					

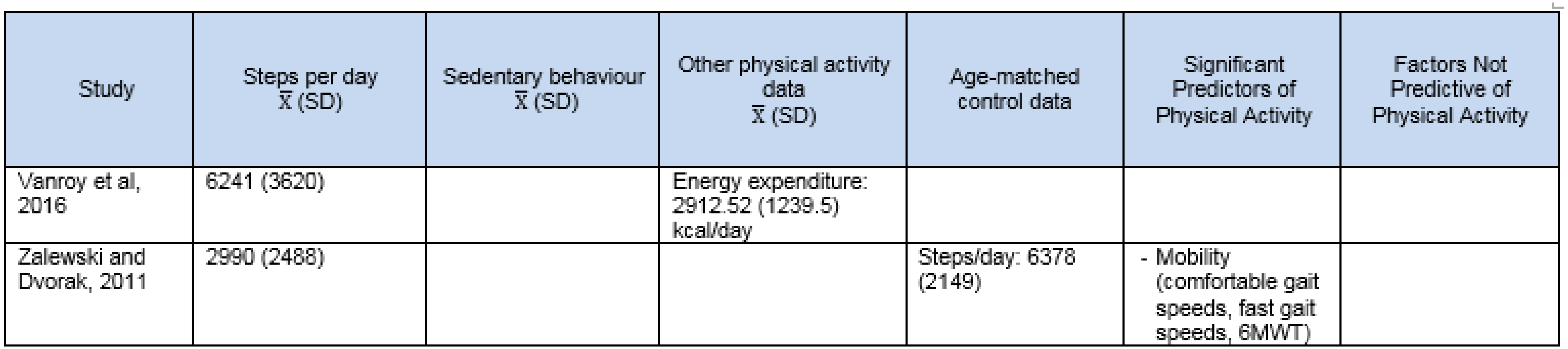
Study	Steps per day $\bar{X}$ (SD)	Sedentary behaviour $\bar{X}$ (SD)	Other physical activity data $\bar{X}$ (SD)	Age-matched control data	Significant Predictors of Physical Activity	Factors Not Predictive of Physical Activity
Moore et al, 2010	3846 (2932)(Whole group baseline data, from 2nd baseline assessment)					
Moore et al, 2013	1 week post-stroke 3111 (2290) 3 months post-stroke 5763 (3026) 6 months post-stroke 5927 (4091)	1 week post-stroke 1383 (43) min/day 3 months post-stroke 1350 (57) min/day 6 months post-stroke 1355 (72) min/day	- Accelerometer derived energy expenditure, kcal: ▪ 1 week: 1840 (354) ▪ 3 months: 2100 (447) ▪ 6 months: 2093 (445) - Average MET (kcal/kg/hr): ▪ 1 week: 1.0 (0.2) ▪ 3 months: 1.15 (0.2) ▪ 6 months: 1.16 (0.2) - Physical energy expenditure min/day: ▪ 1 week: 28 (32) ▪ 3 months: 64 (58) ▪ 6 months: 66 (68) - Absolute no. of breaks in sedentary time: ▪ 1 week: 252 (72) ▪ 3 months: 291 (65) ▪ 6 months: 282 (62)	- Daily steps: 8726 (3735) - Accelerometer derived energy expenditure: 2213 kcal (492) - Average MET (kcal/kg/hr): 1.3 (0.2) - Physical energy expenditure: 98 (63) min/day - Sedentary time: 1372 (272) min/day - Absolute no. of breaks in sedentary time: 341 (64)		

Study	Steps per day $\bar{X}$ (SD)	Sedentary behaviour $\bar{X}$ (SD)	Other physical activity data $\bar{X}$ (SD)	Age-matched control data	Significant Predictors of Physical Activity	Factors Not Predictive of Physical Activity
Mudge and Stott, 2008	6247 (4439)		- No. of steps at low rate (<30 steps/min): 2338 (1051) - No. of steps at medium rate (>30 and <60 steps/min): 2241 (1681) - No. of steps at high rate (>60 steps/min): 1614 (2252)			
Mudge and Stott, 2009	4765 (1225-21273)	% of time with no steps: 83% (53-96)	- No. of steps at low rate (<30 steps/min): 2334 (565) - No. of steps at high rate (>60 steps/min): 655 (0-10590)		- Age (-ve correlation) - Mobility (6MWT)	
Mudge et al, 2009	5719 (3431)	% of time inactive: 83% (8)				

Study	Steps per day $\bar{X}$ (SD)	Sedentary behaviour $\bar{X}$ (SD)	Other physical activity data $\bar{X}$ (SD)	Age-matched control data	Significant Predictors of Physical Activity	Factors Not Predictive of Physical Activity
Paul et al, 2016	4035 (2830)	20.4 hrs/day (2.7)	- Sit to stand transitions/day: 43.5 (13.5) - MVPA (Cadence >100 steps/min): 0.2 (0.2) hr/day - Average walking time (Cadence >20 steps/min): 1 (0.6) hr/day	- Steps/day: 8394 (2941) - Sedentary time: 17.4 (3.8) hr/day - Sit to stand transitions/day: 47.6 (11.3) - MVPA (Cadence >100 steps/min): 0.6 (0.3) hr/day - Average walking time (Cadence >20 steps/min): 1.7 (0.6) hr/day	- Walking speed correlated with overall walking time (Cadence >20 steps/min)	
Preston et al, 2017	4627 (2390)		Duration of moderate physical activity: 47 (51) min/day			
Rand and colleagues, 2009 and 2010		86% of waking hours inactive (13 hrs (2))	- Triaxial accelerometer counts: 53075 (83476) - Accelerometer derived energy expenditure: 156 kcal/day (141)		- Mobility (6MWT) - Impairment (BBS, CMSA lower limb score) - HRQOL (SF-36)	

Study	Steps per day $\bar{X}$ (SD)	Sedentary behaviour $\bar{X}$ (SD)	Other physical activity data $\bar{X}$ (SD)	Age-matched control data	Significant Predictors of Physical Activity	Factors Not Predictive of Physical Activity
Robinson et al, 2011	2540 (2176)				- Fatigue (FSS) - Depression (CES-D)	- Age - No. of comorbidities - Falls self-efficacy (FES(S)) - Balance self-efficacy (ABC) - Perceived difficulty walking - Satisfaction with level of participation
Roos et al, 2012 Data estimated from graphs (like English et al., 2016). No responses from authors to request raw data.	3000 (slow walkers) to 6000 (fast walkers)		- Hours/day walking: 1 (slow walkers) to 1.5 (fast walkers) - Walking bouts: 150 bouts/day	- Steps/day: 10,000 - Walking bouts: 250 bouts/day	Mobility (Gait speed)	

Study	Steps per day $\overline{X}$ (SD)	Sedentary behaviour $\overline{X}$ (SD)	Other physical activity data $\overline{X}$ (SD)	Age-matched control data	Significant Predictors of Physical Activity	Factors Not Predictive of Physical Activity
Tiedmann et al, 2012	4365 (3350)				- HRQOL (SF12v2 physical composite), - Standing balance (postural sway, maximal balance range, choice stepping reaction time), - Mobility (gait speed, 6MWT)	- Age , - Gender, - Vision, - Incontinence, - Total no. of health conditions, - SF12v2 mental composite score, - Fear of falls, - Recurrent falls, - Cognition, - Leg muscle, strength
Tieges et al, 2015		1 month post-stroke: 19.9 hrs/day (IQR=18.4-22.1) 6 months post-stroke: 19.1 hrs/day (IQR=17.8-20.8) 12 months post-stroke: 19.3 hrs/day (IQR=17.3-20.9)	Average sedentary bout duration: - 1 month post-stroke: 1.65 hrs (IQR= 1.35-2.21) - 6 months post-stroke: 1.71 hrs (IQR=1.36-2.09) - 12 months post-stroke: 1.7 hrs (IQR=1.33-2.2)		- Stroke severity (NIHSS), - Less functional independence (NEADL)	- Time since stroke, - Functional ability (6MWT)
Touillet et al, 2010	6973 (2439)					



Study	Steps per day $\bar{X}$ (SD)	Sedentary behaviour $\bar{X}$ (SD)	Other physical activity data $\bar{X}$ (SD)	Age-matched control data	Significant Predictors of Physical Activity	Factors Not Predictive of Physical Activity
Vanroy et al, 2016	6241 (3620)		Energy expenditure: 2912.52 (1239.5) kcal/day			
Zalewski and Dvorak, 2011	2990 (2488)			Steps/day: 6378 (2149)	- Mobility (comfortable gait speeds, fast gait speeds, 6MWT)	

6MWT= 6 Metre Walk Test; 10MWT = 10 Metre Walk Test; ABC = Activities-Specific Balance Confidence Scale; BBAQ = Barriers to Being Active Quiz; BBS = Berg Balance Scale; BDI-II = Beck Depression Inventory-II; CES-D = Centre for Epidemiology Studies Depression Scale; CMSA Lower Limb Score = Chedoke-McMaster Stroke Assessment Lower Limb Score; FAC = Functional Ambulatory Classification; FES-I = Falls Efficacy Scale-International; FGA = Functional Gait Assessment; FMA LE = Fugl-Meyer Assessment – Lower Extremity Subscale; FSS = Fatigue Severity Scale; GDS = Geriatric Depression Scale; HADS = Hospital Anxiety and Depression Scale; MCIR = Modified Cumulative Illness Rating Scale; Mini BESTest = Mini Balance Evaluation Systems Test; MMSE = The Mini-Mental State Examination; MoCA = Montreal Cognitive Assessment; NEADL = Nottingham Extended Activities of Daily Living Questionnaire; NIHSS = National Institutes of Health Stroke Scale; SDHS = Short Depression-Happiness Scale; SF-12 = 12-item Short Form Health Survey; SF-36 = 36-item Short Form Health Survey; SIS = Stroke Impact Scale; SSFWV = Self-Selected Floor Walking Velocity; TUG = Timed Up and Go

3.5. Discussion

The current review identified 44 individual studies that assessed physical activity and/or sedentary behaviour levels in stroke survivors living in the community. Since the searches for the original review by English et al (2014) were conducted in November 2012, 20 additional studies have been conducted and reported in 24 articles. One additional study was identified that was published in 2008 (Mudge and Stott, 2008) that met the inclusion criteria but was not included in the original review. Unlike the 2014 review whereby no studies specifically measured sedentary behaviour, 16 of the included studies in the current review reported sedentary behaviour. Earlier published studies often used measurement protocols that allowed reporting of time not on feet (i.e. sitting or lying down) rather than sedentary behaviour (Alzahrani et al., 2011; Rand et al., 2010; Mudge et al., 2009; Mudge and Stott, 2009). With advancements in sedentary behaviour measurement methods (Owen et al., 2010), a shift from inferring ‘time not on feet’ in earlier studies to objective measurements of sedentary time and patterns of accumulation was observed. Additionally, the original review highlighted the lack of studies investigating the patterns of activity and inactivity, with only three studies reporting patterns of activity (i.e. bouts of stepping) across the day and none reporting patterns of sedentary behaviour accumulation. Although numbers of studies were still limited, five reporting patterns of activity and inactivity and three reporting patterns of sedentary behaviour accumulation were identified in this review. While the initial focus of sedentary behaviour research concentrated on investigating the total levels of sedentary behaviour, recent research now indicates the importance of how sitting time is accumulated and it’s relation to health risk factors (Howard et al., 2013; Peddie et al., 2013; Dunstan et al., 2012b). This is reflected in the three studies that emerged since the original searches were conducted in the 2014 review that report on the patterns of accumulation and breaks in sedentary behaviour. The increased number of studies that have emerged in the five year period since the original searches were conducted (November 2012) provides evidence of the increasing interest in sedentary behaviour and especially sedentary behaviours of stoke survivors. It also provides support for the need for the current review which aimed to update the review completed by English et al. in 2014.

Overall, stroke survivors displayed significantly lower levels of physical activity when compared to healthy controls. They took considerably less steps per day (1193 (Kerr et al., 2016) to 7379 (Manns et al., 2009), compared to age matched controls (5313 (English et al., 2016a) to 14,730 (Manns et al., 2009), and spent less time in all activity intensities (i.e. LIPA and MVPA) when compared to healthy controls. Time not spent in physical activity is evidently related to sedentary behaviour levels as stroke survivors were highly sedentary, with the majority of their waking hours spent in sedentary behaviours (9.3 hours/day (Joseph et al., 2017) to 11.3 hours/day (Ezeugwu and Manns, 2017)). Stroke survivors tended to have prolonged uninterrupted periods of sedentary behaviour, with 51.6% of waking hours being spent in bouts of 30 minutes or greater of sitting (English et al., 2016a).

Three longitudinal studies provided insight into how physical activity and sedentary behaviour levels change over time following a stroke. Mahendran et al. (2016b) documented a significant increase in daily step count from one month to six month post stroke, significant increase in time spent walking and sitting/lying time between one month post stroke and three and six months post stroke. They also noted that the time stroke survivors spend in moderate intensity ambulation also significantly increased over time. Similarly, Moore et al. (2013) observed significant increases in physical activity duration (minutes/day), daily step count and breaks in sedentary behaviour between one week and three months post stroke, but interestingly physical activity levels and number of breaks in sedentary behaviour plateaued between three months and six months. It could be speculated that increases in physical activity and ultimately increases in breaks from sedentary behaviour could be related to rehabilitation and recovery of function following a stroke. Evidence has suggested that recovery of function following stroke has an important three month period when most recovery will occur (Lee et al., 2015). This timeframe matches the longitudinal data whereby most changes in physical activity levels were observed over the first three months after stroke, with a plateau then seen after three months. In support of this, 13 studies examined the influence of walking ability on free-living physical activity, and found significant moderate strength associations between functional ability and levels of sedentary behaviour (i.e. steps/day, accelerometer counts/day, time on feet). This would suggest that as time after stroke passes and functional recovery improves, stroke survivors with the ability to walk will become more physically active. The final longitudinal study focused on sedentary behaviour and observed no significant longitudinal changes in the amount or pattern of sedentary behaviour in stroke survivors over the first year after stroke (Tieges et al., 2015).

One difficulty found during the extraction and analysis of the data within the review was the heterogeneity of the measurements undertaken and recorded by the different studies. Although the majority of studies aimed to measure physical activity, this was defined and measured in different ways. Some studies, particularly ones published earlier, reported number of steps per day as an indicator of physical activity. As highlighted in the original review (English et al., 2014), although step counts are an easy to understand and important measure, it provides little information about the relative intensity of activity. Although other studies described physical activity in terms of the intensity of the activity, which is important to understand amount of LIPA and MVPA stroke survivors participate in, it also raises its own problems. Definition of each of the physical activity categories firstly depended on the outcome being used which varied greatly within the studies (i.e. heart rate, metabolic equivalents, step cadence). Secondly, when a similar outcome was used, different categorisation limits were used to define what constituted each activity level (LIPA and MVPA). For example, three studies used Actigraph accelerometers to measure activity counts and specifically MVPA. Butler et al. (2014) and English et al. (2016a) both used cut-off point around 2000 counts/minute for MVPA, whereas a study by Joseph et al (2017), used a lower cut-off with >1042 counts/minute indicating MVPA. Overall, Joseph et al. (2017) reported higher number of minutes in MVPA compared to the other two studies, which may be explained by the lower cut-off point applied therefore categorising more activity as MVPA compared to the other studies.

Another problem is the variation of tools used to measure both physical activity and sedentary behaviour. In the review, a large variety of measurement tools were utilised including but not limited to; pedometers, accelerometers, heart rate monitors and inclinometers. Similarly, the variation in monitoring periods made it difficult to interpret the data. Within this review physical activity and sedentary behaviour data was either reported over the 24hours period or during ‘waking hours’. Whilst the majority of studies that measured ‘waking hours’ indicated how long this period was, some did not. It is therefore important for future studies to clearly define measurement periods so comparisons can be made across studies.

All of the issues highlighted through this review, with regards to heterogeneity of physical activity and sedentary behaviour measurements made interpretation and analysis of the data difficult, with statistical analysis being deemed not appropriate for this systematic review. Standardisation of measurements would make interpretation of the results easier and allow meaningful comparisons to be made across studies. This may be difficult to do so future studies should also ensure that they clearly outline the measurement details including, devices uses and measurement periods used.

When reviewing the findings of the present review it is also important to consider the validity and reliability of the objective measurement tools used to record physical activity and sedentary behaviour levels in stroke survivors. Whilst many objective measures have been reported in healthy populations (Warren et al., 2010), it has been unclear whether these measures would be valid or feasible for use following stroke. Despite accelerometers and global positioning systems (GPS) demonstrating the potential for use in the stroke population, studies have only recently been conducted to assess the validity and reliability of these methods for measuring physical activity in the stroke population (Mahendran et al., 2016). A review by Fini and colleagues (2015) aimed to describe how physical activity was monitored following stroke and to describe the reported psychometric properties of these measurements. Overall, they found physical activity measurement was highly variable following stroke with many different outcomes being reported, making it difficult to compare results across studies. Validity and reliability data for monitors was limited, with test-retest reliability only being reported in six of the twenty-nine devices (r= 0.44 to r=0.99). Often papers report psychometric properties of the devices in other populations which are not likely to be relevant to stroke survivors. The characteristic slow movement speed, use of gait aids and asymmetry in stroke survivors is likely to affect a device’s ability to accurately measure physical activity in this population (Fini et al., 2015). Accelerometers are also often found to underestimate walking among individuals who walk slowly (Simpson et al., 2015).

The ActivPAL has been shown to have excellent agreement with direct observation for time spent sitting, lying and postural transition in older adults with impaired function, including people with subacute stroke (Taraldsen et al., 2011). It has also more recently demonstrated excellent agreement with direct observations for all measures of time spent walking and most measures of step count during walking tasks. The test-retest reliability for most measures of step count, time spent walking and METs (Mahendran et al., 2016) were also shown to be excellent, demonstrating the valid and reliable nature of the device to measure community ambulation in individuals with chronic stroke. Similarly, a recent study by Campos and colleagues (2018), determined the validity of the ActiGraph activity monitor for individuals who walk slowly post-stroke. They found that wearing the ActiGraph on the unaffected ankle produced the most accurate step count in people with the measurements showing no significant difference from the reference accelerometer. Although studies are emerging that assess the psychometric properties of objective measures of physical activity in stroke survivors, more work is needed to ensure that validity and reliability data is available for all measures so that the most appropriate objective measure is chosen and used in research studies with this population.

Although the main aim of this review was to update the knowledge base with regards to physical activity and sedentary behaviour levels in community dwelling stroke survivors, it also aimed to examine the participants included and determine whether stroke survivors who have significant mobility problems are included in research studies. Of the 44 studies included in this update, all of them included participants who were able to walk short distances independently (with or without aids and devices) with none including stroke survivors who have severe mobility disability and cannot walk. This was highlighted as a limitation in the 2014 review, however five years on no further research has been conducted that involves this specific stroke population. With stroke being the largest cause of disability in the UK with half of all stroke survivors being left with a disability, it is important to include all severities of stroke to create a bigger picture of physical activity and sedentary behaviour profiles for all stroke survivors. Although measurements of physical activity and sedentary behaviour have in the past not been suitable for people in wheelchairs, progress has been made in the field of physical activity measurements in people with disabilities and wheelchair users (Nightingale et al., 2017), with wrist worn and multiple sensor monitors being evaluated for use in this population. Hopefully with the advancement of technology, more research can be conducted to assess the levels and patterns of physical activity in community dwelling stroke survivors who have significant mobility problems. This finding also provides support for the overall project as it evidences the lack of research in stroke patients who have a severe mobility disability, especially in relation to sedentary behaviour, and highlights the need for further research to be conducted.

Whilst this review was being completed, a systematic review was published in July 2017 (Fini et al., 2017). The purpose of the review by Fini et al. (2017) was to describe physical activity across the various stages following stroke (acute, subacute, and chronic). In contrast, the present systematic review aimed to update the systematic review by English et al. (2014) and explored the physical activity and sedentary behaviour levels and patterns in stroke survivors living in the community. It also investigated and presented factors that influence physical activity and sedentary behaviour levels in the community dwelling stroke survivors. Unlike the present review where inclusion of studies was dependent on the inclusion of at least one objective measurement of free-living physical activity or exercise, over a period of at least two days, Fini et al. (2017) included studies with physical activity measurements of at least four hours using either a device (e.g. accelerometer) or behavioural mapping. Additionally, while the searches were conducted at similar times in 2016, the present review also included an updated search in September 2017 and is therefore more up to date. The two systematic reviews are complementary in exploring physical activity and sedentary behaviour levels after stroke. Together they highlight the high levels of sedentary behaviour and low levels of physical activity after stroke from acute through to the chronic stages.

One of the main limitations of the review was the variability in definition and measurement of physical activity and sedentary behaviour. However, the narrative approach to synthesis adopted by the review ensured that all studies included in the review could be summarised and discussed in order to answer the research questions. Despite two reviewers being involved in the study selection, data extraction and quality assessment processes, the second independent reviewer was only able to review 20% of the papers during the study selection stage. The availability of additional reviewers for the review was limited therefore potentially increasing the risk of reviewer bias. However, given the agreement between the two reviewers during the screening of title and abstracts (20% of total) and full text articles (20% of total), it can be assumed that researcher selection bias was kept to a minimum. Additionally, any studies where the primary researcher was unsure about eligibility for inclusion, were discussed with the second reviewer and a third independent reviewer if required.

3.6. Conclusion

The increased interest in physical activity levels and sedentary behaviours and the emergence of research in this field is evidenced through the number of additional studies included in this review compared to the 2014 review (English et al., 2014). Although it was deemed important to update the review to update the knowledge base during the planning phase of the review, the fact that 24 additional articles from the five years between the two searches have been identified and included only supports the need for this current review update.

Overall, stroke survivors had lower levels of physical activity, especially moderate to vigorous physical activity compared to healthy controls. They also spent the majority of their days engaged in sedentary behaviour, particularly in prolonged and uninterrupted bouts. These high levels of sedentary behaviour highlight the need for interventions to reduce sedentary behaviour and ultimately increase light intensity physical activity. With the ultimate goal of becoming more active, it may be easier and more successful to try and reduce sedentary time first as opposed to increasing physical activity levels, especially in stroke survivors with mobility disability (Manns et al., 2012). Interventions are therefore needed to be developed to reduce sedentary behaviour in community dwelling stroke survivors.

All of the 1966 participants that were included in the 44 studies were able to walk short distances independently. Although the increase in studies exploring physical activity and sedentary behaviour provides a great wealth of information, research needs to become more inclusive of stroke survivors who have mobility disability. This finding also supports the rationale for the overall project as during the planning stages and through reviews of the literature it appeared that stroke survivors who have a severe mobility disability were often excluded or underrepresented in research studies. This review confirms this earlier suspicion and supports the empirical work conducted and described in Chapters four and five (Q-methodological study) and Chapter six (Energy expenditures of activities of daily living study).

Chapter 4 - Q-Methodology Study Methods

4.1. Introduction

This Chapter presents the first of two empirical studies that were conducted as part of the research within the remit of this thesis. It introduces the Q-methodology study which aimed to explore sedentary behaviour from the perspectives of stroke survivors with severe mobility disability, their carers and professionals involved in their care and assess their priorities in terms of mobility, sitting, movement and exercise. This Chapter provides a background to the methodology and a rationale for the suitability of the methods for the study purpose. It continues by describing the methods of the study including study design, study set-up, recruitment and data collection.

4.2. Background

While increasing amounts of research is being conducted into sedentary behaviour and stroke, including the perceptions and experiences of the patients, the findings from the qualitative systematic review (Chapter three) confirmed that stroke survivors who have a severe mobility disability are often excluded or underrepresented in research studies.

A study by Ezeugwu (2017) explored the perceptions of sedentary behaviour in stroke survivors and the ways in which it could be changed. Thirteen stroke survivors were recruited to the study and participated in a semi-structured interview to explore their understanding of the concept of sedentary behaviour, their perspectives on the barriers and facilitators to reducing sedentary behaviour and their opinions on potential ways that they could reduce sedentary behaviour in their day-to-day lives. The study found that only six of the participants had an understanding of what sedentary behaviour was and only two were aware of the associated health risks. This study highlighted the limited understanding of sedentary behaviour and limited awareness of the associated health risks amongst stroke survivors. Many barriers to moving regularly were identified including; motor impairments, fatigue, cognitive problems and lack of motivation. Although this study provided important detail on stroke survivors views of sedentary behaviour in order to inform possible intervention development, the study only investigated the perceptions of ambulatory stroke survivors and excluded those who were unable to stand and walk at least five metres with or without a gait aid.

Similarly a study currently being conducted (Nicholson et al., 2016) to better understand the views of stroke survivors on sedentary behaviour and inform future intervention development through qualitative interviews also excludes stroke survivors who are not independently ambulatory. Another recently completed study (Hall et al., 2019) that is part of a larger research project to develop and test an intervention to reduce sedentary behaviour in stroke survivors, used both observation and interview methods with stroke survivors, caregivers and staff to understand current behaviours of stroke survivors. Although the study will inform the development of an intervention to reduce sedentary behaviour and improve health outcomes in stroke survivors, the study and research project has a focus on stroke survivors who are independently ambulatory (with or without the use of a gait aid). No studies therefore exist that specifically aim to explore the perspectives of stroke survivors with severe mobility disability on the topic of sedentary behaviour and possible approaches to trying to reduce sitting time.

Guidance published by The Medical Research Council (MRC) (2008) for developing and evaluating complex interventions states that although a review of the evidence base, through systematic reviews is important for intervention development, it is also vital to draw upon existing evidence to develop a theoretical understanding of the possible process of change. However, as limited evidence is available on the experiences and perspectives of stroke survivors, there is a need for new primary research. More targeted research is required to explore the determinants of sedentary behaviour in people with severe mobility disability after stroke in order to develop tailored interventions.

It is important for stakeholder involvement to be incorporated into every stage of the complex intervention development process, including design, evaluation and implementation, ensuring that the intervention is scientifically informed and implementable (Medical Research Council, 2008). As the informal carers of stroke survivors and healthcare professionals involved in their care are likely to be involved in any interventions to reduce sedentary behaviour in those with severe mobility disability, it is important that they are included in the development process. They often provide regular care and support to the stroke survivors and would therefore not only know what their current activity levels are but also what potential they have to reduce their sedentary behaviour. Due to the limited mobility of these stroke survivors, informal carers and health professionals could also be required to help implement or support the stroke survivor during the intervention. It is therefore important to explore their experience, perspectives and expertise in caring for their family member, friend or patient to help inform intervention development.

The present study was required to provide information on what stroke survivors with severe mobility disability, carers and healthcare professionals understand about sedentary behaviour, if they believe that it can be reduced and what the likely barriers and facilitators might be for them. The study was intended to contribute to recommendations regarding the possible design and content of an intervention that could reduce sedentary behaviour in stroke survivors with severe mobility disability.

4.3. Aims and Objectives

The aim of this study was to conduct a Q-Methodology study with stroke survivors with severe mobility disability, their carers and healthcare professionals involved in their care, to explore and understand their perspectives of sedentary behaviour and assess their priorities in terms of mobility, sitting, movement and exercise.

4.4. Q-Methodology

4.4.1. Origins of Q-methodology

Q-methodology was first introduced by William Stephenson in 1935 in a letter to *Nature* (Stephenson, 1935). As an assistant to Charles Spearman, a statistical theorist who invented factor analysis, Stephenson became concerned with the level of reductionism within social science and psychological research (Stenner et al., 2008; Corr, 2001). His desire to focus on the individual person and what makes t hem unique rather than trying to identify characteristics across large populations of individuals became his driver to develop the novel methodology (Corr, 2001).

Factor analysis was developed as a statistical method that aims to identify patterns of association between a series of measured variables. Methods that employ tests of traits as variables and use sample of persons to operate are given the broad name of R methodology (Watts and Stenner, 2012). Although typically within psychology, R methodological factor analysis is associated with individual differences, Stephenson noted that the factors actually represent the associations and differences between variables recorded at the population level. The resultant factors are therefore not able to define specific individuals in a holistic manner or compare individual differences (Watts and Stenner, 2012). Stephenson developed Q-methodology as a resolution to the inability of the R methodological approach to explore individual differences fully. By inverting the conventional factor analysis, individual people become the ‘variables’ and the different tests or measurable materials become the study sample. Namely, persons become the variables of interest and allow correlations between persons or whole aspects of persons to be explored (Stephenson, 1936b).

In order for Q-technique to effectively operate, a new form of data was required as transposed data gathered for R methodological purposes would not be appropriate. The new form of data is derived when a sample of items are ranked relative to each other by a group of individuals. The scaling or ranking process, named Q-sort, is carried out from a first-person subjective perspective and ensures the holistic or Gestalt quality of the resultant data (Watts and Stenner, 2012). With the development of Q-methodology, Stephenson succeeded in his desire to focus on whole aspects of individual persons and to identify those persons who resemble one another with respect to whole aspects of their personality (Watts and Stenner, 2012; Stephenson, 1936a).

4.4.2. The Q-methodology process

Q-methodology has four distinct phases; Q-set design and construction, Q-sort data collection, statistical analysis and interpretation of the resulting factors.

4.4.2.1. Q-set design and construction

The first step in Q-methodology is the development of the Q-set, a collection of statements that participants sort during the Q-sort. The Q-set must always be broadly representative of the research topic and aim to be suitably balanced to capture the majority of possible viewpoints and opinions of the topic under investigation (Watts and Stenner, 2012). The process of Q-set construction is described in more detail in Section 4.5.

4.4.2.2. Q-sort data collection

Data for factor analysis comes from a process called Q-sorting whereby participants rank-order the Q-set items according to a ‘condition of instruction’. An example of a condition of instruction is; ‘Sort the items according to those with which you most agree (+5) and those you most disagree (-5)’ (Baker et al., 2006). Upon presentation of the Q-set items, on individual cards, participants are advised to initially sort the statements into three piles; ‘agree’, ‘disagree’ and ‘neutral’. Each pile, starting with ‘agree’, then ‘disagree’ and finally ‘neutral’ are then sorted individually and placed on a grid. The grid has the same number of spaces as the number of item cards, but it dictates the number of statements that can be assigned a particular ranking through a forced-choice distribution (See Figure Twelve for an example grid)(Watts and Stenner, 2012).

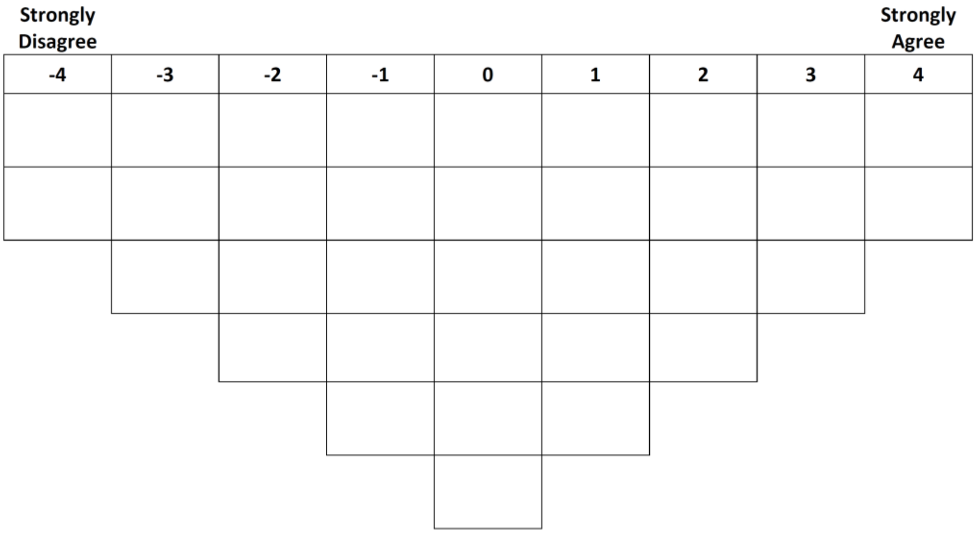


Figure 12 Example Q-grid

To aid interpretation of the emerging factors from the Q-sorts, participants are encouraged to talk about the placing of the statements and their perceived meanings and/or understandings immediately after the Q-sort exercise is completed. Once all statements are placed on the grid, their positioning is then recorded by transcribing numbers associated with each statement onto a data sheet that often has a printed version of the grid.

The population size for Q-methodology can be small (typically around 40-60 participants (Watts and Stenner, 2012)), because the character traits of a large group of participants are not being studied; rather it is the viewpoints of the participants that are of interest (Corr, 2001).

4.4.2.3. Statistical analysis

Analysis of the Q-sort data can either by carried out by a general statistical package (e.g. SPSS) or more commonly by a dedicated Q-software package (PQMethod) (Corr, 2001). First, a correlation matrix of all Q-sorts is calculated. This describes the level of agreement or disagreement between the individual sorts, namely, the degree to which the points of view of the individual participants are similar or dissimilar (Van Exel and De Graaf, 2005). In order to identify the number of different natural groupings of Q-sorts which are similar or dissimilar, the correlation matrix is subjected to by-person factor analysis. People with similar viewpoints will share the same factor. Factor loadings that are determined for each Q-sort, indicates the extent to which each (individual) Q-sort is associated with each factor (Van Exel and De Graaf, 2005). A detailed description of the analysis process used in the present study is presented in section 4.6.5.

4.4.2.4. Interpretation

Each emerging factor is represented by its own best-estimate Q-sort, also termed a factor array. These factor arrays are then subjected to interpretation (Watts and Stenner, 2005) with the aim to tease out the separate accounts underpinning the patterns of Q-sorts, according to their similarities and differences (Baker et al., 2006). Interpretation involves the identification of interesting patterns when comparing and contrasting the statements' position within each factor. Previous research, theories and cultural knowledge can help to aid the interpretation process (Stainton Rogers, 1995). Similarly, the qualitative accounts collected during and after the Q-sorts can act as useful aids during factor interpretation (Baker et al., 2006).

4.4.3. Rationale for methodology

A Q-methodology study was proposed to explore the perspectives of stroke survivors, their carers and professionals involved in their care, in relation to sedentary behaviour. Q-methodology is a useful method to explore perspectives of a subject, as the results describe a population of viewpoints instead of a population of people (Risdon et al., 2003). It allows feelings, beliefs, motives and goals; which form a part of personality that are often largely unexplored but have great influence on behaviour, to be examined (Van Exel and De Graaf, 2005).

Some authors argue that the ranking procedure of the Q-sort activity makes this 'alternative' qualitative method look too much like tests, scales and questionnaires. However, unlike survey and questionnaire methods whereby the investigator often imposes categories on the responses, Q-methodology determines categories that are operant (Smith, 2001, cited in Van Exel and De Graaf, 2005, p.2). It neither tests nor imposes meaning a priori. Instead it prompts the participants to decide what is meaningful, specifically to identify what does and does not have value and significance from their perspective (Watts and Stenner, 2005). This is important as it generates diverse accounts that are not easily characterised as pre-defined attitudes or beliefs (Risdon et al., 2003). Q-methodology also allows exploration of topics where participants would not necessarily have readily constructed responses (Baker et al., 2006). This is important as sedentary behaviour is a relatively new concept and not fully understood by the general population.

One of the main arguments of Q-methodology refers to the lack of reproducibility of the methods. However, Q-methodology makes no claim to identify viewpoints that are consistent with individuals across time and instead is interested in pursuing a ‘snap shot’ of a connected series of subject positions or ‘viewpoints’ at that specific time point (Watts and Stenner, 2005). With regards to reproducibility, despite the method not being concerned with achieving consistent subject results over time, the methods do employ a level of control that allows the study to be reproduced. Standardised instructions to research participants through the ‘Condition of Instruction’ ensures that each participant can perform the Q-sort in a similar manner.

Q-methodology has been quite widely used in health and social care research. The method has proved acceptable to participants from a range of backgrounds and has been successfully used in a range of projects including; understanding nursing practice in stroke units (Clarke and Holt, 2015) evaluation of a day service for younger adult stroke survivors (Corr et al., 2003), comparing a definition of occupational therapy with the experience of ex-consumers of stroke services (Corr et al., 2005), disability-related research (Mckenzie et al., 2011) and understanding of Down’s syndrome (Bryant et al., 2006).

4.5. Development of the Q-set

4.5.1. Background

The first step in Q-methodology is the development of the Q-set, a collection of ‘heterogeneous items’ that participants sort. It is important when designing the Q-set that it allows participants to respond effectively to the research question (Watts and Stenner, 2012). The Q-set must always be broadly representative of the research topic and aim to be suitably balanced to capture the majority of possible viewpoints and opinions of the topic under investigation (Watts and Stenner, 2012). Unlike the design of a questionnaire or test, the generation of potential items in a Q-set does not need to be theory-driven, and should instead be considered a sampling task (Watts and Stenner, 2005).

One of the main limitations of Q-methodology is the time and effort it takes to design and develop the Q-set due to the iterative process of reviewing, synthesising and piloting the items in order to be confident that the final Q-set is balanced and representative (Watts and Stenner, 2012). The design and development process has been described to be “more an art than a science” (Brown, 1980, p.186) and “one place where Q-method is noticeably a craft” (Curt, 1994, p.128-129). It is important to note that although the process has been likened to art or a craft, it takes an appropriate application of system and rigour along with very high levels of skill and patience to produce the best possible Q-set (Watts and Stenner, 2005).

Q-sets typically take the form of a collection of statements, but can be composed of pictures, words, objects, descriptions and behaviours (Donner, 2001). It is generally agreed that a Q-set of between 40 and 80 items is satisfactory, though the exact size is often dictated by the subject matter (Paige and Morin, 2016). It is important to create a Q-set that is large enough to be comprehensive and representative of the topic without being too large and demanding for the participants to complete (Watts and Stenner, 2012; Watts and Stenner, 2005). Although 40 items is considered the lowest acceptable number of items, in some circumstances a limited number of items should be considered in order to make the Q-sort less taxing. This is especially important if participants are children or adults with learning difficulties or cognitive deficits (Watts and Stenner, 2012). If the number of items are limited, statements should be worded or phrased more generally in order to still provide satisfactory coverage of the research topic.

It is often thought when designing a Q-set that, even with effective selection and piloting, the Q-set can never be described as whole as there will always be something else that could be potentially said about the research topic (Watts and Stenner, 2005). However, in Q-methodology the items in the Q-set are not deemed to be the most important part of a study but rather the participants’ engagement with the Q-set; their understandings, meanings and interpretations of the items and research topic. Q-methodology exploits a human’s innate desire to structure and to ascribe meaning to all stimuli and events that are experienced (Watts and Stenner, 2005) and relies on the participants to impose their own viewpoints and meanings onto the items through the sorting process. As Q-methodology aims for meaning to be attributed a posteriori through interpretation rather than through a priori postulation (Watts and Stenner, 2012; Brown, 1980), Q-set design should not be driven by focusing on the meaning of the items. For these reasons, a Q-set that only contains a representative condensation of potential information is considered acceptable as the detail, quality and meaning of the items will be established as the study proceeds (Watts and Stenner, 2012).

4.5.2. Process overview

Limited resources are available to guide the sampling process involved in Q-set design, with the majority of existing literature focusing on the methodological techniques involved in Q-methodology. Although there is no consensus on the best method to design a Q-set, two overall approaches have been suggested to create either structured or unstructured Q-sets. Structured Q-sets are created when the subject topic is broken down, using a preconceived theory, into a series of component themes or issues. Items are then generated relative to the themes or issues, ensuring equal items for each sub-theme (Watts and Stenner, 2012). This deductive process selects items systematically using a structure based on concepts derived from a theory or framework (Paige and Morin, 2016). Alternatively an inductive approach can be utilised to design an unstructured Q-set, with the researcher selecting statements when no pre-existing theory exists in relation to the phenomenon of interest (Paige and Morin, 2016). This approach often still begins with the identification of key themes and issues relating to the research subject, but with the aim then to sample representatively from the whole population rather than quota sample from predefined sub-groups (Watts and Stenner, 2012; Stenner et al., 2008). It is important to note that the word unstructured refers to the flexible nature of the Q-set construction process rather than implying an absence of structure in the final Q-set (Watts and Stenner, 2012).

Constructing a Q-set typically follows a non-linear four stage process, as outlined in Figure Thirteen. The first stage involves drawing from the universe of statements that could be made about the research subject or topic of interest, this is named the concourse (Paige and Morin, 2016; Brown, 1980; Stephenson, 1973). Numerous sources that provide conversational sources of opinion can be explored in order to sample items. It is common for the sampling process to begin with extensive examination of the academic literature as this helps to identify the key themes or issues that characterise the research topic of interest (Watts and Stenner, 2012). Other sources that can be drawn from during the sampling process include but are not limited to; formal interviews, informal discussions, printed media, policy documents, public consultations, internet forum discussions and existing scales and questionnaires (Watts and Stenner, 2005). During this first stage, it is advised to generate an overly large number of items that can be refined and reduced during the subsequent three stages. This is to ensure that all possible viewpoints and opinions of the topics will be covered in the Q-set.

Once all possible statements have been generated from the concourse, it is important to refine and reduce the number of items into a representative sub-set. This is required as a Q-set containing over 100 items would be unmanageable for participants to sort and rank-order during the Q-sort. Selecting the primary sample is the second stage of Q-set construction. Whether the structured or unstructured approach as described before is employed, it is recommended that the sampled items should be sorted into categories and sub-categories. The main purpose of the categories are to ensure that all aspects of the subject of interest to the researchers and participants have been covered by the items (Herrington and Coogan, 2011). In order to reduce the number of items, duplicates should first be removed (Corr, 2001). Next, items with similar content within the categories should be reviewed and combined, rephrasing the items if necessary (Herrington and Coogan, 2011). By selecting the items that are most unalike, the Q-set produced will be representative of the complexity of the phenomenon of interest (Brown, 1980). The aim of the second stage is to create a Q-set of 40-80 items that is broadly representative and provides satisfactory coverage of the research topic.

The next stage in Q-set construction is to evaluate the Q-set items with subject experts in order to determine how closely the items within the Q-set represent the whole subject of interest (Paige and Morin, 2016). They are also able to comment authoritatively on obvious omissions and the phraseology of individual items. Subject experts should be reminded that they do not need to review the accuracy of the content but rather the readability of the items (Paige and Morin, 2016). Following review by subject experts, it is often beneficial to pilot the Q-set items and the Q-sort procedure with lay persons and interested parties (Watts and Stenner, 2012). Again this review allows commentaries on phraseology, omissions and clarity of the statements. It also provides an opportunity to practice the administration of the Q-sort and assesses the clarity of the instructions, the time required to complete the Q-sort and the acceptability of the number of items in the Q-set that require sorting.

Q-set construction is an iterative process that continuously cycles through the stages to edit and refine the statements until a balanced and representative Q-set that is deemed acceptable to the participant group is created. It is important when designing the Q-set that it remains unbiased towards a particular viewpoint and includes statements that people can both agree and disagree with regarding the topic (Herrington and Coogan, 2011). When selecting and editing Q-set items, statements should be avoided that are too difficult to understand, are the direct opposite of another statement or are double barrelled with two or more propositions (Watts and Stenner, 2012). Editing of the items is often required following review by both subject experts and lay persons, however as Brown (1980, p.190) states, edits should be “more akin to cosmetics than to plastic surgery” . Edits should be minimal and generally focused on grammar and syntax corrections, with the essence of the statement from the original source still being retained (Paige and Morin, 2016).

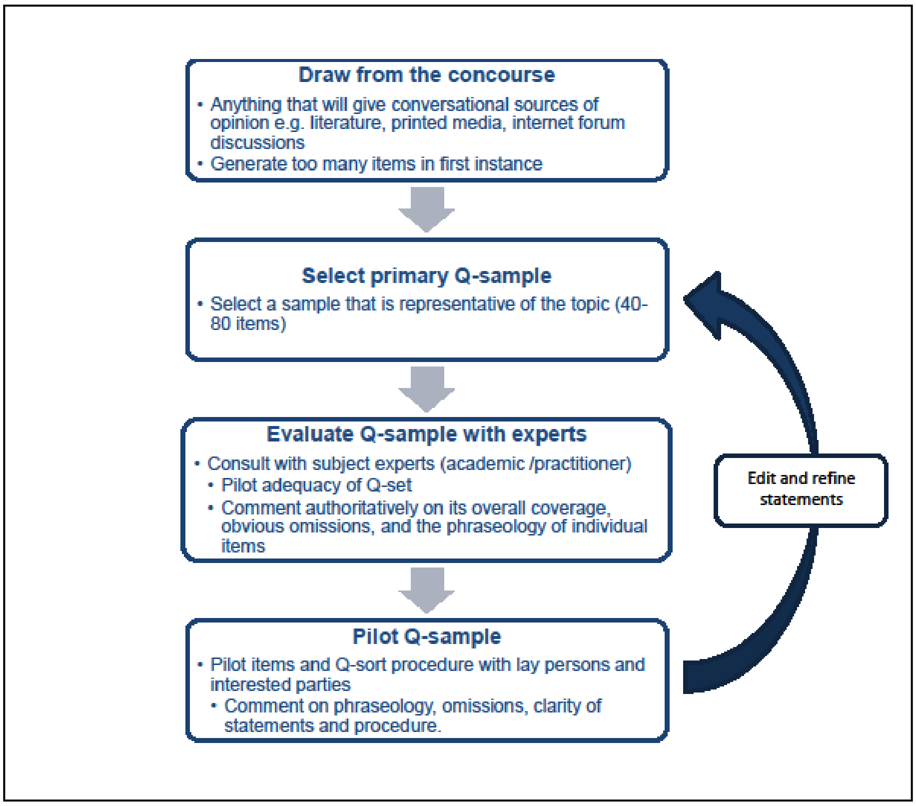


Figure 13 Steps in Q-set construction (Adapted from Paige and Morin (2016))

4.5.3. Design and development of stroke survivor, carer and healthcare professional Q-sets

As the study was designed to conduct a Q-methodology study with stroke survivors, their carers and healthcare professionals, different Q-sets were required for each participant group. It was decided to construct a Q-set for the stroke survivor participant group initially, that could subsequently be adapted to construct the Q-sets for the carer and healthcare professionals. As sedentary behaviour is a relatively new concept and not fully understood by the general population, it was decided to focus on the term ‘movement’ and to incorporate sedentary behaviours and sitting into the statements.

The process began with a review of the academic literature. The qualitative systematic review of sedentary behaviour and disability that was completed at an earlier stage of the PhD project highlighted the lack of research into perspectives of sedentary behaviour in people with a disability but more specifically the stroke population. With the lack of stroke and disability specific information, it was decided to widen the concourse to include sources of information about movement, physical activity, exercise and mobility after stroke, and general information on sedentary behaviour. During an initial review of the academic literature and other sources including government reports and factsheets, nine key themes (Figure Fourteen) were identified to provide a framework for item sampling. As previously described, as sources and information specific to sedentary behaviour and disability were limited, very few statements were taken verbatim from the concourse. Instead, whilst searching the concourse sub-categories were identified and noted in order for statements to be created to cover the identified concepts. The process of identifying the nine key themes and sub-categories is shown in Figure Fifteen.

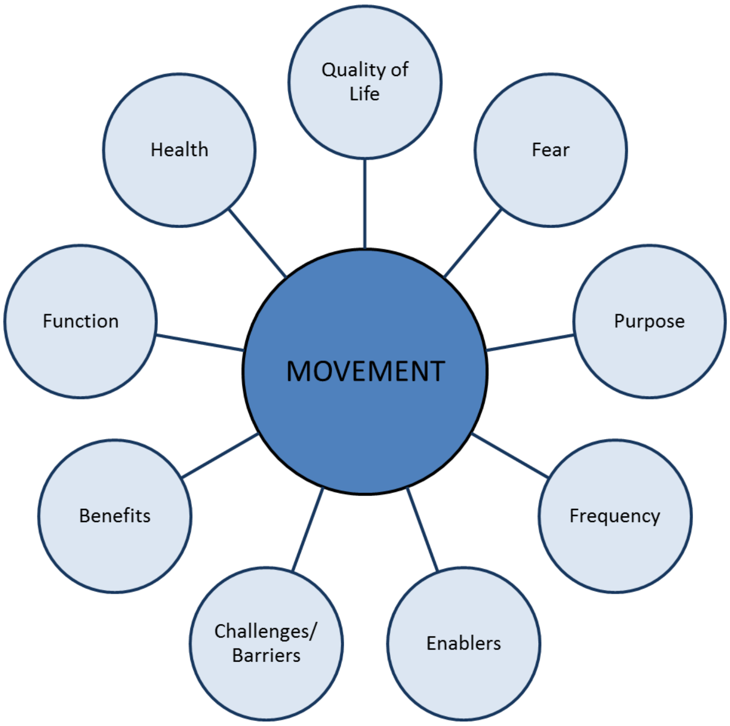


Figure 14 Nine key themes identified in relation to 'Movement'

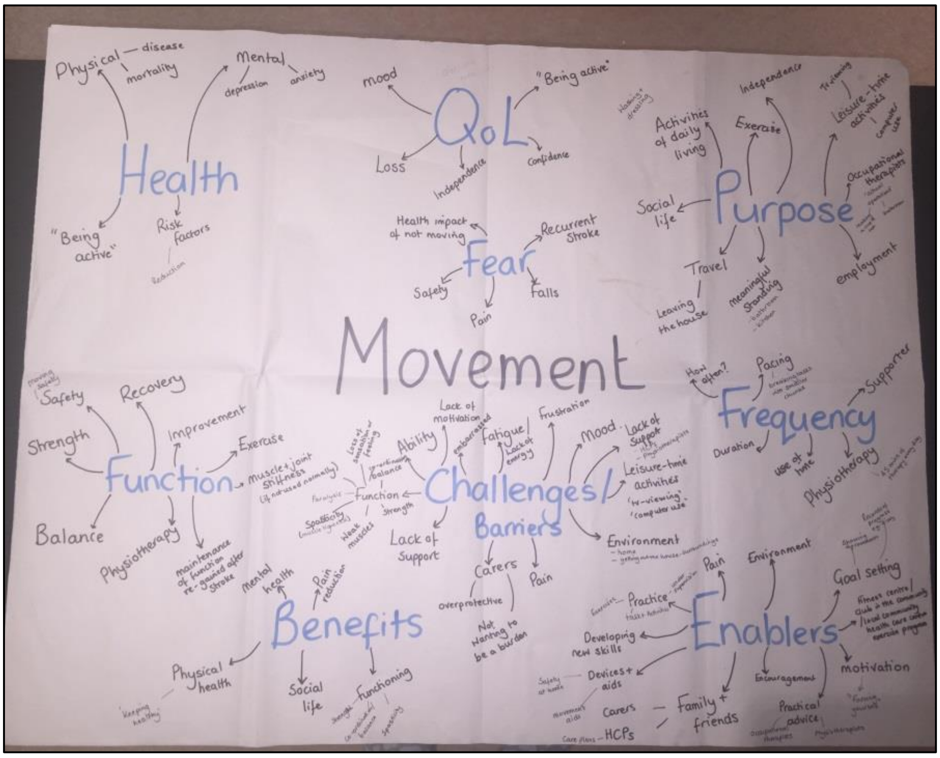


Figure 15 Sampling framework created from nine key themes and sub-categories identified from initial review of the concourse

Numerous sources were reviewed during the item sampling process including but not limited to; academic literature relating to sedentary behaviour and physical activity for both general and stroke populations, guidelines (Intercollegiate Stroke Working Party, 2016), government reports (Davies et al., 2011; The Sedentary Behaviour and Obesity Expert Working Group, 2010), websites and information factsheets from international stroke associations and foundations (Stroke Association, Stroke Foundation, Canadian Partnership for Stroke Recovery, National Stroke Association), internet discussion forums and printed media. Although only one study was highlighted through the systematic review, studies that were excluded during the full text eligibility screen stage of the review were searched for relevance and information that could inform potential statements. Additionally, during the title and abstract eligibility review of studies within the systematic review, excluded studies that were highlighted as interesting were saved within a folder on the reference management system (EndNote), and explored during the Q-set sampling process for further information. Internet discussion forums were searched as they provide a rich source of conversational information. Only discussion forums that were accessible without an account were used as these are considered open to the public domain and can therefore be explored. The UK Stroke Association's TalkStroke forum was initially searched followed by the Stroke Foundation's (Australia) Enable Me forum. Another resource utilised was the Healthtalk.org website which provides information about health issues by sharing people's experiences. The website is organised into categories and the 'Stroke' and 'Disability and impairment' categories were searched alongside other categories of interest for potential statements and information.

Once all sources had been explored and saturation of information was reached, 214 statements were initially collected. The statements were organised into their respective themes and sub-categories. To aid the second stage of Q-set construction, statements were written on post-it notes and displayed on a large piece of paper. This enabled the entire collection of sampled items from the concourse to be viewed at once and aided the process of decision making with regards to item selection and reduction. This strategy has been recommended by Paige and Morin (2016) as it provides a Gestalt view of the entire concourse and helps with the deliberation over item selection. Statements were kept organised within their themes to ensure coverage of the identified concepts was maintained during the selection process. Figure Sixteen shows the items sampled from the concourse on green and yellow post-it notes arranged around their respective themes, written on pink post-it notes. Duplicates were removed first and then items with similar content within the themes were reviewed and combined where possible. At the end of the second stage, a preliminary Q-set was constructed of 63 items (See Appendix I for lists of initial statements collected). It was felt at this stage that external input from both subject experts and lay persons was required to reduce the number of items further.

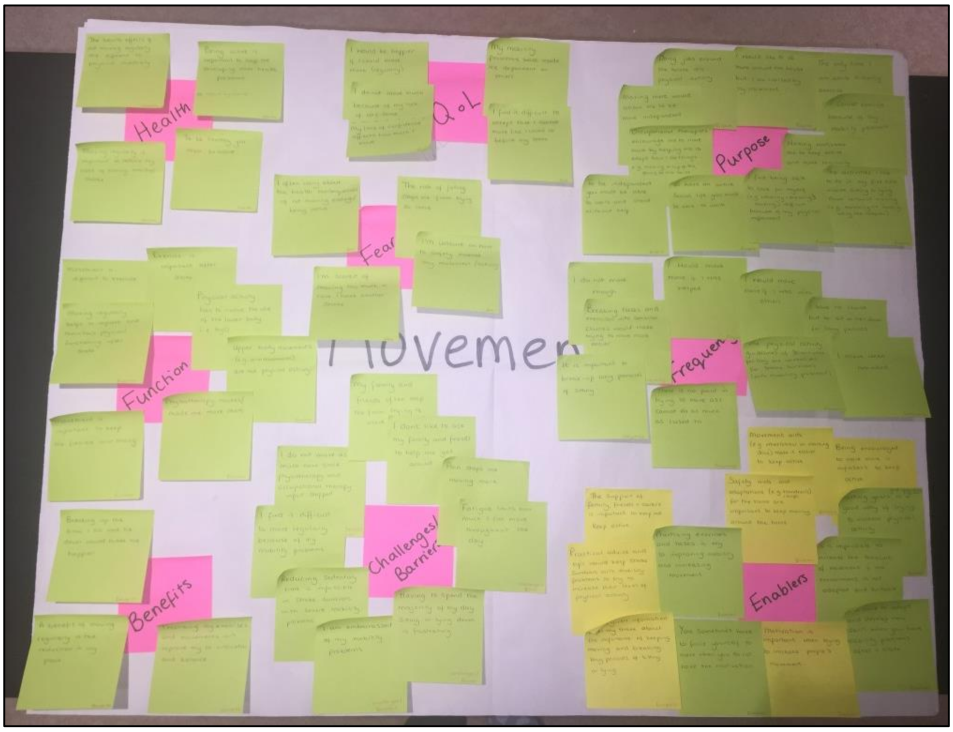


Figure 16 Process of item review and reduction using post-it notes

It was agreed, taking account of previous Q-methodological studies involving stroke survivors and carers as participants, that an adapted Q-set, using lay terminology and with fewer statements, should be constructed for use with this group of stroke survivors and carers. Following a meeting with an expert in Q-methodology, it was decided that a Q-set of around 30-35 items should be aimed for as this number will allow the Q-sort process to be manageable and acceptable to the stroke survivors whilst ensuring sufficient coverage of the subject topic.

The initial shortlisted 63-item Q-set was reviewed by a group of nine subject experts including; a Professor of Stroke Rehabilitation, an Associate Professor in Stroke Care, a Professor in Exercise Science, four stroke research fellows and two healthcare professionals (a nurse and a physiotherapist). The draft Q-set was also presented to a Stroke Consumer Research Advisory Group (CRAG) as part of patient and public involvement. Both subject experts and members of the CRAG were asked to review the draft Q-set and determine if any items were considered irrelevant and highlight any topics that needed to be covered that weren’t already included. They were also asked to comment on the phrasing and terminology used within the statements to ensure that the Q-set was accessible for stroke survivors. To aid the process of reducing the items, subject experts and members of the CRAG were also asked to identify the items that were most important to include and those that could either be removed or combined with other statements. All suggestions from the reviews along with any edits or amendments made to the Q-sets following the reviews process were documented and kept for reference. The stroke survivor Q-set was eventually refined and reduced to 34 items, with the finalised items shown in Table Six.

Table 6 Stroke survivor 34-item Q-set

1	I’m scared of moving in case I have another stroke
2	Problems with my mobility do not stop me from exercising
3	Setting goals and recording progress is a good way of trying to increase physical activity
4	There is no point in trying to move as I cannot do as much as I used to
5	Physiotherapists should be moving me, it’s their job
6	Reducing time spent sitting or lying down is impossible in stroke survivors with severe mobility problems
7	Moving regularly is important to reduce my risks of having another stroke
8	Movement is different to exercise
9	Moving regularly reduces my pain
10	My family, friends and carers stop me from moving
11	I find being able to care for myself difficult because of my physical problems
12	I have no choice but to sit or lie-down for long periods
13	Moving regularly helps to improve and maintain physical functioning after stroke
14	Exercise is important after a stroke
15	Without family, friends and carers I would not be able to keep active
16	My lack of confidence affects how much I move
17	The risk of falling stops me from trying to move
18	I am a hindrance to my family and friends because I cannot move without assistance
19	I’m happy to sit or lie down without moving
20	Fatigue limits how much I can move throughout the day
21	It is important not to spend a long time sitting or lying down without moving
22	You sometimes have to force yourself to move when you do not have the motivation
23	Reducing the periods of time I spend just sitting or lying down would make me happier
24	Practising exercises and tasks is vital to improving mobility and increasing movement
25	You cannot be physically active if you are not moving your legs
26	You cannot be healthy if you are inactive
27	The majority of my free time is spent sitting or lying down without moving
28	Being unable to move unaided does not mean I cannot be useful
29	To be independent you must be able to walk and stand without help
30	Sometimes I cannot be bothered to move
31	An active social life does not depend on being able to move without help
32	I am not embarrassed by my mobility problems
33	Doing jobs around the house is not physical activity
34	I find it difficult to accept that I cannot move like I used to before my stroke

Once the stroke survivor Q-set was finalised, it was modified to create the carer Q-set. Ten statements taken from the stroke survivor Q-set, with no changes made to the phrasing were included. These items were general knowledge statements and therefore did not require refinement to make them specific to the carers. Thirteen statements were adapted in order to make them relevant to the different participant group. Although the phrasing of the statements was changed, concepts behind the statements were retained. Eleven statements from the stroke survivor Q-set were removed and replaced with carer specific statements. The majority of the new statements were adapted from items taken from the sampled concourse that were excluded during the preliminary selection of the Q-set. The editing process of the items was constantly discussed with the research team and the draft Q-set was also reviewed by subject experts. The final 34-items included in the carer Q-set are listed in Table Seven.

Table 7 Carers’ 34-item Q-set

1	I limit their movements to reduce their risk of falls
2	It is important not to spend a long time sitting or lying down without moving
3	Exercise is important after a stroke
4	They have no choice but to sit or lie-down for long periods
5	Moving regularly is important to reduce the risks of having another stroke
6	I often have to remind them to move
7	Setting goals and recording progress is a good way of trying to increase physical activity
8	Having problems with mobility should not stop them from exercising
9	Practicing exercises and tasks is key to improving mobility and increasing movement
10	Moving more would allow them to be more independent
11	They are unable to care for themselves because of their physical problems
12	They do not need long term physiotherapy and occupational therapy input to increase their movement
13	An active social life does not depend on being able to move without help
14	We were given information after their stroke about the importance of keeping moving and breaking up long periods of sitting or lying
15	Reducing time spent sitting or lying down is impossible in stroke survivors with severe mobility problems
16	I’m unsure about how to increase their movement safely
17	Moving regularly helps to improve and maintain physical functioning after stroke
18	It is easier not to include them in activities because of their mobility problems
19	They will not move independently without my encouragement and support
20	Sometimes it’s hard to motivate them to move
21	I find it difficult to accept that they cannot move like they used to before their stroke
22	Their mobility problems have made them dependent on me
23	I regularly try to motivate them to increase their activity.
24	It is hard to support someone with mobility problems after stroke
25	It’s the physiotherapists job to get them moving
26	You cannot be healthy if you are inactive
27	Doing jobs around the house is not physical activity
28	There is no point in them trying to move as they cannot do as much as they used to
29	Fatigue limits how much they can move throughout the day
30	I’m scared of them moving too much in case they have another stroke
31	The fear of falling stops them from trying to move
32	I would be happier if they could move more
33	Without family, friends and carers stroke survivors would not be able to keep active
34	Movement is different to exercise

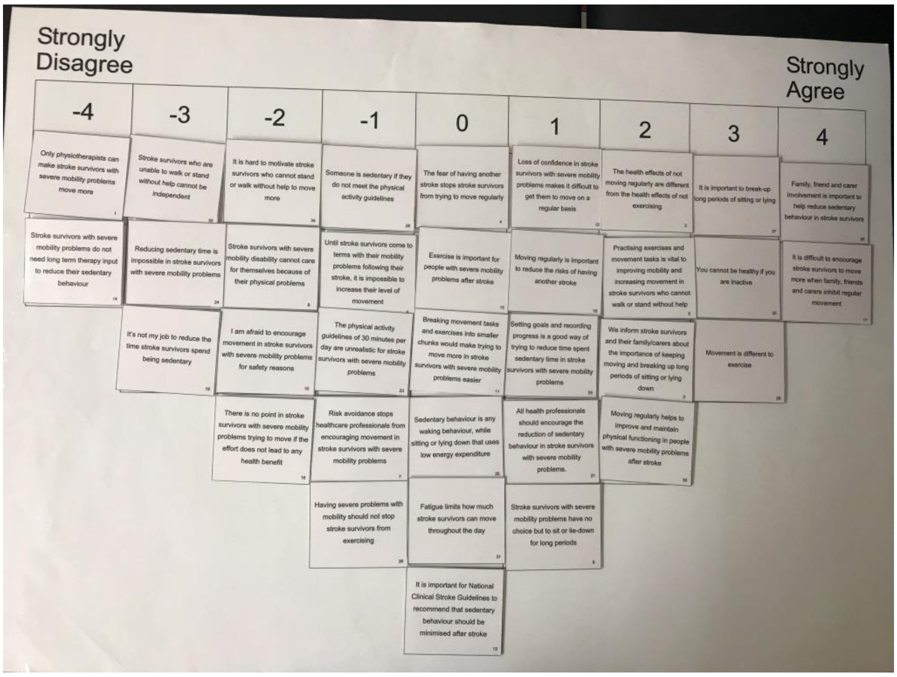
In order to construct the healthcare professionals' Q-set, the nine key themes and sub-categories identified during the first stage of Q-set construction were reviewed and assessed for appropriateness for the population group. The framework was also checked for omissions that were specific to healthcare professionals and their potential viewpoints on movement and sedentary behaviour. The next step involved looking over the stroke survivor and carer Q-sets to identify the statements that applied to healthcare professionals and therefore should be kept, those which needed to be removed and those that required re-wording. Four general knowledge statements taken from the stroke survivor Q-set were retained, with no changes to the wording. Eighteen statements taken from the stroke survivor Q-set were adapted to be included. The wording of the statements was changed to be applicable for healthcare professionals, whilst the concepts behind the statements were retained. Two statements were adapted from items included in the carers' Q-set. The preliminary sampled 64-item stroke survivor Q-set was reviewed and three items that were general knowledge statements were included. The academic literature was again reviewed for healthcare professional specific information, with seven additional items being added. Again, the 34-item Q-set was then sent to subject experts to review. They were reminded to comment on the readability and terminology of the statements rather than the accuracy of the content. Discussion with healthcare professionals from the subject expert group identified that terms focused on participants' knowledge of sedentary behaviour were needed to distinguish what staff members perceive sedentary behaviour to be. The two statements; 'Sedentary behaviour is any waking behaviour, while sitting or lying down that uses low energy expenditure' and 'Someone is sedentary if they do not meet the physical activity guidelines', were included to elicit staff participants' understandings of sedentary behaviour. It was also agreed that statements should include more specific terminology, including 'sedentary behaviour', as the staff members would be more likely to be more familiar with them. The 34-item healthcare professional Q-set is presented in Table Eight.

Table 8 Healthcare Professionals' 34-item Q-set

1	Only physiotherapists can make stroke survivors with severe mobility problems move more
2	We inform stroke survivors and their family/carers about the importance of keeping moving and breaking up long periods of sitting or lying down
3	The health effects of not moving regularly are different from the health effects of not exercising
4	The fear of having another stroke stops stroke survivors from trying to move regularly
5	Practising exercises and movement tasks is vital to improving mobility and increasing movement in stroke survivors who cannot walk or stand without help
6	Until stroke survivors come to terms with their mobility problems following their stroke, it is impossible to increase their level of movement
7	Risk avoidance stops healthcare professionals from encouraging movement in stroke survivors with severe mobility problems
8	Stroke survivors with severe mobility disability cannot care for themselves because of their physical problems
9	Stroke survivors with severe mobility problems have no choice but to sit or lie-down for long periods
10	I am afraid to encourage movement in stroke survivors with severe mobility problems for safety reasons
11	Breaking movement tasks and exercises into smaller chunks would make trying to move more in stroke survivors with severe mobility problems easier
12	Loss of confidence in stroke survivors with severe mobility problems makes it difficult to get them to move on a regular basis
13	It is important for National Clinical Stroke Guidelines to recommend that sedentary behaviour should be minimised after stroke
14	Stroke survivors with severe mobility problems do not need long term therapy input to reduce their sedentary behaviour
15	Exercise is important for people with severe mobility problems after stroke
16	There is no point in stroke survivors with severe mobility problems trying to move if the effort does not lead to any health benefit
17	It is difficult to encourage stroke survivors to move more when family, friends and carers inhibit regular movement
18	Moving regularly is important to reduce the risks of having another stroke
19	It's not my job to reduce the time stroke survivors spend being sedentary
20	Sedentary behaviour is any waking behaviour, while sitting or lying down that uses low energy expenditure
21	All health professionals should encourage the reduction of sedentary behaviour in stroke survivors with severe mobility problems.
22	You cannot be healthy if you are inactive
23	The physical activity guidelines of 30 minutes per day are unrealistic for stroke survivors with severe mobility problems
24	Reducing sedentary time is impossible in stroke survivors with severe mobility problems
25	Setting goals and recording progress is a good way of trying to reduce time spent sedentary time in stroke survivors with severe mobility problems
26	Having severe problems with mobility should not stop stroke survivors from exercising

27	It is important to break-up long periods of sitting or lying
28	Someone is sedentary if they do not meet the physical activity guidelines
29	Movement is different to exercise
30	Moving regularly helps to improve and maintain physical functioning in people with severe mobility problems after stroke
31	Fatigue limits how much stroke survivors can move throughout the day
32	Stroke survivors who are unable to walk or stand without help cannot be independent
33	Family, friend and carer involvement is important to help reduce sedentary behaviour in stroke survivors
34	It is hard to motivate stroke survivors who cannot stand or walk without help to move more

Once the stroke survivor and carer Q-sets were finalised, the statements and Q-sort process were piloted with stroke survivors and carers who would not be involved in the research study. During the piloting stage, the formatting of the Q-methodology resources was tested. Different sized cards with different font sizes and different sized Q-sort grids were presented and trialled to establish the optimum size. It was important to have cards large enough to allow suitable font sizes for participants to read the statements easily. Whilst the Q-sort grid had to be of a suitable size for the cards to be sorted and arranged onto the grid, it also had to be an appropriate size to transport and take into participants' houses. Following the piloting it was decided that the Q-set cards should be 8x7cm in size to allow the statements to be printed in Arial size 20 font. This resulted in a grid size of 55x77cm that was again deemed acceptable by the pilot participants. It was also thought that laminating both the grid and statement cards to ensure durability and to withstand multiple uses would be a good idea. As the Q-sorts were to be conducted in different environments including participants' homes where there may or may not have been an appropriate surface (i.e. a table) to lay the grid out, the cards and grid it was suggested that they would have Velcro attached, to allow movement of the grid without disrupting the placement of the cards that had been sorted (Figure Seventeen). Again, these formatting options were presented during the piloting stage and received positive feedback, resulting in the final presentation of the Q-sort resources being laminated and including Velcro.



Strongly Disagree

Strongly Agree

-4	-3	-2	-1	0	1	2	3	4
Only physiotherapists can make stroke survivors with severe mobility problems move more	Stroke survivors who are unable to walk or stand without help cannot be independent	It is hard to motivate stroke survivors who cannot stand or walk without help to move more	Someone is sedentary if they do not meet the physical activity guidelines	The fear of having another stroke stops stroke survivors from trying to move regularly	Loss of confidence in stroke survivors with severe mobility problems makes it difficult to get them to move on a regular basis	The health effects of not moving regularly are different from the health effects of not exercising	It is important to break-up long periods of sitting or lying	Family, friend and carer involvement is important to help reduce sedentary behaviour in stroke survivors
Stroke survivors with severe mobility problems do not need long term therapy input to reduce their sedentary behaviour	Reducing sedentary time is impossible in stroke survivors with severe mobility problems	Stroke survivors with severe mobility disability cannot care for themselves because of their physical problems	Until stroke survivors come to terms with their mobility problems following their stroke, it is impossible to increase their level of movement	Exercise is important for people with severe mobility problems after stroke	Moving regularly is important to reduce the risks of having another stroke	Practising exercises and movement tasks is vital to improving mobility and increasing movement in stroke survivors who cannot walk or stand without help	You cannot be healthy if you are inactive	It is difficult to encourage stroke survivors to move more when family, friends and carers inhibit regular movement
	It's not my job to reduce the time stroke survivors spend being sedentary	I am afraid to encourage movement in stroke survivors with severe mobility problems for safety reasons	The physical activity guidelines of 30 minutes per day are unrealistic for stroke survivors with severe mobility problems	Breaking movement tasks and exercises into smaller chunks would make trying to move more in stroke survivors with severe mobility problems easier	Setting goals and recording progress is a good way of trying to reduce time spent sedentary time in stroke survivors with severe mobility problems	We inform stroke survivors and their family/carers about the importance of keeping moving and breaking up long periods of sitting or lying down	Movement is different to exercise	
		There is no point in stroke survivors with severe mobility problems trying to move if the effort does not lead to any health benefit	Risk avoidance stops healthcare professionals from encouraging movement in stroke survivors with severe mobility problems	Sedentary behaviour is any waking behaviour, while sitting or lying down that uses low energy expenditure	All health professionals should encourage the reduction of sedentary behaviour in stroke survivors with severe mobility problems.	Moving regularly helps to improve and maintain physical functioning in people with severe mobility problems after stroke		
			Having severe problems with mobility should not stop stroke survivors from exercising	Fatigue limits how much stroke survivors can move throughout the day	Stroke survivors with severe mobility problems have no choice but to sit or lie-down for long periods			
				It is important for National Clinical Stroke Guidelines to recommend that sedentary behaviour should be minimised after stroke				

Figure 17 Example Q-grid with statement cards attached with Velcro

4.6. Methods

4.6.1. Ethical considerations

The study protocol, information sheets, consent forms and all other relevant study documentation were submitted to and approved by Yorkshire and Humber - Leeds East Research Ethics Committee on 4th May 2017 (REC reference – 17/YH/0106, IRAS ID – 223528). This was part of the Health Research Authority (HRA) approval process which was granted on 11th May 2017 (Appendix E and F).

4.6.2. Study design

4.6.2.1. Sample identification

The following eligibility criteria were adopted during recruitment of stroke survivors, informal carers and healthcare professionals to ensure an appropriate participant group were included in the study.

4.6.2.1.1. Eligibility criteria

Inclusion criteria

Stroke survivors were eligible for the study provided they:

- Were aged over 16 years
- Had a confirmed primary diagnosis of stroke
- Had a severe mobility disability (Functional Ambulation Classification's (FAC) categories 1, 2 and 3 - unable to stand or walk without the help of at least one person (Holden et al., 1984))
- Were returning home/ live at home independently or with support from an informal carer (who may be a spouse, child over 18 years), or other family member
- Were able to participate in the Q-study (determined by the completion of both the 6 Item Cognitive Impairment Test (6 CIT) and Frenchay Aphasia Screening Tool (FAST) with scores that met the agreed cut off points (Section 4.6.2.1.3) and the ability to place statements independently or with the help of either a carer/researcher)
- Were able to provide informed consent

Informal carers were eligible for the study provided they:

- Were aged over 16 years
- Would be / were regularly supporting a stroke survivor who met the above eligibility criteria by providing care or support in the stroke survivors' own home
- Were able to participate in the Q-study (assessed through discussion with carer prior to seeking informed consent and prior to participation in the Q-study and interview)
- Were able to provide written informed consent

Health care professionals were eligible for the study provided they:

- Were a registered nurse or registered therapist (physiotherapist, occupational therapist) or physician or healthcare assistant or therapy assistant (occupational therapist assistant, physiotherapist assistant, technical assistant or any variant of this title)
- Had a caseload including adults with post-stroke severe mobility disabilities (Unable to stand or walk without the help of at least one person)
- Were willing to participate in the Q-study
- Were willing to provide written informed consent

4.6.2.1.2. Sample size

Stroke survivors and informal carers were purposively sampled to ensure that stroke survivors with a range of time post stroke, a range of ages and a range of post-stroke mobility impairment severities were recruited. Similarly, healthcare professionals were also purposively sampled to reflect a range of job roles (nurses, physiotherapists, occupational therapists, therapy assistants), experience and services (community, private). The study aimed to recruit approximately 20 stroke survivors, 20 informal carers and 20 healthcare professionals.

As the study aimed to understand and examine participants' beliefs about sedentary behaviour and movement in stroke survivors who have a severe mobility and are living at home, it was anticipated that recruiting 60 participants across the three participant groups would provide sufficient depth and detail in the data to allow meaningful comparison across the participant groups. This decision was also made through discussions with the supervisory team, with consideration given to the difficulty in identifying these stroke patients and the scope and timescales for the project. .

4.6.2.1.3. Screening – Cognitive impairments, Language deficit and Capacity

In order to take part in the Q-methodological study, participants had to be able to comprehend the instructions for arranging the Q-set in rank order, the meaning of the statements and to be able to place the statements in their preferred order (physical assistance could be provided for this part of the Q-sort as long as the participant was able to direct the assistant to place the statements in the participant's preferred order). To help establish whether participants understood and would be able to complete the study, the researcher used the 6-item Cognitive Impairment Test (6 CIT) (Brooke and Bullock, 1999) (Appendix G) and Frenchay Aphasia Screening Test (FAST) (Enderby et al., 1986) (Appendix H) to screen potential participants for cognitive impairment and language deficits respectively. All potential stroke survivor participants were screened by the researcher using the 6-CIT and FAST screening tools before they were invited to take part in the study and provided written consent.

The screening tools are brief and simple validated assessment tools that have been used effectively with stroke survivors (Cullen et al., 2007; Woodford and George, 2007; Salter et al., 2006). The 6CIT produces a score of between 0-28 with a score of 0-7 interpreted as probably normal and scores of 8 or greater interpreted as significant cognitive impairment. The FAST tests across four domains; comprehension, expression, reading and writing and produces a score out of a total of 30. The presence of aphasia is indicated if the participant scores below 27 points (age 20-60) or 25 points (age 61+). For the purpose of the study, participants who received a score of 8 or greater on the 6-CIT and/or below 27 (age-60) or below 25 (age 61+) were excluded from the study.

The importance of inclusiveness in healthcare research in general, and in stroke care in particular is acknowledged. Using the screening tests sought to ensure that stroke survivors with mild cognitive impairment or aphasia were not unnecessarily excluded, as these groups are often under-represented in stroke research. However, including participants who lacked capacity was not believed to be essential to answer the research question. It was considered inappropriate to include those who lacked capacity on the basis that such individuals may not only be unable to comprehend the purpose of the study and the instructions to complete the Q-sort, but may also be caused unnecessary distress as a result of being unable to participate in the Q-sort. All participants were assumed to have capacity to consent , unless it was established that they lacked capacity to consent (*Mental Capacity Act 2005: Code of Practice*, 2007). If capacity couldn’t be established, participants were informed that the study would not be suitable for them but thanked for their time.

4.6.2.2. Recruitment

In total, five NHS Trusts, including both acute and community teams and one private neurophysiotherapy practice acted as recruiting sites for the study. In order to recruit a sample of stroke survivors with severe mobility disability and carers from a range of time points post stroke, a number of overlapping strategies were adopted. Stroke survivors and carers were identified using either a consent to researcher contact method, recruited on the hospital wards, identified using a research register or through voluntary organisations.

Recruiting using consent to contact method

Stroke survivors with severe mobility disabilities who matched the inclusion criteria were identified by treating healthcare professionals from the NHS sites and the private neurophysiotherapy practice and provided with a study information pack. The information pack contained an invitation letter from the researcher, a summary information sheet for the stroke survivor, a summary information sheet for the informal carer, a consent to researcher contact form and a pre-paid reply envelope. If the potential participant was interested in taking part they were to complete the consent to researcher contact form and return it directly to the researcher using the pre-paid reply envelope.

Recruiting on the hospital wards

Treating healthcare professionals identified potentially eligible participants from the inpatient stroke survivors and their informal carers on the stroke wards. The potential participants were identified when they were due to be discharged from the wards. Once identified, the clinically based staff approached the stroke survivors and their informal carers to briefly introduce the study and ask if they would be happy for a researcher to talk to them about the study in more detail. If they agreed, the healthcare professional then introduced the researcher to the stroke survivor and their carers (if appropriate). The researcher then followed-up the patient once they were discharged from the hospital.

Research Register

The Academic Unit of Elderly Care and Rehabilitation (AUECR) at Bradford Teaching Hospitals NHS Foundation Trust holds a database of stroke survivors discharged into the community who have consented to be contacted regarding their participation in future research studies. Before correspondence was sent out, the survival status and addresses of the stroke survivors were checked using the Summary Care Record on the NHS Spine Portal System. The researcher posted out a covering letter, a summary information sheet for stroke survivors, a summary information sheet for informal carers, a consent to researcher contact form and a pre-paid reply envelope. Similarly to the consent to contact method described before, if the potential participants were interested in taking part in the study they would return the consent to researcher contact form to the researcher.

Although the research register does not record severity of stroke, the wording of the letter clearly explained the aim of the project and the specific inclusion criteria (i.e. unable to stand or walk without the help of at least one person). The consent to researcher contact form also included a screening question asking the stroke survivor to indicate their level of ambulation by ticking the box that applied to them. This was included to help the researcher to identify eligible potential participants.

Recruitment through voluntary organisations

Stroke survivors with severe mobility disabilities who matched the inclusion criteria were identified by voluntary organisations (stroke clubs) and provided with a study information pack. The information pack contained an invitation letter from the researcher, an information sheet, a consent to researcher contact form and a pre-paid reply envelope. Similar to the ‘recruiting using consent to contact method’ method described before, if the potential participants were interested in taking part in the study they were asked to return the consent to researcher contact form to the researcher. Additionally, voluntary organisations were also able to advertise the research study in their office/clubs, on their websites and/or via social media.

Healthcare professionals were identified through the recruiting NHS, private practice and voluntary organisation sites. Information sheets were provided to the staff members in order for them to consider participation in the study.

4.6.3. Consent

For all participants (stroke survivors, carers and healthcare professionals), informed consent was obtained prior to starting the Q-sort exercise. Participants were fully supported to provide informed consent during the researcher visit (stroke survivors and carers) and research appointment (healthcare professionals). The researcher encouraged the participant to ask questions and also asked the participant questions to ensure that they understood what was being asked of them. Written consent was obtained after eligibility had been confirmed and the purpose of the study had been explained in full. Each point of the consent form was read out loud to the potential participant before it was signed to ensure that any questions were answered and that the potential participant was happy to proceed.

4.6.4. Data collection

Participants were presented with the 34-item Q-set tailored to their participant group in random order (each printed on a separate card). Participants were required to rank the statements from strongly agree to strongly disagree in relation to each other, from their own individual perspectives based on their beliefs or judgements about the statements. This process was completed in stages, with participants initially being asked to read each statement individually and sort them into those they agree with, those they disagree with and those that they categorise as neutral (i.e. non-relevant statements, have no strong feelings, not sure). Once the 34 items were sorted into the three piles, participants ranked the statements and placed the cards on a grid with a quasi-normal distribution ranging from +4 to -4. Each pile was sorted individually, starting with the agree statements, then the statements sorted as disagree and finally the neutral pile (Figure Seventeen).

Each Q-sort took place in a one-to-one session with the researcher at a place of the participant’s choosing. Each participant was provided with instructions and guidance on how to complete the sort, with the condition of instruction stating; ‘What are your own experiences and perspectives of movement and being sedentary after stroke? Please sort the provided statements in order to best describe your view.’

To aid interpretation of the Q-sorts, participants were encouraged to talk about the placing of the statements and to make comments about the statements and their perceived meaning whilst conducting the Q-sort. An informal discussion also took place immediately after the participant had finished placing the statements, to gain additional information regarding the participants’ perceived meanings of the statements and explanations for the placing of the statements on the grid.

Both the Q-sort process (to record participants’ comments and thoughts during the sorting process) and the informal discussion with the researcher were audio recorded, with permission for this being obtained as part of the consent process. For the purpose of the audio recording, the researcher often repeated phrases or identified the statement number that the participant was referring to in order to produce a meaningful and useful record that could be used for interpretation. Upon completion of the Q-sort, a photograph was taken of the anonymous grid as a record of the placement of statements, again with permission for this being obtained during the consent process.

4.6.4.1. Q-methodological study: stroke survivors and carers

Participants were able to choose the venue and time for the Q-sort. It usually took around 20 minutes for the researcher to explain the study, assess the eligibility of the participants using the two screening tools (6-CIT and FAST) and take informed consent. To set-up, explain and conduct the Q-sort typically took between 40 – 60 minutes, although this time was extended if more time was required to accommodate the need for additional breaks.

Prior to participants sorting the statements, they were asked to complete the data collection form that was included in a response booklet (Appendix J and K). This form collected demographic data about the participants and included; age, gender, ethnicity, time since stroke, length of hospital stay, place of residence (stroke survivor only), relation to stroke survivor and amount of support provided (carer only). The information collected about the participants helped to aid the analysis and interpretation of the Q-sort data.

The researcher also determined the stroke survivor’s level of ambulation using the Functional Ambulation Classification (FAC) (Holden et al., 1984) (Figure Three) and their Barthel Index of Activities of Daily Living score (Collin et al., 1988); in order to determine their current level of ability and therefore independence for ADLs (e.g. grooming, feeding and bathing), and documented the scores on the stroke survivor response booklet.

Once stroke survivors had completed the Q-sort, their informal carers, if appropriate, were then asked to complete the Q-sort from their own perspective. If the carer preferred to complete the study on a different occasion, the researcher arranged an appropriate time for the carer to conduct the study.

4.6.4.2. Q-methodological study: Healthcare professionals

The researcher worked with each of the individual sites to agree a process that would work best for them in order for staff to participate in the Q-study. The researcher ensured to work flexibly around staff members shifts and clinical commitments. Two strategies were adopted by the sites to organise the staff Q-sorts; two sites agreed for the researcher to be present on site for a half or whole day to allow staff members to ‘drop-in’ and participate at different times individually, with staff at two other sites arranging individual appointments with the researcher that best suited their work commitments. Typically, it took between 30-45 minutes to set-up, explain and conduct the Q-study with the healthcare professionals.

Prior to sorting the statements, participants were asked to complete the demographic data collection form that was included in the response booklet (Appendix L). The information about the healthcare professionals was collected to aid analysis and interpretation of the Q-sort data and included; age, gender, ethnicity, profession, grade, length of experience in stroke care and time since qualifying.

4.6.5. Data analysis

The data generated by the study was analysed with the support of Dr Janet Holt (Senior Lecturer and Q-methodologist at the University of Leeds). Data was anonymised before being analysed. As has been highlighted briefly in sections 4.4.2.3 and 4.4.2.4, analysis of data from a Q-methodology study is a multi-stage process and includes; factor extraction, factor rotation and interpretation.

Non-identifiable data (linked to a participant ID number) from the participants' Q-sorts was entered into PQMethod, a dedicated software package designed for analysis of data in Q-methodological studies. First, a correlation matrix is created through the intercorrelation of each Q-sort with the other Q-sorts. This describes the level of agreement and disagreement between the individual sorts, namely, the degree to which the points of view of the individual participants are similar or dissimilar (Van Exel and De Graaf, 2005). In order to identify the number of different natural groupings of Q-sorts for being similar or dissimilar, the correlation matrix is subjected to data-reduction through factor extraction. There are two common factor extraction techniques that are used by Q-methodologists, centroid factor analysis and principal components analysis (PCA), with both being available options through the PQMethod software. Although ultimately the two methods will ordinarily produce very similar outputs, the two techniques are very distinct with PCA not being a form of factor analysis (Watts and Stenner, 2012). Principal components analysis resolves into a single, mathematically superior solution that should be accepted, whereas centroid factor analysis allows the best solution to be explored and theoretically informed as it leaves all possible solutions open for review (Watts and Stenner, 2005). For the purpose of the present study, the analysis options were reviewed with a Q-methodologist and principal components analysis was deemed a suitable factor extraction method and was therefore selected for use in the analysis. PQMethod software programme provides eight un-rotated factors as standard, therefore an analysis of the un-rotated factors was completed in order to determine the number of factors to rotate and include in the study. In order to help decide how many factors should be retained in the factor solution, objective criteria were applied. Eigenvalues indicate a factor's strength and potential explanatory power of an extracted factor. Typically, factors are only retained using the Kaiser-Guttman criterion of 1.00 or above (Guttman, 1954; Kaiser, 1960), as an eigenvalue of less than 1.00 accounts for less study variance than a single Q-sort (Watts and Stenner, 2012).

Two further parameters were employed in order to guide the decision; two (or more) significantly loading Q-sorts and Humphrey's rule. The first method accepts factors that have two or more significant factor loadings. A significant factor loading at the 0.01 level was calculated at 0.44 ($= 2.58 \times \left(1 \div \sqrt{no.of\ items\ in\ QSet}\right)$), however following an initial review of the factor matrices of all three participant groups, a high number of confounding Q-sorts were observed. It was therefore decided to increase the significant factor loading criterion to 0.50, as per the guidance in Watts and Stenner (2012) in order reduce the number of significant factor loadings on the factor matrices. Another method for aiding the decision is Humphrey's rule, which states that a factor is significant if the two highest loadings multiplied exceed twice the standard error ($standard\ error = 1 \div \sqrt{no.of\ items\ in\ QSet}$)(Brown, 1980). Twice the standard error for the present study was 0.34.

Although the objective criteria were applied to the data, they were used as a guide to help aid the decision of how many factors to retain instead of making the decision. The factor matrixes were also reviewed during the process to assess how many significant factor loadings were present across the factors and to assess the total number of participants accounted for in each of the solutions. Additionally, a qualitative exploration of the data was also conducted with preliminary factor arrays for the rotated factor solutions being plotted to assess the variability across the factors in each of the factor solutions. Factor arrays were created using the z scores for each individual item to produce a single Q-sort configured to represent the viewpoint of each factor (Watts and Stenner, 2012). Following a review of the objective criteria and qualitative exploration, the most appropriate factor-solution was decided for each of the three participant groups.

Factor extraction was followed by factor rotation. Similarly to factor extraction, there are two main methods for the rotation of factors; by-hand rotation and varimax rotation. Factor rotation ensures that each factor offers the most meaningful view of the subject matter and allows identification of Q-sorts whose viewpoint closely approximates that of a particular factor (Watts and Stenner, 2012). Often Q-methodologists prefer by-hand rotation for its theoretical approach and ability to reflect the substantive reality of the situation under investigation. Although the subjectivity of by-hand rotation is one of the advantages of the technique, it is also raises suspicion of its unreliability as a result of researcher bias (Watts and Stenner, 2012; Watts and Stenner, 2005). As varimax rotation aims to ensure that each Q-sort significantly loads onto only one factor, the overall solution maximises the amount of study variance explained by the factors (Watts and Stenner, 2005). Varimax rotation was used in the present study for factor rotation.

Following factor rotation, factor estimates (i.e. an estimate of the factor's viewpoint), were created by weighted averaging of the Q-sorts that load significantly on the individual factors alone (Watts and Stenner, 2005). This process was done within the PQMethods software, with the researcher identifying the significantly loaded Q-sorts through a manual process of 'flagging'. A total weighted score for each item in the factor estimate was calculated with a higher score indicating a higher value attributed to the item by the factor. In order to allow cross-factor comparisons, the total weighted score for each item was converted into a z-score from which the final factor array; a single Q-sort displaying the best estimate viewpoint of the factor, was created. The factor arrays produced were then subjected to interpretation.

The final stage in the analysis process was interpretation of the factors, which aims to tease out the separate accounts underpinning the patterns of Q-sorts, according to their similarities and differences (Baker et al., 2006). Interpretation involves the identification of interesting patterns when comparing and contrasting the statements' position within each factor using the factor arrays. In order to achieve a holistic interpretation of the entire item configuration within each factor, the crib sheet method devised and described in Watts and Stenner (2012) was utilised. The crib sheet was created as a method of organisation that ensures that nothing is overlooked or missed during interpretation because it forces engagement with every item within the factor not just those positioned at the extreme rankings (+4 and -4). The first draft of the crib sheet identified the highest and lowest ranked items in the factor array (+4 and -4), and the items that were ranked either higher or lower than the other factors. Once the four categories were identified during the first draft, a second draft was created whereby other items of interest or additional highly ranked items were identified. Consensus statements are the items whose rankings do not discriminate between factors. These statements are often important to consider during interpretation of the factors to assess the shared ranking of items across all of the factors and were incorporated into the crib sheet. The crib sheets allowed a picture to be created of the factor's viewpoint and hypotheses to be suggested in order to try and understand the meaning behind the item's placement on the factor arrays.

In order to support and aid the interpretation process, the participant demographic information as well as the participants' comments from the informal discussions were reviewed. The audio recorded Q-sort discussions were transcribed and reviewed by the researcher. Participant statements that were attributed to specific items were identified and noted to help aid the interpretations of the factors and specific item placement using the crib sheets produced for each factor.

4.7. Conclusion

This study aimed to explore and understand the perspectives of stroke survivors with severe mobility disability, their carers and healthcare professionals involved in their care. A Q-methodology study was chosen as it allows the subjective views of the participants to be studied in a systematic manner and it explores the perspectives of a subject rather than the viewpoints of a population of people (Risdon et al., 2003). Q-methodology has been quite widely used in health and social care research and has proven acceptable to participants from a range of backgrounds.

This chapter described Q-methodology and explained the rationale for choosing the methodology for the study. It described the methods for conducting the study including; development of the Q-set, recruitment, data collection and data analysis. The findings from the study are presented and discussed in Chapter Six.

Chapter 5 - Q Methodology Study Results

5.1. Introduction

In this chapter, the findings from the Q-methodological study described in Chapter Five are presented and discussed. These findings are based upon the Q-sorts and informal interviews undertaken with a total of 49 participants. Details of the Q-methodology process and the data collection and analysis steps are described in the previous chapter.

As this study aimed to explore and understand the perspectives of stroke survivors with severe mobility disability, their carers and healthcare professionals involved in their care in relation to sedentary behaviour, all three participant groups are represented in the study findings. With the Q-sets (sets of statements) being tailored to each participant group, as previously described in Chapter 5, individual participant group analyses were conducted and are reported in this chapter.

Following a description of the individual participant groups' study findings and a discussion of how these compare across the three groups (stroke survivor, carer and healthcare professional), reflections are then made on the methods used in this study and the implications for future work.

5.2. Findings

5.2.1. Stroke Survivors

Seventeen participants consented and participated in the study. Characteristics of the seventeen participants are detailed in Table Nine. Three participants were recruited from the Research register, three from a private neurophysiotherapy practice, six from three NHS sites and five were recruited from a community stroke group. The gender split of participants in the study was almost equal with eight male participants and nine female participants, with an average age of 73.7 years old (SD=9.47). Time since stroke ranged from three months to seven years, with only one stroke survivor having had multiple strokes. Length of hospital stay varied between seven days and fourteen months indicating a range of stroke severities. Eight participants were categorised as level one on the Functional Ambulation Classification denoting an inability to ambulate, four participants were categorised as level two therefore requiring continuous manual contact of at least one person during ambulation on level surfaces to support body weight and/or maintain balance. The remaining five participants were categorised as level three indicating a requirement of continuous or intermittent light touch manual contact from one person during ambulation on level surfaces in order to assist balance or coordination (Holden et al., 1984). The stroke participants scored between two to sixteen on the Barthel Index of Activities of Daily Living (ADLs), typically with lower levels of independence for the ADLs corresponding with lower levels of mobility (i.e. lower FAC associated with lower Barthel Index Scores). The majority of participants resided in a bungalow, ground floor flat or lived downstairs in a house. Of the seventeen participants, eight had informal carers who also participated in the Q-study.

Table 9 Table of Characteristics – Stroke Survivors

Participant ID	Carer ID	Gender	Age	Ethnicity	Time since stroke	Length of Hospital stay	Place of residence	Level of Ambulation (FAC)	Barthel Index
S1	N/A	Male	68	British	1 year	14 days	Bungalow	3	14
S2	N/A	Female	65	British	4 years	7 days	Bungalow	3	15
S3	N/A	Female	65	British	2 years	7 days	House	3	15
S4	N/A	Female	73	British	5 years	4 months	Bungalow	2	11
S5	C5	Male	64	British	7 years	14 months	House lives downstairs	1	8
S6	N/A	Female	80	British	4 months	7 weeks	Bungalow	3	16
S7	C7	Female	85	British	11 months	5 months	Flat ground floor	2	10
S9	C9	Female	71	British	18 months	4 months	Flat ground floor	1	7
S10	C10	Female	67	British	8 months	4 months	House lives downstairs	1	8
S11	C11	Male	58	British	2 years	8 months	Bungalow	3	7
S12	C12	Male	91	British	6 months	19 weeks	Bungalow	1	2
S13	C13	Female	67	British	1st- 10 yrs 4 months 2nd- 3 months	2nd - 1 month 15 days	Flat ground floor	1	8
S15	N/A	Male	73	British	4 years 7 months	-	House lives downstairs	1	7
S16	N/A	Male	88	British	2 years 6 months	1 week	Bungalow	1	5
S17	N/A	Female	83	British	1 year 4 months	6 months	House lives downstairs	1	8
S18	N/A	Male	74	British	18 months	4 weeks	Bungalow	2	7
S19	C19	Male	81	British	3 years	9 months	Bungalow	2	13

5.2.1.1. Factors

In order to help decide how many factors should be retained in the factor solution, the process described in section 4.6.5 was followed. After an initial review of all eight factors, factors six, seven and eight all had eigenvalues less than 1.00 and were therefore discarded from the analysis. Similarly, although factor one had an eigenvalue of 5.47 therefore exceeding the cut-off criterion, as other factor solutions were available with the potential to explain the most study variance, it was decided to rule out a one-factor solution.

Only a two-factor and a three-factor solution met the three objective criteria, as displayed in Table Ten. Following a review of the objective criteria and qualitative exploration, it was decided that a three-factor solution was deemed the most appropriate for the stroke survivor data. The three-factor solution accounted for fourteen participants' Q-sorts. Three participants were not associated with the three-factor solution, with two Q-sorts being non-significant and not loading onto any factor and one confounding Q-sort that had significantly loaded onto both factor one and two.

Table 10 Quantitative summary of a two to five factor solution for stroke survivor data

Factor solution	**Eigenvalues greater than 1.00**	**Two significantly loading participants per factor**	**Humphrey's rule**	**Total number of participants accounted for in the solution (n=17)**	**Consensus statements**
2	Yes	Yes	Yes	14 (8, 6)	15
3	Yes	Yes	Yes	14 (7, 4, 3)	9
4	Yes	No	No	14 (6, 4, 3, 1)	5
5	Yes	Yes	No	15 (7, 2, 3, 1, 3)	1

Interpretation and explanation of the three-factor solution will be discussed in the next sections. Tables Eleven - Thirteen present the factors, including only statements that were most agreed (ranked +3 and +4) and disagreed (-3 and -4) with for each of the factors.

5.2.1.1.1. Factor One: Willing but less able

Factor one had an eigenvalue of 5.47 and explained 32% of the study variance. Seven participants loaded onto factor one. Participants comprised of four female and three male stroke survivors with an age range of 64 to 88 years old. Time since stroke varied in this group of stroke survivors between eleven months to seven years. Two stroke survivors scored at level one on the functional ambulatory classification (FAC), two at level two and three at level three, suggesting a range of ambulatory abilities.

Table 11 Patient Factor One: 'Willing but less able' (most strongly agree/disagree only)

Number	Statement	Rank
14	Exercise is important after a stroke	+4
16	My lack of confidence affects how much I move	+4
15	Without family, friends and carers I would not be able to keep active	+3
21	It is important not to spend a long time sitting or lying down without moving	+3
24	Practising exercises and tasks is vital to improving mobility and increasing movement	+3
1	I'm scared of moving in case I have another stroke	-3
6	Reducing time spent sitting or lying down is impossible in stroke survivors with severe mobility problems	-3
10	My family, friends and carers stop me from moving	-3
4	There is no point trying to move as I cannot do as much as I used to	-4
5	Physiotherapists should be moving me, it's their job	-4

These stroke survivors understood the importance of exercising after a stoke (statement 14: +4) and related moving regularly with improvement and maintenance of physical functioning after their stroke (statement 13: +2). They believed that practising exercises and tasks was vital in order for them to improve their mobility and adopted a 'practice makes perfect' attitude (statement 24: +3). Setting goals and recording progress was believed to be a good way of increasing their physical activity and a strategy that they found worked for them (statement 3: +2). They strongly disagreed that there was no point in trying to move because they couldn't do as much as they used to prior to their stroke (statement 4: -4). They felt that they shouldn't just give up and without practicing or trying they would never know what they were capable of achieving or make any progress. Their understanding of the importance of keeping active and their drive to keep moving may be explained by their belief that individuals cannot be healthy if they are inactive (statement 26: +1). Therefore in order for them to remain healthy they must try and remain as active as possible.

> *"No. I can't do as much as I used to but I like to have a go. If you have a go at doing something it does help but not doing anything it's you've just given up and I disagree, you shouldn't give up".* (Participant S3)

> *"No. You've got to try…because you must try. If you don't try you don't get anywhere."* (Participant S4)

Although the participants appreciated the importance of exercise after stroke, they also understood the problems of sedentary behaviour, believing that it is very important not to spend a long time sitting or lying down without moving (statement 21: +3). This belief was supported by their view that reducing sedentary behaviour is not impossible in stroke survivors with severe mobility problems (statement 6: -3). Although they acknowledged that it would be difficult to reduce time spent sitting or lying down due to their mobility problems, they believed that everyone should be able to do something to reduce sedentary behaviour.

> *"Well it's difficult to say, you know, it depends how active you're able to be, but I think I would have thought that most people would be able to do something."* (Participant S6)

Although this group acknowledged that they spent a lot of time being sedentary (statement 27: -1), unlike the other two factors, they felt that they were still being active by either moving their limbs, taking breaks from sitting or associating using their brains as being active, for example doing crosswords. This is supported by their view that people can still be active if they are not moving their legs (statement 25: -2). They are still able to move other parts of their bodies with some participants describing how they exercised while sitting down including taking part in chair aerobics.

> *"I am busy with my brain when I'm sitting all day."* (Participant S7)

> *"No, because you can move the rest of you if you can't move your legs can't you."* (Participant S6)

There was an overall agreement that they were not happy to sit or lie down without moving (statement 19: -2), these participants felt that reducing the periods of time that they spent just sitting or lying down would make them happier (statement 23: +2). Ultimately they were not happy with their situation and would prefer to be more active but explained that it was difficult for them because of their mobility problems. Out of the three factors, the participants loading on factor one disagreed most that they had no choice but to sit or lie-down for long periods (statement 12: -1). However, the placement of the statement close to the middle of the grid (-1) indicated that although they do have a choice, it is extremely hard work and takes more effort, planning and help to achieve it.

> *"You do have a choice of moving around. There's not such a thing as you don't have, you do, if you want to move around you get the willpower to do it. Might take a long time but at least if you get started then it will increase as it goes along."* (Participant S3)

All three factors suggested that stroke survivors with mobility problems find being able to care for themselves difficult as a result of their physical problems (statement 11: +2). However participants loading on factor 1 strongly emphasised the help and support that they required from family, friends and carers especially in relation to keeping them active and moving (statement 15: +3). Their reliance on family and friends to help them with day-to-day activities was also evident in their belief that to be independent they must be able to walk and stand without help (statement 29: +1), indicating that as they have problems with their mobility, they cannot be fully independent.

> *"I can't do anything for myself if they don't help…For the simple reason I can't walk and I can't grip."* (Participant S7)
>
> *"I'd be a lot more independent if I could walk. Go to the toilet on my own to start with and that is important to me."* (Participant S7)

They were extremely grateful for the help and support provided to them by their family members and friends but believed that they were a burden to their family as a result of the continued support needed (statement 18: +1). Stroke survivors very strongly disagreed that their families, friends and carers stopped them from moving (statement 10: -3) as from their experiences, they did not stop them but were instead integral in enabling them to keep moving and also trying to increase and improve their movement.

> *"Well I say I'm a hindrance and they say you're not…And I say it because I can't move without assistance."* (Participant S7)

> *"No I disagree with that one. I can't see families and friends and carers stop people moving when they're there to help. They're not there to stop them moving."* (Participant S3)

Unlike the other two factors, participants in factor one strongly agreed that their lack of confidence following their stroke affected how much they moved, with the statement being rated as +4 (statement 16:+4). Participant S6 especially believed that her lack of confidence affected her movements outside of her house with it limiting how much she got out of the house, but felt more confident moving around within her own home.

> *"My lack of confidence affects how much I move, now within the house that, it doesn't…But if I want to go out it does."* (Participant S6)

Participants in this factor also highlighted that fatigue (statement 20:+1) and the risk of falls (statement 17:+1) were barriers to them trying to move throughout the day with both statements being equally ranked as +1 on the Q-grid. Often participants described how they would feel extreme tiredness during the day and couldn't understand why as they hadn't done anything. The fear of falls was often a result of the participants' experience of falling following their stroke or knowing of other stroke survivors who had fallen. This links with their affected confidence with regards to movement and fear of falling discussed previously (statement 16: +4). It is not that the stroke survivors do not want to move but they are often afraid to. Participant S4 linked the fatigue that she regularly experienced with her fear of falls. When she was tired she was more at risk of falling and had in the past fallen and broken her shoulder, resulting in her being more afraid of moving and therefore limiting her movement.

> *"Yesterday I was ever so tired…So I sat and, I sat, just sat here and didn't even have the television, I was so tired. And I don't know why because I haven't done anything."* (Participant S4)

> *"Yes. I do sit down for a long time. I have no choice because I'll get tired and I'm frightened I'll fall. The thing is, you know, you're not frightened until you fall…and then when you fall you're a bit more careful aren't you."* (Participant S4)

> *"I would try more if I thought I wasn't going to fall."* (Participant S7)

Participants did not associate moving with increasing their risk of having another stroke, with the statement being ranked similarly to factor two at –3 (statement 1: -3). Some participants however described how they had an initial fear of moving in case they had another stroke early after having their stroke. This fear then disappeared over time once they realised that moving more may actually help them to reduce their risks of another stroke.

> *"Yeah. Well I was at first. That feeling's gone now."* (Participant S7)
>
> *"I mean I'm more likely to have one if I don't move aren't I?"* (Participant S6)

Participants that loaded onto this factor were the only ones who indicated that they were embarrassed by their mobility problems compared to the other two factors (statement 32: -2). All participants were embarrassed initially following their stroke, with some having continued feelings of embarrassment even many years following their stroke.

> *"I am sometimes embarrassed. You know, like I'll want to get up often in a public place and say, and tell everyone, 'I used to be normal, like you."* (Participant S5)

Factor one participants strongly disagreed that physiotherapists should be moving them as it is their job (statement 5: -4). The participants strongly believed that although it is the physiotherapists' job to help them to get moving, they have ultimately got to want to move and to continue to do it themselves. Physiotherapists can provide advice but as they are not an unlimited resource, with the stroke survivors receiving limited therapy once they were discharged, the participants believed that it was important for them to be driven and continue their recovery themselves.

> *"No it's not their job to move me, but it's their job to advise me isn't it?"* (Participant S6)
>
> *"I don't think it's because it's their job, it's because I want to."* (Participant S7)
>
> *"I should be moving myself."* (Participant S11)

5.2.1.1.2. Factor 2 – I'm still a person

Factor two had an eigenvalue of 2.12 and explained 12% of the study variance. Four participants significantly loaded onto the factor, with three female participants and one male participant with an age range of 67 to 71 years old. Similar to factor one, time since stroke varied in the group of stroke survivors with a range between three months and four years seven months. All participants scored level one on the functional ambulatory classification (FAC), indicating that all of the stroke survivors have severe mobility impairments and are therefore unable to ambulate.

Table 12 Patient Factor 2: 'I'm still a person' (most strongly agree/disagree only)

Number	Statement	Rank
28	Being unable to move unaided does not mean I cannot be useful	+4
34	I find it difficult to accept that I cannot move like I used to before my stroke	+4
11	I find being able to care for myself difficult because of my physical problems	+3
12	I have no choice but to sit or lie-down for long periods	+3
24	Practising exercises and tasks is vital to improving mobility and increasing movement	+3
1	I'm scared of moving in case I have another stroke	-3
10	My family, friends and carers stop me from moving	-3
26	You cannot be healthy if you are inactive	-3
4	There is no point trying to move as I cannot do as much as I used to	-4
18	I am a hindrance to my family and friends because I cannot move without assistance	-4

This group of stroke survivors found it extremely difficult to accept that they could not move like they used to before their strokes (statement 34: +4). It is not just the physical aspects of their mobility impairments that are hard to deal with, the psychological aspects are especially hard to deal with. Coping with what has happened is also hard as their strokes have resulted in huge changes to their lives.

> *"I do get weepy don't I [husband]…especially when I see people walking on that…it's because I could for 70 years and now I can't…It's getting your head round that."* (Participant S9)

> "*I've got to accept that because it's true…I mean I don't want to sit around all day but, I'd like to do gardening but I can't"* (Participant S15)

With the participants loading onto this factor ranging in time post stroke from 3 months to over 4 years, it is evident that coming to terms with the effects of a stroke and gaining acceptance takes time. These participants struggled with the transition of becoming disabled and battled to keep a positive attitude and make sure that they are still seen as a person not just a stroke survivor who cannot ambulate. This is supported by their views that just because they are unable to move does not mean that they cannot be useful (statement 34: +4). They were still able to help out around the house or contribute to daily tasks ultimately giving them purpose.

> *"Well if we're making meals from scratch there's no reason at all why I couldn't prepare the veg on here or the potatoes or whatever."* (Participant S9)

> *"Well I think I am useful in a way because I sort out my own medicines, phone the doctors and the chemist and things like that, operate the television controls [laughs]"* (Participant S13)

The participants loading on this factor did not think that it was important to break-up long periods of sitting time (statement 21: -1) compared to those loading onto the other two factors. This belief could be explained by the fact that the majority of their day was spent sitting or lying down without moving (statement 27: +2). As a result of their mobility problems, without assistance from others they do not have a choice but to sit or lie-down for long periods (statement 12: +3). This group of participants was also the only group to rank statement 19; 'I'm happy to sit or lie down without moving', as neutral (statement 19: 0). As these stroke survivors do not have a choice but to sit as they are unable to ambulate, they may have had to accept their limitations on movement by their disability and are therefore resigned to sitting for long periods as they have limited alternatives. However, as this group strongly agreed that they found it difficult to accept that they couldn't move (statement 34: +4), it may be more of an adaptation to their situation rather than an acceptance and have found sitting activities that they enjoy and get pleasure from doing including watching TV.

> *"'I'm happy to sit or lie down without moving', Watching TV, yes"* (Participant S15)

Stroke survivors loading on this factor believed that their mobility problems did stop them from exercising (statement 2: -2) which correlated with their functional ambulatory classification level of one (unable to ambulate). The placement of statement six (statement 6: 0) implies an uncertainty as to whether it is actually impossible or whether they are just unaware of how to try with their specific mobility limitations. Although they found exercising difficult or impossible following their stroke, they understood the importance of exercise after a stroke (statement 14:+2). These results indicate that for this group of stroke survivors exercise is more important than reducing sedentary behaviour unlike the other two factors who believed that both were really important.

> *"'Problems with my mobility do not stop me from exercising', well I can't exercise, so I'd disagree with that"* (Participant S13)
>
> *"'Exercise is important after a stroke', yes, but need help"* (Participant S13)

Although this group of stroke survivors had highlighted that they struggled to accept their mobility problems and found exercising very difficult, they were of the strong belief that there was a point to continuing in trying to move even though they could not do as much as they used to before their stroke (statement 4: -4). They found that practising exercises and tasks was a good way of improving their mobility and increasing their movement (statement 24: +3). Even if they found it extremely difficult to do themselves, repetitive task practice for increasing movement could be used by all stroke survivors to achieve improvements. Participants loading on this factor also quite strongly disagreed that you cannot be healthy if you are inactive (statement 26: -3). This may have been a reflection on themselves with them still classing themselves as healthy despite their mobility problems. They also questioned what 'inactive' refers to; although they were unable to move their lower limbs they could still use their unaffected upper limb(s) and keep an active mind.

This group of stroke survivors highlighted fatigue as a big barrier for them with regards to how much they move throughout the day (statement 20: +2). In contrast, they did not feel that the risk of falling (statement 17: -1) or a lack of confidence (statement 16: -2) affected how much they tried to move or exercise. Instead of these barriers identified by the other factors, the amount of movement in these participants was determined by their lack of ability to move themselves.

The family, friends and carers of the participants in factor two did not inhibit their movement (statement 10: -3). Their movement was instead restricted by their physical impairments and in some cases by healthcare professionals' advice for safety reasons to reduce the risk of falls and injury to both the stroke survivor and carer.

> *"Well they don't stop me from moving, because I can't, the physios have told, decided that I couldn't walk.* (Participant S13)

Despite this group of stroke survivors finding it very difficult to care for themselves following their stroke as a result of their physical problems (statement 11: +3), they strongly did not believe that they were a hindrance to their family and friends (statement 18: -4). Although they accept that they need help from their family, friends and carers, they still want to be seen as the people they were before their stroke and part of accepting and coping with their disability is trying to maintain their identity and keeping a positive 'not giving up' attitude.

> *"Well I don't think I'm a…well apart from poor Mavis but I don't think I'm a hindrance.* (Participant S13)

5.2.1.1.3. Factor 3 – I know the importance, but what's the point

Factor three had an eigenvalue of 1.64 and explained 10% of the study variance. Three participants were significantly associated to the factor. The participants were comprised of one male, aged 91 who was six months post-stroke, one female, aged 65 who was four years post-stroke and another female, aged 83 who was 1 year 4 months post-stroke. Two participants scored level one on the functional ambulatory classification (FAC), indicating that they were unable to ambulate as a result of their mobility impairments, with the remaining participant scoring level three (requiring continuous or intermittent light touch manual contact from one person during ambulation on level surfaces in order to assist balance or coordination) .

Table 13 Patient Factor 3; ‘I know the importance, but what’s the point’ (most strongly agree/disagree)

Number	Statement	Rank
14	Exercise is important after a stroke	+4
24	Practising exercises and tasks is vital to improving mobility and increasing movement	+4
2	Problems with my mobility do not stop me from exercising	+3
8	Movement is different to exercise	+3
21	It is important not to spend a long time sitting or lying down without moving	+3
16	My lack of confidence affects how much I move	-3
18	I am a hindrance to my family and friends because I cannot move without assistance	-3
19	I’m happy to sit or lie down without moving	-3
15	Without family, friends and carers I would not be able to keep active	-4
33	Doing jobs around the house is not physical activity	-4

Participants loading on factor three appeared to know and understood how important both exercise (statement 14: +4) and movement (statement 21: +3) were after a stroke and believed it was important to not sit for a long time without moving. For them, it was important to keep moving and exercising to help their bodies recover from the stroke despite their mobility problems. They were also the only group that believed that exercise and movement were different concepts and understood what the difference was (statement 8: +3). From their experiences of doing jobs around the house before their stroke, they also deemed doing these tasks as physical activity (statement 33: -4), knowing from experience how difficult some of the tasks can be. Although they were clear that movement and exercise were different and also what constituted physical activity, they were unsure whether you could be physically active if you are not moving your legs (statement 25: 0) or whether you can be healthy if you are inactive (statement 26: 0), placing both statements at zero.

> *“Well because the longer you lay inactive the weaker your limbs get, so unless you exercise your limbs, if you recover from your stroke you have a long, long way to go.”* (Participant S12)
>
> *“It makes my bones work.”* (Participant S17)
>
> *“So I try to wash up to help him or I sit on my commode to clean the bathroom”* (Participant S2)

> *"'Doing jobs around the house is not physical activity', certainly is…Because I used to do all those jobs and I know how difficult it all used to be"* (Participant S12)

Although they moved and exercised to keep their joints moving, they believed that moving was more important to reduce their risks of having another stroke (statement 7:+2) rather than to improve and maintain their physical functioning (statement 13: 0). As two of the participants in this factor were severely disabled (FAC level 1), it may be that they knew that they would not continue to improve much and therefore for them trying to reduce their risk of a recurrent stroke would be their priority. Similarly participant S2 may have felt that as four years had elapsed since her stroke, no more improvement would occur. Despite their physical problems and unlike those loading on the other two factors, the participants associated with this factor did not feel that that their mobility problems stopped them from exercising (statement 2: +3). However, compared to the other participants, these stroke survivors sometimes felt that there was no point in trying to move as they couldn't do as much as they used to (statement 4: +2). This also accompanied their view that they have no choice but to sit for long periods without moving (statement 12: +1), which is consistent with their level of physical disabilities. These are surprising results given that these stroke survivors know the importance of keeping moving and don't feel that their mobility problems stop them from exercising, yet they still think that there is sometimes no point in trying to move. One possible explanation for this viewpoint could stem from how they are following their stroke and their recovery trajectory. All three stroke survivors were 6 months or longer since their stroke and could feel that any recovery that they were to have has already occurred. If they believe that their recovery is halted and they won't get much more improvement they may not feel that they have much of a choice or need to keep trying for improvement. This is supported by the placement of statement three, 'setting goals and recording progress is a good way of trying to increase physical activity' which they disagreed with (statement 3: -1). For them, they may have felt goal setting was not as important for them in relation to the other statements. With these stroke survivors not believing that they have a choice in how much they get to move throughout the day, they are unsurprisingly very unhappy about having to sit or lie-down without moving (statement 19: -3) and said that being able to sit less would ultimately make them happier (statement 23: +2).

Similarly to participants loading on the other two factors, these stroke survivors acknowledged their struggle to care for themselves as a result of their physical problems (statement 11: +1) and felt that they had lost some of their independence (statement 29: -1) which was often frustrating.

> *"Well because I was my wife's carer before I had my stroke, so I was used to cooking all the meals, doing all the jobs around the house and now I see jobs that want doing and I can't do them."* (S12)

Participants loading on this factor strongly disagreed that a lack of confidence affected how much they moved (statement 16: -3) and unlike the other two factors fatigue was not a barrier (statement 20: 0). This supports the idea that for these participants their activity levels are ultimately dictated by their physical disabilities and not affected by other barriers that are problematic for other stroke survivors.

One of the distinguishing views that in this factor was the strong disagreement that without family, friends or carers they would not be able to keep active (statement 15: -4). For participants S12 and S17, this could either be because they do not receive the help or maybe because their mobility problems are so severe and complex that actually family and friends are unable to provide help safely. As participant S2 had less problems with her mobility and was further post-stroke than the other two participants, she may have developed adaptations and strategies to complete tasks and therefore did not need to rely on her family as much. These stroke survivors also believed, unlike those loading on the other factors, that physiotherapists should be helping them to move (statement 5: +2).They believe that it is the physiotherapists' job to get them moving and keep them active. At first thought this could be the stroke survivors expressing their wishes for longer term therapy input. However another possibility is the thought that as these stroke survivors have such complex needs, maybe specialist input and assistance that their family and friends are unable to provide is required. There was a disagreement that their family, friends and carers inhibited their movements (statement 10: -2) suggesting that just because their family and friends are unable to or do not need to provide the assistance, does not mean they are actively stopping their movements, as participant S12 states in the below quotation:

> *"It's a ridiculous statement is that!"* (Participant S12)

5.2.1.2. Consensus Statements

Analysis in Q-methodology considers where participants' subjective views differ (distinguishing statements) but also considers where there is agreement amongst participants (consensus statements). Nine consensus statements did not discriminate between factors for the stroke survivors (Table Fourteen).

Table 14 Stroke Survivor consensus statements

No.	Statement	F1	F2	F3
8	Movement is different to exercise	0	0	2
10	My family friends and carers do not stop me from exercising	-3	-3	-2
11	I find being able to care for myself difficult because of my physical problems	+2	+3	+2
22	You sometimes have to force yourself to move	0	+2	0
23	Reducing the periods of time I spend just sitting or lying down would make me happier	+2	+1	+1
24	Practising exercises and tasks is vital to improving mobility and increasing movement	+3	+3	+4
29	To be independent you must be able to walk and stand without help	+1	+1	+1
31	An active social life does not depend on being able to move without help	-1	0	-1
33	Doing jobs around the house is not physical activity	-2	-2	-3

There was consensus that to be fully independent, individuals must be able to walk and stand without help. As the statement was rated as one by all participants, this indicates that these stroke survivors believe that you can have some form of independence still even if you are unable to ambulate (statement 29: 1, 1, 1).

A moderate disagreement that doing jobs around the house is not physical activity was observed (statement 33: -2, -2, -3). They acknowledged that as they used to be able to do the activities they understand how difficult some of them can be and how it is physical activity. This supports the notion that activities of daily living could be incorporated into interventions to reduce sedentary behaviour as they already have an understanding that completing these everyday activities has benefits.

There was also consensus in response to statement 10 with stroke survivors strongly disagreeing that their family, friends and carers stopped them from trying to move (statement 10: -3, -3, -2). This is encouraging as it shows that carers are not actively discouraging movement and is supported by the majority view that without family, friends and carers they would not be able to keep active (discussed in previous sections). Statement 23, ‘Reducing the periods of time I spend just sitting or lying down would make me happier’, was moderately agreed with, indicating that they would prefer not to have to sit down without moving and would potentially welcome an intervention that aimed at trying to reduce or break-up their sitting time. A neutral to moderate agreement was observed with statement 22, ‘You sometimes have to force yourself to move’ (statement 22: 0, +2, 0). The difficulty in motivating stroke survivors to move matches some of the findings from both the carers and staff data.

No matter what their views were in relation to movement and exercise with their mobility problems, they all believed that practising exercises and tasks was vital to improving mobility and increasing movement following a stroke (statement 24: 3, 3, 4).

5.2.1.3. Summary

Stroke survivors who loaded onto factors one and three both understood and acknowledged the importance of breaking up long periods of sitting with regular movement and also of exercising after stroke. The shared understanding of the benefits of exercise and reducing sedentary behaviour suggests that these stroke survivors understand the difference between the two concepts but equally believe that both should be targeted during rehabilitation. In contrast, although factor two believed that exercise was important following a stroke, they did not agree that reducing sedentary behaviour was important. With stroke survivors in factor two all being classified as FAC level one and therefore being unable to ambulate; their view that breaking up periods of sitting is not important may reflect their abilities. These stroke survivors know how difficult it is for them to try and move and therefore may be suggesting that it is not important to reduce sedentary behaviour protects them as they know they cannot do it unaided. They see exercise as important to seeing improvements therefore their focus is on increasing exercise over reducing sedentary behaviour to ultimately try and improve their condition. Habitual physical activity was not checked before the stroke survivors took part in the study as part of the data collected prior to undertaking the study. However, when sorting the items relating to exercise and physical activity, participants did discuss with the researcher during the Q-sort process about how active they were and what exercises they could and could not do. As with the Barthel Index of Activities of Daily Living score which was calculated in order to determine their current level of ability and independence for ADLs, upon reflection it would also be important for a measure of habitual physical activity to be included in future studies. This would help to understand how active they currently are so that comparisons and associations can be made with their viewpoints identified through the Q-sort.

The overall consensus across all stroke survivors was that reducing sedentary behaviour is not impossible for stroke survivors with severe mobility problems. This is encouraging as it suggests that an intervention to reduce sedentary behaviour may be welcomed by stroke survivors. What the three factors highlighted was the varying degrees of support required by the stroke survivors. The first factor exemplified a group of stroke survivors with varying degrees of mobility impairment but who appeared to believe that they would continue to improve and are therefore willing to keep trying. In order to do this they acknowledged that the help and support of their family and friends was essential for them to keep active and improving. The second group of stroke survivors in factor two stressed the importance of identity in recovery since their stroke. Most importantly for them was that they wanted to be still seen as useful and still classed as a person not just a stroke survivor with mobility problems. This determination and positivity drove their focus and although they considered that reducing sedentary behaviour is very difficult they also believed it not to be impossible. They have a ‘you have to keep going’ attitude despite it being very difficult with all of the stroke survivors having a FAC of one. Factor three highlights the difficulty that having very severe mobility impairments can have. Despite these stroke survivors knowing the importance of moving and exercise after stroke and not feeling that their mobility problems stopped them from exercising, they also believed that there is sometimes no point in trying to move as they cannot do as much as they used to. Unlike the other two factors, they believed that specialist help from physiotherapists was more important to them than input from family and friends in order to help them to move.

5.2.2. Carers

Twelve carers consented and participated in the study; their characteristics are detailed in Table Fifteen. Two participants were recruited from a private neurophysiotherapy practice, six from one of three NHS sites, two from a community stroke group and two from a local charity for carers. Significantly more female participants were recruited to the study, with nine female and three male carers, with an average age of 65.8 years of age. Eight of the participants were wives of a stroke survivor, two were husbands, one cared for her sister and one was the grandson of a stroke survivor. These informal carers provided care to their relative daily, with the time since stroke ranging from three months to seven years. Eight participants were linked to stroke survivors who also participated in the study, with the other four carers completing the study independently as a result of their relative either being unable to take part or wishing not to.

Table 15 Table of Characteristics - Carers

Participant ID	Stroke Survivor ID	Gender	Age	Ethnicity	Relationship to stroke survivor	Time since stroke	How often do provide support to the stroke survivor
C5	S5	Female	60	British	Wife	7 years	Everyday
C7	S7	Male	25	British	Grandson	11 months	Everyday
C9	S9	Male	73	British	Husband	18 months	Everyday
C10	S10	Male	82	British	Husband	8 months	Everyday
C11	S11	Female	52	British	Wife	2 years	Everyday
C12	S12	Female	86	British	Wife	6 months	Everyday
C13	S13	Female	62	British	Sister	1st 10 years 2nd 3 months	Everyday
C19	S19	Female	79	British	Wife	3 years 2 months	Everyday
C20	-	Female	69	British	Wife	6 years 2 months	Everyday
C98	-	Female	58	British	Wife	8 years 5 months	Everyday
C97	-	Female	82	British	Wife	16 years 6 months	Everyday
C99	-	Female	62	British	Wife	6 months	Everyday

5.2.2.1. Factors

In order to help decide how many factors should be retained in the factor solution, the same processes that were used for the stroke survivors' data were followed (section 5.2.1.1). After an initial review of all eight extracted factors, factors six, seven and eight all had eigenvalues less than 1.00 and were therefore discarded from the analysis. Only a two-factor solution met the three objective criteria (Table Sixteen). However, following a review of the factor matrices and a qualitative exploration of the data through factor arrays, both the two-factor solution and the three-factor solution were considered for inclusion in the study. The three-factor solution accounted for the same number of participants as the two-factor solution but had four less consensus statements. Although only one participant was associated with the third factor in the three-factor solution, following review of the individual factor arrays and the participant characteristics it was decided that a three-factor solution was deemed the most appropriate for the carers data. Participant C97, who significantly loaded onto factor three, was the wife of a stroke survivor who had had his stroke over sixteen years previously. As she was the only carer to have provided care for over ten years it was believed that including the single participant factor was important in order to provide the viewpoint of a long-term carer (over ten years). The factor array was judged to provide significant nuances that separated it from the other two factors and supported its position as a separate factor.

Table 16 Quantitative summary of a two to five factor solution for Carer data

Factor solution	Eigenvalues greater than 1.00	Two significantly loading participants per factor	Humphrey's rule	Total number of participants accounted for in the solution (n=12)	Consensus statements
2	Yes	Yes	Yes	10 (7, 3)	12
3	Yes	No	No	10 (7, 2, 1)	8
4	No	No	No	11 (7, 2, 1, 1)	6
5	No	No	No	12 (5, 2, 1, 1, 3)	1

The three-factor solution accounted for ten participants' Q-sorts. Two participants were not associated with the three-factor solution, with their two confounding Q-sorts significantly loading onto two factors. Interpretation and explanation of the three factor solution will be discussed in the next sections. Tables Seventeen - Nineteen present the statements that were most agreed with (+3 and +4) and disagreed with (-3 and -4) for each of the factors.

5.2.2.1.1. Factor 1 – Practice makes perfect

Factor one had an eigenvalue of 5.05 and explained 42% of the study variance. Seven participants were significantly associated with the factor (C5, C7, C10, C12, C20, C98, C99). The participants were comprised of two male and five female informal carers. Four carers were linked to stroke survivors who also took part in the study (C5, C7, C10, C12), with the remaining three stroke survivors not being able to take part as a result of the cognitive and communication deficits caused by their stroke. The family members they cared for were scored level one or level two on the functional ambulatory classification (FAC), indicating an inability to ambulate or requiring continuous manual contact to stand or walk. Time since stroke ranged from six months up to eight years five months, with four participants being under twelve months post stroke and the remaining three over six years.

Table 17 Carer Factor 1: 'Practice makes perfect' (most strongly agree/disagree only)

Number	Statement	Rank
3	Exercise is important after a stroke	+4
9	Practising exercises and tasks is key to improving mobility and increasing movement	+4
7	Setting goals and recording progress is a good way of trying to increase physical activity	+3
8	Having problems with mobility should not stop them from exercising	+3
23	I regularly try to motivate them to increase their activity.	+3
16	I'm unsure about how to increase their movement safely	-3
25	It's the physiotherapists job to get them moving	-3
30	I'm scared of them moving too much in case they have another stroke	-3
12	They do not need long term physiotherapy and occupational therapy input to increase their movement	-4
28	There is no point in them trying to move as they cannot do as much as they used to	-4

The placements of statements in the higher columns indicating a strongly agreed viewpoint highlighted these carers' strong will to help the stroke survivor to move more. They believed that exercising was extremely important following a stroke (statement 3: +4), not only for the physical aspects but also psychologically improving the stroke survivors' mood. They also held the view that the physical problems caused by the stroke did not stop stroke survivors from exercising and should not be used as an excuse. Participant C99, a wife of a stroke survivor with a FAC of one stated that despite her husband's inability to ambulate, he often sits pedalling on a mini exercise bike.

> *"Exercise is important after a stroke. Well it's important whether you have or haven't had a stroke isn't it?"* (Participant C5)
>
> *"I think this one is self-evident really, that the stroke stops you doing physical things, and if you're going to get those back it must be right to exercise, apart from all the other things you might do with medicines etc. it must be the number one thing to get moving, as [wife] does."* (Participant C10)
>
> *"Well I think first of all, like the physical reason, that obviously exercise is going to improve muscle tone, you know for that aspect of it, but I think mentally as well, that it can lift your mood."* (Participant C99)
>
> *"Having problems with mobility shouldn't stop you from exercising. Absolutely not, you know, the reverse really"* (Participant C5)
>
> *"He feels like he's doing something and he's making progress, and you know, he's not just sitting there, he does quite like pedalling actually and just, you know, watching the telly or whatever and he'll pedal quite happily, and you know, and if I say to him, have you had enough, often he'll say, no I'm fine, you know and he'll carry on, and I think that makes him feel that he's doing something and he's being productive, you know, helping, you know, to make things that little bit better."* (Participant C99)

They also understood the importance of not spending a long time sitting or lying down without moving (statement 2: +1), but felt that exercise was more important for the potential improvements that exercising could provide. The believed that moving regularly helped to improve and maintain their family members' physical functioning after their stroke (statement 17: +2) and that it was also important to reduce their risks of having a recurrent stroke (statement 5: +1).

> *"It is important not to spend long times without…no, he has to move so I agree with that, even if it's only being moved in bed and his chair"* (Participant C12)

This group of carers regularly motivated their family members to increase their activity (statement 23: +3). Often they were seen as 'nagging' or 'pushy' but felt they needed to get them motivated to allow them to reach the potential that they can see for them. As carers they are doing everything that they can to help as they know the importance of moving and the potential for improvement in the stroke survivors' mobility disability.

> *"It's called nagging…you say I'm nagging you"* (Participant C5)
>
> *"Yeah. All the time, taking her to the toilet and things like that in-between carer visits, always trying to walk and things like that really…Got that Hoover so she could hoover up round her"* (Participant C7)
>
> *"'Because, for example, my husband, he can do…I've seen when he does things regularly he improves but when he can't be bothered it goes backwards. But I battle all the time to push him to do more because I know he can do more and he makes progress and I think his balance is not 100% and that's why he doesn't walk independently but I think if he just had and would do it more that he could probably get more independent with it."* (Participant C98)

The carers loading on factor one were confident in their knowledge and ability to increase their family members' movement (statement 16: -3). They strongly disagreed that this was a barrier to movement and acknowledged that they had either been taught or had worked it out for themselves over time. Similarly they were not afraid to encourage movement for fear of causing another stroke (statement 30: -3). This links to their belief that there are no excuses when it comes to increasing movement and activity levels.

> *"I strongly disagree with that because I know, well I've been trained so."* (Participant C5)
>
> *"I'm not anymore because I've worked it out myself after six years of trying."* (Participant C20)
>
> *"'I'm scared of moving them too much in case they have another stroke. No, you know, it won't happen, I mean it might but you can't put somebody in cotton wool."* (Participant C5)
>
> *"No. I'm very much a believer in if it happens it happens and I don't think her getting exercise would…affect that."* (Participant C7)
>
> *"'I'm scared of them moving too much in case they have another stroke'. Pfff to that. I was to start with mind you because I never got any information as to what he could do and what he couldn't do that might cause the risk of a*

> *stroke, so it's only from confidence in the fact that he hasn't had another stoke that we have actually carried on."* (Participant C20)

With the overall view of the carers loading onto this factor wanting to help stroke survivors to move more and do everything they can to help and support the process, they believed that goal setting (statement 7: +3) and constant and regular practice was key to improving and increasing the stroke survivors' movement (statement 9: +4).

> *"Well we do this…Yeah we have a goal. At the moment the goal is to stand up without pushing down, to use his legs to stand up and we do that."* (Participant C20)

> *"For [Husband] it's very important…so you have a sense of progression so that you, enables you to keep positive, you know, go back to saying when [Husband] first came home he was almost still being hoisted out of bed and you, it's like a child, watching a baby or a child grow, you forget the stage that they were at."* (Participant C5)

Overall participants loading onto this factor strongly disagreed that there was no point in the stroke survivors trying to move as they couldn't do as much as they used to (statement 28: -4). There is a point as they strongly believe that exercise is important after a stroke and that practising is crucial to achieving improvement. The stroke survivors may not be able to do much now but without trying and practising they will never progress or know what improvements they are capable of.

> *"And there's no point, then that's you, trying to move as they cannot do as much as they used to. That's very defeatist. And we won't be defeated will we [Wife]!"* (Participant C10)

> *"Well, yes they obviously can't do as much as they used to, but I just don't like that 'there is no point', you know, there's every point, you know, totally, to try and get them to do as much as they possibly can, you know, to realise whatever potential's there, that you're helping them, you know, to reach it. And I, I think you can relearn things as well, you know, so keep, just keep encouraging them and get them to do as much as you possibly can. Oh yeah, yeah I strongly disagree with that one."* (Participant C99)

Despite the carers being very keen for the stroke survivors to keep moving and trying to improve, they acknowledged that their family members were dependent on them (statement 22: +2) as they struggled to care for themselves as a result of their stroke (statement 11: +1). They knew that without their help they would not be able to keep active (statement 33: +2) but were extremely dedicated to helping and supporting their family member to improve and get active. They hoped that trying to get them moving more would not only be good for health reasons but allow them to regain some independence (statement 10: +2). They admitted that it was hard to support someone with a mobility problem following a stroke (statement 24: +1), but their focus was on continued progression and helping their loved one improve. Similarly they would be happier if they could move more (statement 32: +1), but are more focused on doing all they can to get them moving and improving their physical functioning even if it is only small movements.

> *"Well because, you, know, [Husband] is reliant on, on me because of his mobility problems and it's just , you know, a stark bold fact that I am the sole, principal carer I should say, and of course I'd be happier if he could move more from the physical sense but also an emotional and psychological sense, because he gets very frustrated as well. And I do have to ask him, remind him to move and that can cause friction and clearly if, if, if he did move more then that would help to increase independence."* (Participant C5)

> *"Well, he does have to have most things done for him and I have a lot to do, even though he has carers because he just can't get anything or do anything himself, so…Yes it does, he is dependent on, of course, yeah…I know he's not happy about that, but it's there."* (Participant C12)

> *"And it is hard to support someone with mobility problems after a stroke because it's all-encompassing and, you know, spontaneity that you'd have, one has in your life when you can move, it's gone, you've got to stop and think."* (Participant C5)

With regards to external support, these carers strongly disagreed that stroke survivors with severe mobility disabilities did not need therapy input in the long term (statement 12: -4). This was evident with some of the carers who were able to pay for additional private physiotherapy believing that without this longer-term input their family members would not have been able to improve to the extent that they had. They also strongly disagreed that it was the physiotherapist's job to get them moving (statement 25: -3). Although they believed that it was part of their role, they strongly thought that it was the job of the stroke survivor and family to continue. As it is the family who spend the majority of time with the stroke survivor unlike the physiotherapists who can spend only a few hours per week, it is important for them along with the stroke survivors to take responsibility for their continued rehabilitation

> *"They do not need long-term physiotherapy and occupational therapy input to increase their movement. Oh please, you know, I mean I get so angry when I think of the people who are not able to access what we're able to do because they couldn't afford it and you see, you will see it clearly, tremendous deterioration which happens very, very quickly."* (Participant C5)

> *“It’s the physiotherapist’s job to get them moving. No it isn’t, they only show how to do it and encourage and assist but the good practice hopefully happens all the time at home and that’s so one hour or two hours a week is, is minimal compared to living.”* (Participant C5)

> *“Well, yeah I can see in some cases it would have to be physio, you know if some stroke patients don’t have the support at home, they would be relying on the physio to come in and help them to do whatever. But if they’ve got people to help, then no, you can do it can’t you, and I, I’ve just tried to do, whatever the physios have suggested then I’ve tried to do my bit, and they’ve taught me how to do things as well, you know, which means that you can actually do it and then if some days the physios can’t come, then you can actually do it, and again for you that makes you feel that you're helping, that you’re doing something positive, you know, that might just help them to get that bit better, make that progress. So yes, yeah, I don't think it’s just the physiotherapists, no, not al all.”* (Participant C99)

5.2.2.1.2. Factor 2 – Fait Accompli

Factor two had an eigenvalue of 1.71 and explained 14% of the study variance. Two participants significantly loaded on to the factor (C9, C13). Both were carers of stroke survivors who were unable to ambulate (FAC level one). Participant C9 was the husband of a stroke survivor who had her stroke 18 months ago. Participant C13 cared for her sister who had had a first stroke over 10 years ago and had recently had a recurrent stroke only three months previous. Both carers provided support to their family member every day.

Table 18 Carer Factor 2: ‘Fait Accompli’ (most strongly agree/disagree only)

Number	Statement	Rank
24	It is hard to support someone with mobility problems after stroke	+4
33	Without family, friends and carers stroke survivors would not be able to keep active	+4
4	They have no choice but to sit or lie-down for long periods	+3
23	I regularly try to motivate them to increase their activity.	+3
34	Movement is different to exercise	+3
1	I limit their movements to reduce their risk of falls	-3
5	Moving regularly is important to reduce the risks of having another stroke	-3
28	There is no point in them trying to move as they cannot do as much as they used to	-3
8	Having problems with mobility should not stop them from exercising	-4
26	You cannot be healthy if you are inactive	-4

The viewpoint of participants who loaded onto factor two, had a strong focus on the huge life event that a stroke was and the impact it had on their lives. They agreed that it was extremely hard to look after and support their relative (statement 24: +4) and that without their help and support the stroke survivor would not be able to move and keep active (statement 33: +4). This was supported by the fact that the stroke survivors' mobility problems had made them dependent on the carers (statement 22: +2), with the stroke survivors not being able to care for themselves as a result of their physical problems following the stroke (statement 11:+1). The carers that associated with this factor not only reported the difficulty of supporting someone following a stroke but also the difficulty in obtaining support for themselves to help them to cope in their carer's role. As a result their health is often affected as they are unable to look after themselves and often neglect their own health and care needs.

> *"Yeah, I mean to put it in a nutshell [wife] is confined to either that chair or a wheelchair…She can feed herself but I have to cut her food for her so that's it, that's it really isn't it [wife]?...You can put a bit of slap on in the morning…and that's about it, yeah."* (Participant C9)

> *"And to start off with, of course, when anything's new you get help and support from family and friends but over the years that falls away. And it becomes far more difficult and, you know, there's no provision for my health and of course my health's got worse and worse really."* (Participant C13)

> *"Yes, you're dependent on me but that's what I'm here for isn't it?"* (Participant C13)

These carers found it very difficult to adjust to their life after their family member or friend's stroke and struggled to accept that they were unable to move like they used to (statement 21: +2). They not only struggled with the realisation of what had happened but also the effect that it had had on their family. They believed that an active social life does depend on being able to move without help (statement 13: -1), and although they did not like to admit it, they felt that it was sometimes easier not to include their family member in activities due to the complex issues arising from their mobility problems. Their lives have changed dramatically as a result of the stroke and they are still trying to adjust and accept the consequences years down the line.

> *"Well it would be nice to have an active social life but it's very hard and I think it does depend on being able to move without help."* (Participant C13)

> *“It is easier not to include them in activities because of their mobility problems. Well I used to do that I think in the olden days because when [sister] could walk and get in the car, a lot of days you just didn’t have the time to do it so you’d sacrifice you going out so I could do it quickly.”* (Participant C13)

With regards to their views on movement and exercise, they strongly believed that the two concepts were different (statement 34: +3). A score of zero for statement number three indicated that they were unsure if exercise is important after a stroke (statement 3: 0). They also strongly believed that having problems with their mobility does stop them from exercising (statement 8: -4), which is a polar opposite view to the participants loaded onto the other two factors who believed that having mobility problems should not stop them from exercising.

> *“Exercise is important but obviously you can’t exercise can you?”* (Participant C9)

> *“Exercise is important after a stroke. Well I strongly agree with that but of course we’re, it’s gone for us…But it is important.”* (Participant C13)

> *“Having problems with mobility should not stop you from exercising, but it does more so as your problems get worse.”* (Participant C13)

In contrast to the other participants loaded onto factor one and three, these two carers did not think it was that important to break up long periods of sitting and lying down without moving (statement 2: -1). This could be explained by their associated viewpoint that their family members do not have a choice but to sit or lie down for long periods as they are reliant on their formal carers who transfer them in a morning and evening (statement 4: +3). This is supported by their feelings that moving regularly is not important to reduce the risk of having another stroke (statement 5: -3), nor is it important to improve and maintain physical functioning (statement 17: -1). It could therefore be suggested that their thoughts on movement and it not being very important, may be a coping mechanism as they feel that the stroke survivor does not have a choice and therefore increasing their movement is impossible. They have a sense of resignation, of powerlessness to change the situation rather than not believing that movement and exercise is not important.

> *“‘It’s important not to spend a long time sitting or lying down without moving’. But then you get to the position where that’s dictated by other things, you know. We know that but we can’t do anything about it so we are shackled by the care system…The carers can only come so many times a day.”*(Participant C13)

> *"'Moving regularly is important to reduce the risks of having…', well we used to believe that and do things about it but we're less able to do it now."* (Participant C13)

Despite these carers believing that their family members were not able to engage in exercise or movement as they have no choice, they still strongly believed that there was a point in them trying to move even though they couldn't do as much as they used to (statement 28: -3). Even though they cannot do much, the carers still tried to remind the stroke survivor to move (statement 6: +1) and thought it important to keep motivating and encouraging them to increase their activity (statement 23: +3). Participant C13 described how following her sister's first stroke she regularly tried to motivate her to move more but due to the severe mobility impairments caused by her second stroke, there was no point in doing the same as her sister was unable to move. These carers also strongly believed that someone could be healthy if they were inactive (statement 26:-4), suggesting that despite their family members' limited movement they were still healthy as they were able to remain active in other aspects of their life i.e. mentally active.

> *"I often have to remind them to move, well we used to do that but we don't anymore…There is no point, see that would have applied at the beginning but not so much now."* (Participant C13)

> *"You cannot be healthy if you are inactive'. See, healthy is different all the time isn't it, your definition of health varies as your condition varies doesn't it? So, like, at the minute it's very important for [sister] to have healthy skin and also there's a lot of work that goes into maintaining her beautiful skin and all parts of her body, so I don't know what I'd, I don't agree with that…Yes and we try to keep our minds as active as we can."* (Participant C13)

Although the carers did not feel that they limited the stroke survivors' movement (statement 31: +2) as they weren't afraid of them falling, they strongly believed that their family members were extremely afraid of moving for fear of falling (statement 1: -3). This contrasting view may potentially be explained by the fact that these carers can no longer limit stroke survivors' movements due to the already restricted movement following the stroke. Whereas the stroke survivors may still be fearful as they know they have limited control over their movements and therefore are reliant on their formal carers to help them transfer from bed to chair.

> *"'I limit their movements to reduce the risk of falls.' I think I always viewed it as I, if I'm here then I can help her not to fall in those days, you know, but if you were walking through I'd have the chair behind her and things. So I limit them…I used to try not to limit your movements but I did try to reduce the risk of falls so."* (Participant C13)

Out of all of the carers, the two loading on factor two were not provided with information on the importance of keeping moving following stroke (statement 14: -2). The carers may have felt that this was due to the very limited movement that the stroke survivors had at time of discharge. Compared with the other two factors, these two carers believed that some long term therapy would be helpful for their family members but scored the statement as -1 as they knew that it isn't available. Similarly they gave a neutral score for statement number 25 'It's the physiotherapist job to get them moving' indicating a belief that maybe they do not believe it to be as important for their stroke survivors as other aspects of their recovery.

> *They do need long-term physiotherapy and occupational therapy. See I think that's the big mistake all the way along, they need that more and more…From the word go…day one you need it."* (Participant C13)
>
> *"I just feel that especially for stroke victims, physiotherapy is the central thing. And if it's not available at home, it should be, and alright , I don't know, people can pay for things but you can't, there's so many things you have to contribute to as well isn't there? And so especially for the first year or two or three after a stroke, they should put in as much physiotherapy as they possibly can to every patient. And just for confidence alone, even if they can't make great physical improvement, it helps doesn't it? And it's somebody who is interested in them every week who comes and takes them out into the garden or helps them to walk a few steps…That's better than all the drugs!"* (Participant C13)

5.2.2.1.3. Factor 3 – With time comes adaptation and acceptance

Factor three had an eigenvalue of 1.10 and explained 9% of the study variance. Only one participant (C97) significantly loaded onto this factor, however it was deemed important to include it in the results as the carer was the only one who was a long-term carer of over 10 years. The experience she gained over the 16 years following the stroke provided a unique insight into the needs and experiences of a long-term stroke survivor. The participant was the wife of a stroke survivor who provided daily care to him. Her husband was initially scored level one on the functional ambulatory classification (FAC) following discharge but had improved to level two over time with him being able to stand with help.

Table 19 Carer Factor 3: ‘With time comes adaptation and acceptance’ (most strongly agree/disagree only)

Number	Statement	Rank
26	You cannot be healthy if you are inactive	+4
32	I would be happier if they could move more	+4
13	An active social life does not depend on being able to move without help	+3
24	It is hard to support someone with mobility problems after stroke	+3
33	Without family, friends and carers stroke survivors would not be able to keep active	+3
1	I limit their movements to reduce their risk of falls	-3
6	I often have to remind them to move	-3
16	I’m unsure about how to increase their movement safely	-3
11	They are unable to care for themselves because of their physical problems	-4
28	There is no point in them trying to move as they cannot do as much as they used to	-4

Unlike the other two groups of carers, this participant, C97, did not think that exercise was that important following a stroke (statement 3: -1) but instead thought that it is was more important to not sit for long periods without moving (statement 2:0). This participant strongly agreed that someone cannot be healthy if they are inactive (statement 26: +4). Although the placement of this statement at first suggests that she believes her husband may not be healthy, following discussion with the participant it emerged that she strongly believed that it was extremely important to keep active in order to be healthy with numerous different ways to be active, not just physical activity.

> *“Well you’ve got to have something to do. I mean it’s not just physical mobility, it’s mental and without the Sudoku that my husband does every morning like a piece of work…the day would lack shape and that’s being active and then he has, since we moved here and it created all these extra jobs because it’s easier, it’s a small much more compact house and he doesn’t have to rail a long way from the sitting room to the bedroom to the kitchen. So yes, it is right.”* (Participant C97)

One of the important things for the stroke survivor and the carer after so many years post-stroke is to keep as healthy as possible. This was reflected in the participant’s response that moving regularly is more important to reduce the risks of future strokes (statement 1: +2) than to try and improve physical functioning (statement 17: 0). As the participant’s husband had reached a plateau in recovery, for them their focus was on remaining as happy and healthy as possible. Out of all of the factors, this one was the only one to somewhat agree that reducing sedentary behaviour in stroke survivors with severe mobility problems is impossible (statement 15: +1). Experience may have allowed this carer to understand and appreciate how difficult it is to get a stroke survivor moving more when they have severe mobility limitations and are confined to a wheelchair. Similarly they believed that their mobility limitations do stop them from exercising and getting them to try is often very difficult. The participant didn't feel that reminding (statement 6: -3) or trying to motivate (statement 23: -1) her husband to move more was necessary as after 16 years it wouldn't matter what she asked or encouraged him to do as he now does what he wants.

> *"I regularly try to motivate them, I don't… I disagree with that because I don't think it would work…You know, if he didn't want to do it he wouldn't do it."* (Participant C97)

Participant C97 was honest when discussing the journey of recovery that she has experienced with her husband. She has played a big part in her husband's recovery and without her support he would not have been able to remain active (statement 33: +3). Although she has relished the opportunity to provide help and support she was not afraid to acknowledge how difficult caring for her husband has been since his stroke (statement 24: +3). Her response to statement number 21 ' I find it difficult to accept that they cannot move like they used it before their stroke', by sorting it as neutral (statement 21: 0), indicates that she is unsure if she finds it difficult to accept anymore. Perhaps the length of time since the stroke has allowed them time to cope and adapt to their new situation.

This participant strongly disagreed that stroke survivors were unable to care for themselves because of their physical problems (statement 11:-4). They believed that the stroke survivors can care for themselves as with time has come adaptation and working out how to do things. In the case of participant C97, their home that they were in when he had his stroke was restrictive and made him more dependent. But following a house move, her husband has been able to do a lot more for himself and regain a lot of his independence (statement 22: -2). Despite the increase in independence over time, being able to move more would ultimately allow the stroke survivor to be even more independent (statement 10: +2). It would also make the carer much happier if her husband was able to move more (statement 32: +4) as it would not only reduce the strain on them but also allow him to live a more independent and 'normal' life.

> *"Well I think things have moved on so that my husband is pretty independent, bearing in mind that we have a carer that comes in in the mornings, we have now just from the last month got 7 days a week care to help him get dressed but that's because of my limitations now. I can't…I broke my hip 18 months ago and I can't physically do as much as I did before…But otherwise he does…In the evenings he does get himself to bed and I go in and rearrange the furniture so it's easy in the morning."* (Participant C97)

> *"Well that's just a broad overall thing, I mean you're just learning to live with a totally different scenario and of course one would wish they were better able to cope and could do more. I mean it's just a kind of a long term wish but…A big adapt…A huge adaptation."* (Participant C97)

The carer associated with factor three strongly disagreed that there was no point for them to try moving as they couldn't do as much as they used to. They believed that there was a point in moving, no matter what they are able to achieve in order to be healthy and to work on increasing their level of independence. There was also a disagreement with statement number four, as participant C97 believed that her husband did have a choice to not sit or lie-down for long periods (statement 4: -2) but acknowledged that it was much more difficult with his mobility problems.

> *"Well, my husband was a long-distance walker, you know, the adaptation for him has been monumental…I think you…well whatever he can do and wants to do and we can encourage and the family can support, it's great!"* (Participant C97)

Another benefit of being many years post-stroke was the knowledge and experience in how to provide daily care for the stroke survivor including transfers and encouraging movement safely. Participant C97 did not actively restrict her husband's movements to stop him from falling (statement 1: -3), nor was she unsure about how to increase his movement safely (statement 16: -3). After years of learning and trying different things, they now know how to safely move and transfer the stroke survivors correctly and understand that they will not fall and hurt themselves if they follow the correct procedures.

Although the stroke has affected their lives significantly, they have managed to adapt to life over the years following the stroke. This factor was the only one to agree that an active social life does not depend on being able to move without help (statement 13: +3). They believed that is was important to maintain an active social life and that it was possible with careful planning. However, despite it being hard to admit, this factor were also honest in saying that sometimes it is easier not to include the stroke survivor in plans because of their mobility restrictions (statement 18: +2).

5.2.2.2. Consensus Statements

Eight consensus statements did not discriminate between factors for carers (Table Twenty).

Table 20 Carer consensus statements

No.	Statement	F1	F2	F3
1	I limit their movements to reduce their risk of falls	-1	-3	-3
15	Reducing time spent sitting or lying down is impossible in stroke survivors with severe mobility disability	-1	0	+1
16	I'm unsure about how to increase their movement safely	-3	0	-3
19	They will not move independently without my encouragement and support	-2	-2	0
20	Sometimes it's hard to motivate them to move	0	0	-1
27	Doing jobs around the house is not physical activity	-2	-2	0
28	There is no point in them trying to move as they cannot do as much as they used to	-4	-3	-4
29	Fatigue limits how much they can move throughout the day	0	+1	0

Overall the carers did not limit their family members' movement (statement 1: -1, -3, -3) and either strongly disagreed that they were unsure about how to increase the stroke survivors' movement safely or were uncertain (statement 16: -3, 0, -3). They have been trained or have worked out, through trial and error, how to move the stroke survivors safely and have understood what their limits are in order to not push them too far.

The carers were uncertain whether reducing sedentary time in stroke survivors with severe mobility disability was impossible (statement 15: -1, 0, +1). Even if it is possible, they acknowledge that it would be very difficult as many barriers would have to be overcome in order to achieve it. There was an extremely strong disagreement across the carer participants that there is no point in the stroke survivors trying to move as they cannot do as much as they used (statement 28: -4, -3, -4). They all agreed that it was important for them to continue moving as much as possible not only for physical functioning but also for recovery. Similar to the stroke survivors, the carers also believed that doing jobs around the house is physical activity (statement 27: -2, -2, 0)

There was a general ranking consensus that it is sometimes difficult to motivate their family members to move (statement 20: 0, 0, -1). Although it may be hard to support them to regularly move they either do not feel that motivation is much of a problem for them or they don’t feel that it a problem that cannot be overcome. In support of this, the carers acknowledged that the stroke survivors do move independently without help and encouragement suggesting that lack of motivation is not a significant barrier.

Similarly, they believed that fatigue was neither a problem nor a significant barrier to increasing their movement (statement 29: 0, 1, 0). They believed that this could be easily overcome by planning activities and breaks throughout the day to ensure that fatigue is minimised.

5.2.2.3. Summary

Three factors emerged from the carers’ data, each describing a different viewpoint of caring for a stroke survivor with severe mobility disabilities. Factor one included carers of stroke survivors with a range of functional ambulation abilities. Their overall view was that they needed to keep trying and not give up. They understood how important exercise is after a stroke and out of the three factors also appreciated the importance of not spending too long sitting or lying down without regular breaks. They acknowledged that in order for them to improve and recover, their family members relied on their constant help and support. In contrast factor two represented carers who have struggled with the transition into a carer and find it extremely difficult to support the stroke survivor. As the stroke survivors had very severe mobility problems leaving them unable to ambulate, they felt that they did not have a choice but to sit or lie-down for long periods. They did not feel that exercise or reducing sedentary behaviour was that important for their family members as their mobility problems inhibited them. These carers were resigned to the fact that their family members were so severely disabled that they would not recover anymore. Factor three highlighted a very different viewpoint from a single carer. As a carer of a stroke survivor for over sixteen years, she described how with time she and her husband have learnt to accept the stroke and it’s health consequences. She also explained that over time she and her husband learnt how to adapt not only their environment but also their routines to allow them to live as normal a life as possible. She agreed that it had been difficult to support and help her husband over the years, but it has become easier with time.

Overall carers were unsure whether reducing sedentary behaviour was possible in stroke survivors with severe mobility disability, with statement number fifteen being ranked neutrally. No matter how severe the stroke survivors' mobility impairments were, there was a strong agreement across the three factors that they should keep trying to move despite them not being able to move as much as they used to.

5.2.3. Healthcare Professionals

Twenty participants consented and participated in the study. Characteristics of the twenty participants are detailed in Table Twenty-One. Six participants were recruited from a private neurophysiotherapy practice, three from a community stroke team and eleven from an NHS site that provided both acute rehabilitation and early supported discharge care to stroke survivors. Significantly more female participants were recruited to the study; nineteen females and one male participant, with an average age of 41.2 years of age (SD=12.15). A range of professions were recruited to the study including; twelve physiotherapists, four occupational therapists, one physiotherapy assistant, one therapy assistant, one senior therapy assistant and one assistant practitioner. No members of the nursing team (e.g. nurses, healthcare professionals) or doctors were recruited to the study. A range of seniority and experience in stroke care was observed in the sample, with grades ranging from a band two to a band seven, and length of experience in stroke care ranging from four months to over thirty years.

Table 21 Table of Characteristics – Healthcare Professionals

Participant ID	Gender	Age	Ethnicity	Profession	Grade	Time since qualifying	Length of experience in stroke care
H1	Female	47	British	Physiotherapist	-	8 Years	8 Years
H2	Female	59	-	Physiotherapist	Specialist	36 Years	30+ years
H3	Female	42	White British	Physiotherapist	Band 7	21 Years	11 years
H4	Female	59	British	Physiotherapist	-	39 years	17 years
H5	Female	35	White British	Physiotherapist	Band 7	15 years	12 years
H6	Female	50	White British	Physiotherapist	Band 7	29 years	23 years
H7	Female	25	British - Indian	Occupational Therapist	Band 5	2 years	1 year and 3 months
H8	Female	26	White British	Physiotherapist	Band 6	5 years	2 years
H9	Female	32	British	Physiotherapy assistant	-	9 years	1 year
H10	Female	55	White British	Physiotherapist	-	14 years	12 years
H11	Female	23	White British	Physiotherapist	Band 6	2 years	6 months
H12	Male	32	White	Physiotherapist	Band 5	3 years	4 months
H13	Female	50	White British	Therapy Assistant	Band 2	8 years	9 years
H14	Female	43	White British	Senior Therapy Assistant	Band 3	18 years	19 years
H15	Female	23	White British	Occupational Therapist	Band 6	2 years	8 months
H16	Female	29	White	Physiotherapist	Band 6	8 years	3 years 6 months
H17	Female	54	White British	Occupational Therapist	Band 5	14 years	2 years
H18	Female	51	White British	Physiotherapist	Band 7	30 years	18 years
H19	Female	45	White British	Assistant Practitioner	Band 4	4 months	5 years
H20	Female	43	British	Occupational Therapist	Band 7	21 years	20 years

5.2.3.1. Factors

In order to help decide how many factors should be retained in the factor solution, the same processes that were used for the stroke survivors' and the carers' data were followed (described in section 5.2.1.1). After an initial review of the eight extracted factors, only factor solutions one and two had eigenvalues greater than 1.00 (Table Twenty-Two). Brown (1980) argues that using the Kaiser-Guttman criteria to determine if a factor should be included can often lead to meaningful and significant factors, with eigenvalues of less than 1.00, being excluded from the interpretation. Therefore in order to assess the factor solutions for inclusion and exclusion a holistic approach was taken with both objective measures and a qualitative exploration of the factor arrays being used. Factors seven and eight did not meet any of the objective criteria and were therefore discarded from the analysis. A review of the factor arrays indicated that factors five and six were weak with interpretations of the factors being very similar and limited numbers of distinguishing statements per factor. It was therefore decided to exclude these factors from the analysis. With the four-factor solution accounting for sixteen out of the twenty participants with fifteen consensus statements, and it meeting the majority of the objective criteria it was judged to be the most appropriate factor solution for the healthcare professional data.

Table 22 Quantitative summary of a two to five factor solution for Healthcare Professional data

Factor solution	**Eigenvalues greater than 1.00**	**Two significantly loading participants per factor**	**Humphrey's rule**	**Total number of participants accounted for in the solution (n=20)**	**Consensus statements**
2	Yes (1.00)	Yes	Yes	12 (7, 5)	25
3	No (0.94)	No	No	13 (1, 5, 7)	24
4	No (0.81)	Yes	Yes	16 (6, 4, 3, 3)	15
5	No (0.70)	Yes	Yes	17 (3, 3, 3, 3, 5)	10
6	No (0.59)	Yes	Yes	18 (2, 3, 2, 2, 5, 4)	10

The four-factor solution accounted for sixteen participants' Q-sorts. Four participants were not associated with the four-factor solution, with their four confounding Q-sorts significantly loading onto two factors. Interpretation and explanation of the four factor solution will be discussed in the next sections. Tables Twenty-Three – Twenty-Five present the statements that were most agreed with (+3 and +4) and disagreed with (-3 and -4) for each of the factors.

5.2.3.1.1. Factor 1 – We're all in this together

Factor one had an eigenvalue of 13.25 and explained 66% of the study variance. Six participants were significantly associated to the factor. Participants were comprised of a mix of professions and included four physiotherapists, one therapy assistant and one occupational therapist. All participants were female except for one physiotherapist who was the only male participant to take part in the study. Experience working in stroke care ranged from 4 months up to 23 years.

Table 23 Healthcare Professional Factor 1: 'We're all in this together' (most strongly agree/disagree only)

Number	Statement	Rank
21	All health professionals should encourage the reduction of sedentary behaviour in stroke survivors with severe mobility problems.	+4
33	Family, friend and carer involvement is important to help reduce sedentary behaviour in stroke survivors	+4
2	We inform stroke survivors and their family/carers about the importance of keeping moving and breaking up long periods of sitting or lying down	+3
25	Setting goals and recording progress is a good way of trying to reduce time spent sedentary time in stroke survivors with severe mobility problems	+3
30	Moving regularly helps to improve and maintain physical functioning in people with severe mobility problems after stroke	+3
1	Only physiotherapists can make stroke survivors with severe mobility problems move more	-3
8	Stroke survivors with severe mobility disability cannot care for themselves because of their physical problems	-3
19	It's not my job to reduce the time stroke survivors spend being sedentary	-3
16	There is no point in stroke survivors with severe mobility problems trying to move if the effort does not lead to any health benefit	-4
32	Stroke survivors who are unable to walk or stand without help cannot be independent	-4

'We're all in this together' was the overall message portrayed by the healthcare professionals in factor one. They believed that everyone should be involved in the reduction of sedentary behaviour, with all healthcare professionals actively encouraging regular movement in order to break up sedentary time (statement 21:

+4). They strongly believed that it should be a team effort, evidenced by their view that it isn't just physiotherapists that can make stroke survivors with severe mobility problems move more (statement 1: -3) and a strong disagreement with statement 19, that it's not their job to try and reduce sedentary behaviour (statement 19: -3). Those loading onto this factor shared the view that care should be a continuous process from the acute setting to the rehabilitation through to GP practices and neuro-rehabilitation teams once they have been discharged, with everyone involved responsible for rehabilitation and promoting regular movement.

> *"Absolutely, because it's an MDT approach with all our stroke patients, so it's not just down to the fact always letting the physios or the OTs do it, it's down to everyone."* (Participant H12, physiotherapist)

> *"I think if they've had quite a debilitating stroke, it's going to be hard, but I think if we're trying to get them moving and doing as much as possible while they're an in patient that needs to carry on once they're discharged, hence why we send discharge summary onto the GP so they know what they're doing. And I think it's then up to the GP to try and keep them going with the rehab."* (Participant H13, Therapy assistant)

> *"'It's not my job to reduce the time stroke survivors spent being sedentary'. I, yeah, I wouldn't be a physio if I didn't…I think I'm going to put the physios, only physios can make stroke survivors motivated to move more because it's just not true. No it's more because family, carers, all of them, everybody works, nurses, healthcare professional, the patient are the ones to make them move more because we aid it but we don't, we're not the only ones that can do it."* (Participant H8, Physiotherapist)

Despite the importance of healthcare professionals being involved in the stroke survivors' rehabilitation, they also strongly believed that the team effort should also include the stroke survivor themselves and their family, friends and carers (statement 33: +4). Once the stroke survivor has been discharged from hospital, although they may receive some therapy in the community (from a community team or privately), this will be limited and ultimately family members and/or friends will be with the stroke survivors for the majority of time once the therapists have left. It's important therefore that they are involved from an early stage so that they can continue the rehabilitation once they are at home. In order to get them involved, the staff members felt that it was really important to inform the family and carers about the importance of keeping moving and breaking up long periods of sitting and lying down (statement 2: +3). Taking the time at the beginning to work with the family, friends and carers and provide them with the knowledge to continue to care once they are home is vital in the stroke survivors' recovery.

> *“Because I think the family, friends and carers need to be on-board and helping the patient to keep moving because it’s like use it or lose it kind of thing, yeah. And I think they’re there 24/7, or they’re not necessarily but potentially more than any therapist going in, so I think the whole sort of friends and family needs to be involved.”* (Participant H6, Physiotherapist)

> *“I think depending on ethnicity, some people are quite happy to disable family members, so I think we need to get them to be more on-board with the rehab side, so I do think it’s important that even if they’re not doing much they need to get them out of bed, and instead of just being in a chair in one room, if they’re able to bring them into family times, so I think family, friends and carers, whoever’s dealing with them, need to get them on-board.”* (Participant H13, Therapy assistant)

Like the other three factors, the staff loading on factor one strongly believed that there was still a point in stroke survivors trying to move even if it doesn't lead to any health benefits (statement 16: -4). Moving regularly is important to help improve and maintain physical functioning in stroke survivors with severe mobility problems (statement 30: +3). It was also believed that moving regularly was more important for rehabilitation purposes than for reducing the risks of having another stroke (statement 18:+1).

> *“So I strongly disagree with that because any sort of movement can be good. Yes, you want people to move in as normal way as possible and the therapist can educate with that but actually movement is good to prevent risk of…All the health benefits of not moving outweigh…Do you know what I mean?...It’s so important that they continue to move in as little a way as possible but at least it’s form of movement.”* (Participant H20, Occupational therapist)

> *“Again it’s about moving, you’re keeping your muscles active, you’re keeping things moving, going, and so you can actually maintain, even if not improve it can definitely maintain the ability you’ve got as you left hospital because we worked hard to get there. If you go home and just sort of sat around then…Yeah, sort of maintain.”* (Participant H6, Physiotherapist)

The use of tools to aid rehabilitation and encourage movement was favoured by the staff, and included setting goals (statement 25: +3), practising exercises and movement tasks (statement 5: +2) and breaking movement tasks and exercises into smaller chunks (statement 11: +2). Goal setting and recording progress was used by all of the healthcare professionals as it motivated the patients to engage with the rehabilitation programme and see improvements. Being able to record and review their progress further increased their motivation and ultimately their confidence.

> *"Because if we don't make goals, that's not going to, it's not going to help a patient. Goals are really, I think goals are really important to give patients the encouragement to work towards what they want to. In that we include talking to family."* (Participant H8, Physiotherapist)

Similarly with the other three factors, those loading on factor one agreed that exercise is important following a stroke (statement 15:+2) and also believed that having mobility problems should not stop stroke survivors form trying or completing exercise (statement 26: +2). They acknowledged that fatigue was a barrier to movement in these patients (statement 31: +1), however with a ranking of +1 it indicates that it is not an impossible barrier to overcome and that other barriers may be more of an issue for rehabilitation.

> *"I think that is a limiting factor…Yeah. And I think, and after any kind of brain insult, fatigue does play a part and a lot of kind of times you can be, yeah, if you try and beat it then you pay for it the day after. So it's about educating people at which point they need to stop and recognising that point because often it's mind willing, not body."* (Participant H6, Physiotherapist)

> *"See, fatigue does limit how much they can do but it still means that they can do something. So, like, they might not be able to do 30 minutes a day but they could do 10 minutes in the morning, 10 minutes in the afternoon and, like, spread it out as they need to…I suppose again it's the pacing themselves and you then teach them how to pace themselves rather than doing it all in one."* (Participant H8, Physiotherapist)

Although these healthcare professionals acknowledged that reducing sedentary behaviour was somewhat important in these stroke survivors (statement 27: +1), they ranked it the lowest out of all of the factors indicating their belief that rehabilitation and exercise is more important in stroke survivors who have severe mobility problems. This is supported by their view that they agree that reducing sedentary behaviour should be included in guidelines (statement 13: +1), but again it is not the most important aspect of a stroke survivor's recovery.

This group of healthcare professionals were passionate in their view that just because stroke survivors may have severe mobility impairments this does not mean that they cannot care for themselves (statement 8: -3). Similarly they strongly disagreed that these stroke survivors cannot be independent as a result of their mobility problems. There are differing aspects of care and levels of independence, so although they may not be able to ambulate independently they can still be responsible for other aspects (e.g. self-care).

> *"I think people can be able to care for themselves in the right settings with the right support mechanisms. I think just because you've had a stroke doesn't mean to say you're going to go and live in a nursing home. I think a lot of stroke survivors do go home to live alone and survive, okay with care packages but that's what people, anybody with disabilities they're able to, yeah."* (Participant H6, Physiotherapist)

> *"There's different degrees of independent, so yes they can't walk, or they can't stand, but there's nothing to stop them being able to make themselves a drink, or toilet themselves with a bottle, or answer the phone or change the TV depending on the cognitive abilities…Just some form of independence, they may not be as independent as they were, but as long as they can do something for themselves, they need to work on that independence."* (Participant H13, Therapy assistant)

Risk avoidance does not stop healthcare professionals from encouraging movement (statement 7: -2) and the healthcare professionals loading on factor one also stated that they were not afraid to encourage movement in stroke survivors with severe mobility impairments (statement 10: -2). Healthcare professionals assess the risks as part of their jobs; they have been trained to deal with potential safety issues.

> *"Risk management, I don't really agree with that, weighing up the pros and cons of risk, there are some things you've got to avoid but the majority of what we do is, there's an element of risk in it to get them moving in the first place otherwise there'd be no point us doing anything."* (Participant H8, Physiotherapist)

> *"Yeah, I mean that's not what we kind of…That's not what we do. We cannot be afraid to move patients because we're afraid of safety, you know, when we're treating patients if we think that this patient needs double or triple then we'll kind of clinical reason that while we're treating the patient, so it's not like kind of being afraid, we're in the wrong job if we're afraid aren't we?"* (ParticipantH12, Physiotherapist)

In contrast to the other three factors, participants loading on factor one did not feel that long term therapy input was essential for stroke survivors with severe mobility problems (statement 14:0). They may need some input but maybe not intensive. Maybe the involvement of family, friends and carers (statement 33:+4) can allow the therapists to start the rehabilitation process but then the responsibility should then transfer to the stroke survivor and their support.

> *"I think that links very much to this one here about family…involvement because I think from my experience of stroke, quite long-standing, I think people think that therapy is the answer to everything and they don't realise that we can be like the guidelines and, but we can't do everything for everybody. And I often kind of think that my time is best spent with those new*

> *stroke patients because we're a limiting factor, we're not endless availability for us, yeah. So we're a limited resource so we have to use that resource as efficiently as we can. And I also say we're not a one-stop shop, you can see us, we can set goals, can work on things, once you get to resource we're booked out and then when things change down the line, good or bad, can get back in touch with us. Yeah…So that's why I think, I think people think therapy is the answer to everything and I don't think we are. I think we can facilitate things but we can't do it all for everybody."* (Participant H6, Physiotherapist)

> *"Yeah, I think again depending on how far they go it may be that family can take on more if family are able, so it doesn't have to be a professional therapy input, it can be family therapy input, as long as they know what they should be doing."* (Participant H13, Therapy assistant)

Despite agreeing more with the correct definition of sedentary behaviour; 'any waking behaviour while sitting or lying down that uses low energy expenditure' (statement 20: 0), compared to the other definition; 'someone is sedentary if they do not meet the physical activity guidelines'(statement 28:-2), the positioning of the statement at zero may suggest that the participants felt more strongly about some of the other statements and may have been unconcerned with the definition, especially as they were not aware that their knowledge of sedentary behaviour definitions was being tested. Similarly, they were unsure whether the health effects of moving regularly were different to not exercising (statement 3: 0) and slightly disagreed that movement was different to exercise (statement 29: -1). The comments below may add to the argument that the concept of sedentary behaviour is not well known and understood.

> *"I'm not sure what sort of the definition of sedentary is, really, I know what it is, but I'm not sure…Somebody who stays still, doesn't move, so sits in their chair for long periods of time, stays in bed for long periods of time, doesn't get up and move, or move around as much as they're able to, so they may not be able to walk or stand up because of their physical disability. So I could be sedentary if I decided to stay on the sofa all day [laughs]."* (Participant H5, Physiotherapist)

> *"Someone who is sedentary, they do not meet the physical activity guidelines. I'm just not too sure about that one."* (Participant H8, Physiotherapist)

5.2.3.1.2. Factor 2 – Therapy gets people moving

Factor two had an eigenvalue of 1.00 and explained 5% of the study variance. Four participants were significantly associated to the factor. All of participants were female and were comprised of three occupational therapists and one assistant practitioner. Experience working in stroke care ranged from 8 months up to 5 years.

Table 24 Healthcare Professional Factor 2: ‘Therapy gets people moving’ (most strongly agree/disagree only)

Number	Statement	Rank
5	Practising exercises and movement tasks is vital to improving mobility and increasing movement in stroke survivors who cannot walk or stand without help	+4
31	Fatigue limits how much stroke survivors can move throughout the day	+4
13	It is important for National Clinical Stroke Guidelines to recommend that sedentary behaviour should be minimised after stroke	+3
25	Setting goals and recording progress is a good way of trying to reduce time spent sedentary time in stroke survivors with severe mobility problems	+3
27	It is important to break-up long periods of sitting or lying	+3
9	Stroke survivors with severe mobility problems have no choice but to sit or lie-down for long periods	-3
16	There is no point in stroke survivors with severe mobility problems trying to move if the effort does not lead to any health benefit	-3
24	Reducing sedentary time is impossible in stroke survivors with severe mobility problems	-3
1	Only physiotherapists can make stroke survivors with severe mobility problems move more	-4
19	It’s not my job to reduce the time stroke survivors spend being sedentary	-4

Healthcare professionals loading on this factor had a strong focus on getting the stroke survivors moving, especially movement with a functional emphasis. This is unsurprising as the majority of the participants who were associated with this factor were occupational therapists. They strongly believed that sedentary behaviour should be reduced and understood the importance of it (statement 27:+3). In contrast to the other factors, they did not feel that exercise was that important (statement 15: 0), which again supports their view that functional movement should be the focus of the rehabilitation.

> *“I’m going to say that’s more important, I don’t think it’s necessarily exercise, I think it’s more just the general moving around, yeah. But I don’t know if that’s just because my definition of exercise is a bit too hardcore for these people.”* (Participant H15, Occupational therapist)

Their views about movement were supported by their belief that reducing sedentary behaviour in stroke survivors with severe mobility disability is not impossible (statement 24: 3) and that there is still a point in trying to move even if it doesn't lead to a health benefit (statement 16: -3). Out of all of the factors, the staff associated with factor two disagreed the most that these stroke survivors have no choice but to sit and lie-down for long periods (statement 9: -3). They believed that everyone has a choice and it should be for the healthcare professionals to work with the stroke survivor to figure out what can be done and how best to approach it in order to enable the stroke survivors to be as independent as they can be (statement 32: -2). Their overall view was that priority should be to reduce sedentary behaviour not just to increase exercise. Smaller movements that have more of a functional purpose are more important for the rehabilitation of these stroke survivors.

> *"I suppose it's different from exercise. Movement, lots of movements make up exercise."* (Participant H7, Occupational therapist)

> *"Um, I think that exercise is more, or a formal term. A patient might think of exercise as something that they have to do, sort of they've been given their exercises because we have cognitive exercises as well with workbooks and so on. Whereas movement, a patient would consider perhaps that they need to move their arm to reach for the cup and they wouldn't think of that as an exercise…But from a professional viewpoint you could consider that movement, all movement is a form of exercise."* (Participant H17, Occupational therapist)

The group of health care professionals who loaded on factor two strongly believed that it was important for national clinical guidelines to recommend that sedentary behaviour should be minimised after stroke (statement 13: +3). Guidelines provide a platform for healthcare professionals to tailor and guide their practices, therefore in order to get the reduction of sedentary behaviour into everyday practice, it is important for it to be outlined in guidance. Interestingly, participant H19 suggested that another incentive to follow guidelines is to ensure that what is outlined is being followed given the open access of the guidelines. Guidelines are freely available to everyone including family and friends, therefore if it is not being followed, family and friends may question the rehabilitation that their family or friend is receiving.

> *"Because I think the more that it's sort of set out into guidelines the more it will be followed and the more people seem to take notice of it and think actually we need to be looking at this and we need to be doing what the stroke guidelines, because anybody can go on and look at stroke guidelines and I think even patient's carers and families can go on and think, you know, we've recently had somebody that's been on the stroke guideline and said "I know we should be getting this, this, this and this" and that's fair enough. And people should be aware of what, you know, what we should be aiming for and be able to achieve."* (Participant H19, Assistant Practitioner)

In order to increase movement, these staff members agreed that tools were important to help them to achieve it. They had a ‘practice makes perfect’ attitude and felt that practising exercise and movement tasks was vital to improving and increasing movement (statement 5: +4). Similarly, goal setting was an important part of their rehabilitation programmes with the stroke survivors (statement 25: +3). Together these tools were very therapy focused and helped with the ultimate aim of increasing levels of movement. Although they thought ‘chunking’, the action of breaking tasks and exercises into smaller ‘chunks’ was a good way of improving movement (statement 11: +2), practice and goal setting was more important.

> *“I found that like I’ve worked in two Trusts, so this one and another one, and the Stroke Team in both of them, and I’ve found that here where we set a lot more goals on a regular basis and a lot more thorough goals and we engage the patients in setting them goals, I feel that that actually gets them in a place where they want to be moving a lot more, they want to be active. They know what benefits their therapy and what doesn’t.”* (Participant H7, Occupational therapist)

> *“I think as OTs we’re quite like goal orientated”* (Participant H15, Occupational therapist)

Out of all of the factors, these staff members acknowledged how much of a barrier fatigue is for stroke survivors during rehabilitation in trying to get them to increase their movement (statement 31: +4). They also acknowledged that loss of confidence following a stroke affects a stroke survivors level of movement and can obstruct their rehabilitation (statement 12:+2). It is important to acknowledge the barriers that can affect movement in order to plan and overcome them.

> *“Just because on a daily basis we see that all the time with our patients, sometimes we have to cancel half of their scheduled therapy sessions with them just because they are that fatigued. And on instances where we see them one day, you tire them out that much that they are unable to participate the next day. Or that they remember how fatigued they felt and they don’t want to engage so.”* (Participant H7, Occupational therapist)

All of the therapists loaded on this factor strongly disagreed that only physiotherapists can make stroke survivors with severe mobility problems move more (statement 1: -4) and felt that it was a big part of their job as occupational therapists and assistant practitioners (statement 19: -4). Physiotherapists should assess the stroke survivors movement early on and then advise and provide guidance to the other therapists and healthcare professionals in order for them to continue the rehabilitation.

> *"Because I'm an OT and I do that as well, so because I feel in my role, we help people with severe mobility problems move more as well so it's not just physios. We work collaboratively, especially in the Stroke Team it's quite a multidisciplinary effort so yeah, to work collaboratively."* (Participant H7, Occupational therapist)

> *"I wouldn't say. Only physios can make stroke survivors move more. I'd say it's, I would say they take a lead on it but they can offer us guidance on like how to move people so we can do it as well. And nurses obviously as well."* (Participant H15, Occupational therapist)

Unlike the other three factors, those loading on factor two ranked statement 21 'All health professionals should encourage the reduction of sedentary behaviour in stroke survivors with severe mobility problems' lower (statement 21: +2). This suggests that although everyone should be involved, they take more responsibility as they believe it is part of their role and do not just rely on everyone else to do it.

> *"Because it's not just for like the physiotherapists, it should be part of the multidisciplinary team that everybody's responsible for making sure that patients get up and move and not just when they're in some sort of therapy session. And like encouraging not only moving but independence as much as possible as well."* (Participant H19, Assistant practitioner)

Interestingly, those loading on factor two also did not believe that family, friend and carer involvement was as important as the other three factors and indicated that therapy and stroke survivor involvement was more important in the rehabilitation of the stroke survivors (statement 33: +1).

In regards to the definition of sedentary behaviour, those loading on this factor did believe the correct definition was slightly more appropriate (statement 20: +1) than the definition stating sedentary behaviour was a lack of physical activity (statement 28: 0) to express their opinion. However, the placement of the statements suggests that they are still uncertain about the true definition of sedentary behaviour. This is supported by their view that movement is different to exercise (statement 29: +1) but their uncertainty whether the health effects are different for not moving regularly and not exercising.

> *"Actually I have to say… I have to be honest, I don't know what the full definition is for sedentary…Well you hear of the term sedentary lifestyle a lot used by laypeople but I would think it's linked into time, how much time somebody spends sedentary because I think everybody in the world spends a certain amount of time in a sedentary state. I would think time is a key factor there. But I don't know what the timeframe is."* (Participant H17, Occupational therapist)

5.2.3.1.3. Factor 3 – Focused on the barriers

Factor three had an eigenvalue of 0.95 and explained 5% of the study variance. Three participants were significantly associated with the factor, all were female. These participants were physiotherapists working at a private neurophysiotherapy practice and had experience of working in stroke care for eight years or longer. As these physiotherapists worked privately, they were the therapists who had contact with stroke survivors in the long-term and had experience of providing rehabilitation to these patients, years following their strokes.

Table 25 Healthcare Professional Factor 3: Focussed on the barriers' (most strongly agree/disagree only)

Number	Statement	Rank
17	It is difficult to encourage stroke survivors to move more when family, friends and carers inhibit regular movement	+4
33	Family, friend and carer involvement is important to help reduce sedentary behaviour in stroke survivors	+4
12	Loss of confidence in stroke survivors with severe mobility problems makes it difficult to get them to move on a regular basis	+3
21	All health professionals should encourage the reduction of sedentary behaviour in stroke survivors with severe mobility problems.	+3
34	It is hard to motivate stroke survivors who cannot stand or walk without help to move more	+3
10	I am afraid to encourage movement in stroke survivors with severe mobility problems for safety reasons	-3
14	Stroke survivors with severe mobility problems do not need long term therapy input to reduce their sedentary behaviour	-3
16	There is no point in stroke survivors with severe mobility problems trying to move if the effort does not lead to any health benefit	-3
1	Only physiotherapists can make stroke survivors with severe mobility problems move more	-4
19	It's not my job to reduce the time stroke survivors spend being sedentary	-4

Family, friends and carers' involvement in the rehabilitation of the stroke survivor was deemed extremely important by these physiotherapists. As these are the people that spend the majority of time with the stroke survivor, they can continue the work that the therapists are able to do in the limited time that they spend with the patient (statement 33: +4). Despite the importance of them being involved, the physiotherapists acknowledged the difficulty of involving them and how they can often be a hindrance to their family member or friend's recovery (statement 17: +4).

Participants suggested family members can be too loving and over protective of their relative and as a result inhibit their movement. Appropriate training of the carers is therefore needed to ensure that they can provide helpful care and support rather than being a hindrance to their recovery.

> *"Yeah. So just because they're the people that are with that person for the majority of the time, so if they can get involved in motivating the stroke survivor to move then I think they're a strong influence on the person…"* (Participant H3, Physiotherapist)

> *"Yeah. Quite often. I think it's because they are so upset that their family member has had a stroke and they just want to help, so they don't know the difference between being encouraging and seeing it as part of their rehab, to wanting to protect them because they've gone through such a devastating thing. I think their emotions are mixed and there's a clash, there's a mismatch of how to help really."* (Participant H1, Physiotherapist)

Factor three had a strong focus on the barriers and negative aspects of the rehabilitation process. The loss of confidence that occurs as a result of the stroke often makes it difficult to get them to move on a regular basis (statement 12: +3). Similarly they agreed that it was often very difficult to motivate the stroke survivors to engage with rehabilitation and getting them to move more (statement 34: +3). Often the lack of confidence adds to the problems of motivation, making it really difficult to increase their movement.

> *"So if people are very frightened and anxious about moving that can be a real impedance to their process."* (Participant H2, Physiotherapist)

> *"I think because stroke is such, can be such a devastating, uh, not illness, has a devastating effect on people and it's such a long process for recovery, for a lot of my clients if they can't see that they're going to improve then what's the point?...So that's the kind of feedback I get back from them. You can't get them to do it because they just think "well what's the point in me doing it?" That's the impression I get."* (Participant H1, Physiotherapist)

Fatigue was also deemed a significant barrier that these physiotherapists witnessed in these stroke survivors (statement 31:+2). The focus on fatigue as a barrier and the additional problems identified by these physiotherapists highlights the complex needs that these stroke survivors have and the barriers they face, not only immediately after the stroke but also in the long-term following their stroke.

> *"I think the main reason people don't move around is because of fatigue, which is on there, and fear."* (Participant H1, Physiotherapist)

> *“Fatigue can limit how much stroke survivors can move, and sometimes it can have a massive impact, as can people’s cognitive abilities.”* (Participant H2, Physiotherapist)

> *“’The fear of having another stroke stops stroke survivors from trying to move.’ You see I haven’t asked anybody that…Yeah so I’m guessing. I would imagine if it was me I think I would worry about that”* (Participant H1, Physiotherapist)

As these stroke survivors with severe mobility problems have a multitude of problems and barriers highlights a need for longer term therapy. This group of physiotherapists, along with factor four, believe that long term therapy is essential for recovery and to reduce patients’ sedentary behaviour (statement 14: -3). As all of the participants in this factor are private physiotherapists, there is an argument that these are the only therapists that see these stroke patients in the longer term and are therefore more familiar with the range of experiences and complex problems this group of stroke survivors present with. Another argument is that as private physiotherapists, this is what they target and what their work specialises in and therefore they need to promote longer term therapy input.

> *“And again I think that’s commonly the thing that I hear is people get discharged from hospital and then they just feel like they don’t know what to do then, there’s nothing to do. And I think if you’re somebody who’s had a stroke who’s motivated and is cognitively intact, who has got a really supportive family or is financially better off and is able to get services to try and help you to be mobile, then great, but if you’re not one of those people it’s really hard.”* (Participant H3, Physiotherapist)

The physiotherapists who associated with factor three strongly believed that it should be a team effort to increase stroke survivors’ movement. As already mentioned family, friends and carers are vital in improving level of movement (statement 33: +4). Although they believe that it is their job to get them moving (statement 19: -4), they also strongly believed that all healthcare professionals should be involved (statement 21: +3) as it is not just physiotherapists that can increase a stroke survivor’s movement (statement 1: -4).

> *“It is my job, yeah. I think I’ve got a duty to point out or make the patient aware, and the families aware, that they need to get up and move more because they get more musculoskeletal problems, they get more tightness, they get more cardiovascular unfit, so yeah. We do always encourage them to do more.”* (Participant H1, Physiotherapist)

> *“Yeah. So I suppose it links in with why I so strongly agree with friends and family. So I think physios definitely have a role, we’ve got, you know, like we’re clinicians and specialists and whatever for working with stroke, people*

> *who've had a stroke but I think if it was only us then we'd have a big task on our hands. So I think we need other people to be able to do it, to help with that. So I strongly disagree."* (Participant H3, Physiotherapist)

Although the physiotherapists recognised that there were tools available to help to improve and increase movement in these stroke survivors, the placement of the statements at +1 indicates that they are not a priority. Instead it is extremely important to address the barriers and problems first before any tools are used to ensure that the stroke survivors are ready to engage in their rehabilitation and aim to produce longer-lasting results (statements 2, 5, 11, 25: +1). This also links with their view that stroke survivors with severe mobility problems require longer-term therapy input. The process for increasing movement is a complex and slow process whereby barriers should be addressed and overcome prior to incorporating strategies to try and improve their movement. As this process can take a while, therapy input may also be required for an extended period of time to ensure that the full process is completed.

> *"I think that's good for us. Setting goals and recording progress is a good way of trying to reduce time spent sedentary. Um, we think it's important but the patient necessarily doesn't."* (Participant H1, Physiotherapist)

Those loading on factor three had an understanding that sedentary behaviour was more than not exercising (statement 20: +1), with them disagreeing that someone is sedentary if they do not meet the physical activity guidelines (statement 28: -2). Participant H1 highlighted the misunderstandings and confusion around sedentary behaviour with her belief that someone is sedentary if they do not have any social interaction. Despite their limited knowledge of sedentary behaviour, out of all of the factors, those loading on factor three did not think that movement and exercise were different (statement 29: -1) nor did they believe that the health effects of not moving regularly are different to the health effects of not exercising (statement 3: -1).

> *"Yeah. It's a good question actually. It's not something I've really thought about. Somebody is sedentary that doesn't have social interaction with anybody else than either their carer or family, so they don't go out, don't do any tasks, they don't have any activities of daily living apart from get up, get washed with a carer, go down and watch TV. That's what I class as sedentary. Don't have any social interaction."* (Participant H1, Physiotherapist)

> *"…That's a matter of definitions of the term isn't it really? No, lots of people don't meet the guidelines and they're still not sedentary…"* (Participant H2, Physiotherapist)

With regards to exercise and movement, factor three believed that exercising regularly (statement 15: +2) was just as important as trying to break-up extended periods of sitting and lying down (statement 27: +2). There were also under the belief that recommendations to reduce sedentary behaviour do not need to be included in guidelines as clinical practice would continue without guidance (statement 13: -1).

> *"It's not something I've really kind of, I don't have in my mind when I'm treating "oh I need to think about this clinical stroke guidelines"."* (Participant H2, Physiotherapist)

Out of all the factors, the physiotherapists in factor three were unsure whether reducing sedentary behaviour in stroke survivors with severe mobility disability is impossible (statement 24: 0). Stroke survivors with severe mobility disabilities have complex needs and barriers that last for a long time following their stroke that make increasing movement very difficult.

5.2.3.1.4. Factor 4 – Keep moving no excuses

Factor four had an eigenvalue of 0.81 and explained 4% of the study variance. Three participants were significantly associated to the factor, all of which were female. Two of the participants were physiotherapists and one was a physiotherapy assistant. Experience working in stroke care ranged from 1 year up to 17 years.

Table 26 Healthcare Professional Factor 4: ‘Keep moving no excuses’ (most strongly agree/disagree only)

Number	Statement	Rank
26	Having severe problems with mobility should not stop stroke survivors from exercising	+4
30	Moving regularly helps to improve and maintain physical functioning in people with severe mobility problems after stroke	+4
15	Exercise is important for people with severe mobility problems after stroke	+3
27	It is important to break-up long periods of sitting or lying	+3
33	Family, friend and carer involvement is important to help reduce sedentary behaviour in stroke survivors	+3
1	Only physiotherapists can make stroke survivors with severe mobility problems move more	-3
14	Stroke survivors with severe mobility problems do not need long term therapy input to reduce their sedentary behaviour	-3
32	Stroke survivors who are unable to walk or stand without help cannot be independent	-3
16	There is no point in stroke survivors with severe mobility problems trying to move if the effort does not lead to any health benefit	-4
24	Reducing sedentary time is impossible in stroke survivors with severe mobility problems	-4

Those loading on factor four strongly believed that exercise was important for people with severe mobility problems after a stroke (statement 15: +3), rating it the highest out of the all four factors. Equally they believed that breaking up long periods of sitting or lying down was important (statement 27: +3). Although they understood the importance of moving regularly to improve and maintain physical functioning (statement 30: +4), they were also of the strong belief that there is a point to moving even if it does not lead to any health benefit (statement 16: -4). They believe that there are other benefits to moving, therefore any movement is worth doing even if they are limited by their mobility, they can do something.

> *“Because I think by exercising they’re going to learn new skills, they’re going to be able to learn to move more or achieve the tasks that they’re trying to achieve by practicing the exercising, also it sort of helps their cardiovascular fitness and sense of wellbeing and...”* (Participant H4, Physiotherapist)

> *“Well because obviously measuring what kind of health benefits someone with severe mobility problems is going to get from something, like there’s, you can’t just say don’t move if you’re not going to then end up being able to walk by yourself or like just any muscle contraction helps with blood circulation, everything like, so it might not be a long lasting health benefit or anything that’s noticeable but you’re better moving than not.”* (Participant H16, Physiotherapist)

Everyone should exercise as it is important for health and wellbeing. It shouldn't be stopped by a person's mobility as everyone should be able to do something (statement 26: +4). Similarly they do not believe that reducing sedentary time is impossible in stroke survivors with severe mobility problems (statement 24: -4). Although it may difficult, there will be something that these stroke survivors can do and with the right help and support it can be achieved.

> *"I think it's probably always possible to reduce people's sedentary time, I suppose it depends on the person, but I imagine there's always something that can be done if a person's willing to do it."* (Participant H9, Physiotherapy assistant)

> *"Yeah. I think pretty much most people are able to exercise unless you're comatose, you should be using what you've got…Because I think if they don't exercise, everything's going to go very downhill for them quite quickly, and then you're going to get more complications and more health problems."* (Participant H9, Physiotherapy assistant)

As demonstrated by the previous statements, these healthcare professionals believed the importance of keeping moving and exercising and that there are no excuses that should stop rehabilitation. This is supported by their view that no barrier is too big not to be overcome. From their experience, fear of having another stroke was not an issue in these stroke survivors (statement 4: -2). They also disagreed that until stroke survivors come to terms with their mobility problems following their stroke, it is impossible to increase their movement (statement 6: -2). They believed that their movement levels can be increased even if just a small amount. It may be very difficult but it is possible and worth the effort of trying. Again, fatigue was not deemed to be much of a barrier by this factor (statement 31: -1). Loss of confidence was deemed the most likely barrier in these stroke survivors by this factor, but with a rating of zero it was again not viewed as being much of an issue (statement 21: 0).

> *"Um, I'm not sure it stops them from trying to move regularly, although there is often a fear that they're going to have another stroke isn't there?"* (Participant H4, Physiotherapist)

> *"Fatigue limits how much stroke survivors can move throughout the day. Yes, it's a problem after stroke. I feel that some people use it as a bit of an excuse…But that's, it's still… But the actual fatigue, I don't believe that it's always the actual fatigue, it's more their like perception of the fatigue."* (Participant H16, Physiotherapist)

> *"Yeah, I think you'd work in a way to sort of give them tasks that they can manage, to build up their confidence, so although I agree with it in some*

> *points but maybe not as strongly as others, so..."* (Participant H4, Physiotherapist)

Healthcare professionals loading on factor four acknowledged that a vital part of rehabilitation of these patients is the involvement of family, friends and carers in the process (statement 33: +3). They believed that their help is key to help keep the stroke survivors active. This statement was ranked higher than statement 21, indicating that although they believe that it is important for all healthcare professionals to encourage the reduction of sedentary behaviour (statement 21: +2), they feel that family and friends should be more involved and responsible to help reduce sedentary behaviour. This could be explained by their view that although they can provide initial support and guidance, family and friends spend the majority of their time with them and can therefore continue rehabilitation when the therapists are not present. Interestingly, they did not believe that informing stroke survivors and their families about the importance of keeping moving and breaking up long periods of sitting or lying down was as important as the other three factors (statement 2: +1). Although they value and need the help of family and friends, they do not believe that information provision is high up on their priorities.

> *"The family involvement I think is very important…Yes, I think that is very important. I think it really has a big impact on the outcome if they've got a supportive spouse, carer, somebody with them. And it's very important to involve the family and friends so they know what the person's doing and why and they can encourage and help them to achieve it."* (Participant H4, Physiotherapist)

Compared to the participants loading onto the other three factors, the participants who loaded onto factor four did not disagree as strongly that it is not their job to reduce the time stroke survivors spend being sedentary (statement 19: -1). They do however still disagree with the statement believing that it is part of their job. They also strongly disagreed that only physiotherapists are able to make stroke survivors with severe mobility problems move more (statement 1: -3). The sorting of the statements could potentially be explained by their view that it isn't just their job to reduce sedentary behaviour. This also matches their belief that family, friend and carer involvement is extremely important when trying to increase someone's movement (statement 33: +3).

> *"Ha! It's not my job to reduce the time, all we end up doing, move, move, move!"* (Participant H16, Physiotherapist)

> *"Everybody…So yes, it's annoying when families inhibit but also you can get the amazing families that if they didn't have them they wouldn't be where they are because they just, they facilitate them getting up and moving around and everything. And it annoys me when people are like "well when they're having physio" and it's like it's not just about the physio, like it's what you do in-between, so the attitude that it is just physios can be quite damaging."* (Participant H16, Physiotherapist)

Those loading on factor four believed it important for recommendations for reducing sedentary behaviour to be included in the National Clinical Guideline for Stroke (statement 12: +2). They also agreed that stroke survivors with severe mobility problems would benefit from long term therapy input but it might not need to be intensive (statement 14: -3). They also believed that family and carers could be involved more in taking responsibility for continued rehabilitation.

> *"Um, you would hope that the therapist will follow the guidelines and therefore anything really important needs to be in the guidelines, so keeping people active is really quite a key thing in everybody, stroke or not, so it should be there."* (Participant H9, Physiotherapy assistant)

> *"Well I don't think that you have this time where it's important to have physio and then it drops off and it stops, I think certainly people that have got quite severe problems often benefit from not necessarily intensive long-term input but having that ability to have some physiotherapy at different, you know, at intervals is what I'm trying to say."* (Participant H4, Physiotherapist)

From how the participants in factor four sorted the statements, it could be interpreted that they did not have an understanding of what sedentary behaviour was with both definitions being disagreed with (statement 20, 28: -2). However, the informal discussions with the participants exposed their knowledge of sedentary behaviour and the correct definition. This disparity between their Q-sorts and their verbalised thoughts suggests that they do have a basic understanding of what sedentary behaviour is but a formal definition is perhaps not clear to them.

> *"How do you define sedentary, good question. Well if somebody's not able to get up and move about regularly or stand regularly. But yeah, that's an interesting one that isn't it?"* (Participant H4, Physiotherapist)

> *"To me sedentary would be more if you're sitting down, not doing anything. So you could be sitting down but you could be really active in sitting."* (Participant H9, Physiotherapy assistant)

5.2.3.2. Consensus Statements

Fifteen consensus statements did not discriminate between factors for healthcare professionals (Table Twenty-Seven).

Table 27 Healthcare professionals' consensus statements

No.	Statement	F1	F2	F3	F4
1	Only physiotherapists can make stroke survivors with severe mobility problems move more	-3	-4	-4	-3
3	The health effects of not moving regularly are different from the health effects of not exercising	0	0	-1	0
4	The fear of having another stroke stops stroke survivors from trying to move regularly	-1	-1	0	-2
6	Until stroke survivors come to terms with their mobility problems following their stroke, it is impossible to increase their level of movement	-1	-1	-1	-2
7	Risk avoidance stops healthcare professionals from encouraging movement in stroke survivors with severe mobility problems	-2	-1	-1	0
10	I am afraid to encourage movement in stroke survivors with severe mobility problems for safety reasons	-2	-2	-3	-1
11	Breaking movement tasks and exercises into smaller chunks would make trying to move more in stroke survivors with severe mobility problems easier	+2	+2	+1	+1
16	There is no point in stroke survivors with severe mobility problems trying to move if the effort does not lead to any health benefit	-4	-3	-3	-4
18	Moving regularly is important to reduce the risks of having another stroke	+1	0	0	+1
21	All health professionals should encourage the reduction of sedentary behaviour in stroke survivors with severe mobility problems	+4	+2	+3	+2
22	You cannot be healthy if you are inactive	-1	0	0	0
25	Setting goals and recording progress is a good way of trying to reduce time spent sedentary time in stroke survivors with severe mobility problems	+3	+3	+1	+1
28	Someone is sedentary if they do not meet the physical activity guidelines	-2	0	-2	-2
30	Moving regularly helps to improve and maintain physical functioning in people with severe mobility problems after stroke	+3	+2	+2	+4
32	Stroke survivors who are unable to walk or stand without help cannot be independent	-4	-2	-2	-3

The healthcare professionals strongly believed that moving regularly is important to help to improve and maintain physical functioning in people with severe mobility problems after stroke (statement 30: 3, 2, 2, 4). However there was as a strong disagreement amongst them with the statement that there was no point in stroke survivors with severe mobility problems trying to move if it leads to no health benefit (statement 16: -4, -3, -3, -4). They argued that movement has many benefits, so even if they were unable to make any further improvements, the mental benefits alone would make trying to move worth it. Movement is also extremely important for these stroke survivors to change position and reduce the risks of pressure sores and other positioning health problems. Similarly there was a strong belief that these stroke survivors can still be independent despite having severe mobility problems (statement 32: -4, -2, -2, -3). Although they may not be able to independently walk and stand there are many other aspects of their daily lives whereby they can be independent.

There was a strong consensus view that it isn’t just physiotherapists who are able to make stroke survivors move more (statement 1: -3, -4, -4, -3) and that all healthcare professionals should encourage movement in these patients (statement 21: 4, 2, 3, 2). Although physiotherapists can conduct initial assessments with the stroke survivors to assess the mobility levels, it should be for all healthcare professionals to use their advice and continue the work of the physiotherapists by trying to get the stroke survivors moving more.

A few of the consensus statements highlighted the uncertainty around the definitions and concepts of sedentary behaviour and physical activity. Statement three, ‘The health effects of not moving regularly are different from the health effects of not exercising’ (statement 3: 0, 0, -1, 0), was mainly sorted as neutral by the healthcare professionals indicating a lack of knowledge of the health implications of sedentary behaviour. Similarly, there was a similar neutral placement of statement 22 indicating some consensus regarding whether an individual can be healthy if they are inactive (statement 22: -1, 0, 0, 0).

Despite the healthcare professionals expressing an uncertainty about the definition of sedentary behaviour during the Q-sorts, a neutral to moderate disagreement with statement 28, ‘Someone is sedentary if they do not meet the physical activity guidelines’, indicates that they are aware that it does not relate only to the lack of physical activity.

These healthcare professionals did not feel afraid to encourage movement in stroke survivors with mobility problems and expressed that is was part of their jobs to assess risks and ensure movement is done as safely as possible (statement 10: -2, -2, -3, -1). However, statement seven was ranked neutral to moderately disagree suggesting that although they feel confident to move patients, their perception may be that other healthcare professionals may be afraid to encourage movement for example some nursing staff and healthcare assistants (statement 7: -2, -1, -1, 0).

5.2.3.3. Summary

One of the main findings from the healthcare professionals' data was the apparent lack of understanding and knowledge around sedentary behaviour. The sorting of the statements relating to sedentary behaviour were often sorted neutrally either indicating an uncertainty around the topic or that the definitions were not perceived to be as important as other statements in the Q-set. Although the sorting of the statements highlighted the general lack of knowledge, the informal discussions with the staff members indicated that some of them did understand what it was and what was meant by it, but were not confident with definitions and terminology of this concept. Overall the healthcare professionals agreed that reducing sedentary behaviour in stroke survivors with severe mobility disability is possible despite the many barriers that exist for these patients.

Participants loading on factors three and four strongly believed that stroke survivors with severe mobility disability require long term therapy input, with those loading on factor two agreeing slightly less and participants loading on factor one having a neutral opinion. This diversity of viewpoints feeds into a bigger argument on recovery trajectories and how long after stroke patients should receive therapy input. Evidence suggests that a plateau in recovery is observed after three months post stroke indicating that intensive therapy input should occur within these three months in order to achieve the best possible recovery (Lee et al., 2015). Healthcare professionals loading on factor three were a group of neurophysiotherapists who worked in a private practice and had caseloads of patients that were several years post stroke. They strongly believed that these stroke survivors require long-term therapy in order to firstly address the plethora of barriers before trying to increase their movement. From their experience they believe that stroke survivors still have the potential for significant improvement after the three month 'plateau' phase. This finding supports the opposing view of the recovery trajectory following stroke, that recognises that recovery can occur longer term past the typical recovery plateau of three months (Page et al., 2004).

Although those loading on the other three factors also agreed that long-term therapy input would be helpful they also strongly believed that family, friends and carers should take on a significant role in continuing therapeutic activity with stroke survivors in the future. As the majority of the other participants loading onto factors one, two and four were NHS based healthcare professionals they often suggested that although long term therapy would be good, restrictions on resource limits how much therapy a patient can receive after a stroke (i.e. commissioning of early supported discharge (ESD) to time limited period usually not exceeding eight weeks), therefore supporting the involvement of family and friends.

There was an obvious distinction between occupational therapists and physiotherapists, evidenced by the observed difference between factor two (n= 4 occupational therapists) and factor four (n= 2 physiotherapists and 1 physiotherapy assistant). Occupational therapists believed that functional movement was most important to the stroke survivors in order for them to gain independence and live as normal life as possible. In contrast, the physiotherapists generally believed that exercise was extremely important after a stroke to help to improve and maintain physical functioning in the stroke survivor. This finding reflects differences in the philosophy underpinning the professional training of these groups as well as the practice focus of their daily practice in most cases.

Healthcare professionals often discussed how a stroke survivor’s personality influenced how motivated they were and how easy or difficult it made rehabilitation. They suggested the initial challenge is to assess whether the stroke survivor has a ‘determined’ or ‘defeated’ attitude to then be able to tailor how they approach rehabilitation and therapy. Generally they did not believe that motivation was a significant barrier (except participants loading on factor three), with different strategies being used depending on the stroke survivors’ emotional response to their stroke, their coping styles and individuals’ adaptation to long-term disability.

The informal discussion with the healthcare professionals also highlighted some other issues that regularly affect a stroke survivor’s level of movement that were not included in the Q-set. Although there was a general agreement that involvement from family and friends is extremely important in the rehabilitation of the stroke survivors, it was also agreed that they can often inhibit their movement in order to protect them, with cultural background influencing how much they get involved. The healthcare professionals explained that this often occurred in south Asian families who believe that it is their role to love and support their family member, especially ‘elders’ by doing everything for the stroke survivor. Although this is deemed to show love and being caring, it also often inhibits a patient’s recovery as they are stopped from moving and doing activities of daily living for themselves.

Another problem that was highlighted by the participants was the effect that cognitive issues have on a stroke survivor's level of movement. Often severe mobility problems are accompanied by severe cognitive impairments as a result of a severe stroke. The staff described cognitive impairments as another layer of difficulty which again supports the requirement of family, friend and carer involvement. Severe cognitive impairments affect the stroke survivor's ability to process the information provided during rehabilitation and they may not have the capacity to initiate exercise or move regularly. Therefore the help and support of their loved ones is often needed to encourage movement and continue rehabilitation in these patients.

5.3. Discussion

This study aimed to explore and understand the perspectives of stroke survivors with severe mobility disability, their carers and healthcare professionals involved in their care in relation to sedentary behaviour. The three factors generated for stroke survivors, three factors generated for carers and four factors generated for healthcare professionals, identified participants' subjective responses about sedentary behaviour in this specific group of stroke survivors.

A majority view across the three participant groups suggested that reducing sedentary behaviour is important for stroke survivors, however most participants believed that exercise was more important for these individuals. Exercise was seen as important in order to improve and maintain their physical functioning and therefore should be engaged with as much as possible in order to try and continue to recover. There was an obvious divide between physiotherapists who favoured exercise, to occupational therapists who preferred to focus on smaller more functional movements. Generally, the stroke survivors knew and understood the importance of not sitting for long periods without regular breaks whereas the carers were unsure and again favoured exercise. This could be explained by their hope for continued recovery through exercise therefore prioritising it over increases in movement.

Overall there was consensus that reducing sedentary behaviour in stroke survivors with severe mobility disability was possible. Both stroke survivors and healthcare professionals quite strongly agreed that it was possible whereas the carer participants had a neutral view indicating an uncertainty of how or if it could be achieved. Despite the general view across participants that reducing sedentary behaviour in this stroke population is possible, the numerous barriers that affect levels of movement and rehabilitation highlighted through the study also indicates that the process would be complex and difficult.

One of the main findings from the study was the general lack of knowledge and understanding around the topic of sedentary behaviour. Although through the informal discussions it was gauged that all participants have a general understanding that we should move regularly and not sit for too long, the sorting of the two statements across all participant groups relating to definitions and others referring to the concept of sedentary behaviour (statement 3: ‘The health effects of not moving are different from the health effects of not exercising’, statement 22: ‘You cannot be healthy if you are inactive’, statement 29: ‘Movement is different to exercise’) indicated that there was an overall uncertainty about the topic, with the majority of the statements sorted neutrally.

The Sedentary Behaviour Research Network (SBRN) terminology consensus project agreed a standard definition for sedentary behaviour that can be used by researchers, practitioners and industry (‘any waking behaviour characterised by an energy expenditure ≤1.5 metabolic equivalents (METs), while in a sitting, reclining or lying posture’). Unfortunately, the media often portrays sedentariness as a lack of physical activity rather than its true definition. Although the SBRN’s work to standardise terminology and understanding is a huge step forward in the sedentary behaviour field, their work was not aimed at the general public. More work is therefore needed to raise awareness of sedentary behaviour in the general public and make everyone from patients to healthcare professionals aware of what it is, what the health effects are and what can be done to reduce it.

Overall there was a general belief that stroke survivors with severe mobility disabilities would benefit from long-term therapy input to help increase movement and reduce sedentary behaviour. However, staff members were also clear that limited resource of both time and staff numbers was a big problem that affected rehabilitation and therapy provision for patients. As resource was limited, healthcare professionals described how therapy was targeted to patients who were deemed to make the most progress, often within the first three months after stroke. This meant that long-term therapy was usually not available. It was observed through the study that unless an individual has enough money to afford private physiotherapy, unfortunately therapy input will stop. This highlights why it is therefore important to have family, friends and carers help and support to continue the rehabilitation not only during the same period whereby therapy is provided but also once therapy input stops.

Another important message to emerge from the data was the variety of stroke presentations within the ‘severe mobility disability’ category. The healthcare professionals found it difficult to sort some statements during the Q-sort as they drew on their experiences of working with patients who are classified as levels one, two and three on the functional ambulatory classifications (Holden et al., 1984) (Figure Three). Even though the stroke survivors were categorised by their level of mobility impairments, within the categories there is variance in how the stroke presents itself, the individual’s recovery trajectory and the barriers to movement that are specific to the individual, including cognitive deficits. No two strokes are the same which makes rehabilitation of stroke survivors very complex. Although grouping these stroke survivors into one category of severely mobility impaired helps to identify the patients, due to the complex nature of the stroke and recovery process, rehabilitation should take an individual patient-centred approach with each stroke survivor being assessed and managed as an individual not as a group of patients. It is important that this translates into future interventions to reduce sedentary behaviour in this population as a personalised tailored approach would allow the intervention to be acceptable to the individual patients. This was also highlighted through the results from both the stroke survivors and carers who through the numerous viewpoints showed how different stroke survivors require differing amounts of support and strategies to get them moving.

The study aimed to recruit approximately sixty participants in total, with twenty in each participant group. Recruitment of stroke survivors to the study was difficult and time consuming, a factor evident in other studies of this population (Lloyd et al., 2018b). Severe mobility problems following a severe stroke are often also accompanied by cognitive impairments and language and communication difficulties. In order for the stroke survivors to take part in the study they had to have a certain level of cognitive, language and communication capacity, to be able to comprehend the instructions for the study and participate accordingly. These criteria significantly reduced the number of stroke survivors available for inclusion in the study therefore a sample size of seventeen was deemed acceptable especially given the small timescales associated with data collection. Another issue that may have arisen during the sampling and recruitment process is self-selection of participants’ bias. As participants were able to express an interest in taking part once they had received information about the study, the type of 'self-selecting' participants may be of a similar personality and not be representative of the target populations. These participants may be more obedient and motivated to take part in studies and therefore been more inclined to provide socially acceptable answers.

Recruitment of carers to the study was extremely difficult with only twelve being recruited and participating in the study. Stroke survivors who were recruited to the study often did not have any family members or friends who provided help and support to them. Additionally where carers were associated to the stroke survivor, some declined to participate because they either did not want to take part or felt that they were so busy with looking after the stroke survivor and running the house that they did not have the time to participate themselves. Despite only twelve participants taking part, the three factors that were generated from the carers' data show three strong and important viewpoints that add significantly to the results of the study. The target number of healthcare professionals recruited to the study was achieved and participants were comprised of physiotherapists, occupational therapists and therapy assistants. The study planned to recruit a range of healthcare professions including doctors, nurses and therapy staff. However recruitment of medical and nursing staff was limited by the staff who were able and available to take part, with therapy staff finding it easier to schedule. It would be interesting to assess whether the inclusion of a more diverse staff participant group including doctors and nursing staff would produce significantly different viewpoints and results. The study did not exclude these staff groups from participation but recruitment of them to the study was extremely difficult due to workload pressures and staff availability.

One of the main strengths of the Q-methodological study was the opportunity given to this group of stroke survivors, who have to date been excluded, to have a voice, allowing their experiences, views and needs to be heard in relation to movement and their rehabilitation. Another strength of this study was the involvement of stakeholders. With this research possibly leading to an intervention it was important that all individuals who could potentially be involved in the design, delivery and target of the intervention should be included in the study. It is likely that any intervention that could be developed in the future would involve both informal carers and healthcare professionals involved in the stroke survivors' care. It was therefore important to include not only the target stroke survivor population but also family, friends and carers who provide regular support and healthcare professionals to gauge their thoughts and perspectives on the topic of sedentary behaviour.

The methodology was accepted and participation in the process enjoyed by the majority of the participants. The card sorting procedure (Q-sort) was praised for its interactive method as it allowed conversations to be initiated using the statements and their position on the grid to explain and understand what each participant's views were. Discussions were led by the participants rather than being guided by the researcher using an interview schedule, and the relaxed nature of the process allowed participants to be open and comfortable. Although the placement of the statements on the grid allowed the generation of the factors, the informal discussion data was vital to help determine how many factors to include and to interpret the viewpoints.

Whilst the participants enjoyed the different methodology, the majority of participants found ranking the statements difficult, especially for the statements that they strongly agreed and disagreed with. Often participants wanted to put more statements than allowed on +4 and -4 columns on the grid. This forced-choice method, although often difficult to complete, allows subtle nuances in the participants' viewpoints to be observed. Out of the three participant groups, the healthcare professionals found the forced-choice Q-sort method the most difficult. They regularly deliberated over the statements and where they should be placed on the Q-sort in relation to the others and described how they did not want to get it wrong or say the wrong thing, despite being informed that there was no right or wrong way to complete the Q-sort.

One of the main limitations of the present study was the three participant groups completing the Q-sorts with slightly different Q-sets. This inhibited the overall analysis of the data as the participants from the three groups could not be directly compared in one large factor analysis. The decision was made during study development to create a Q-set specific for the stroke survivors that was then adapted and made relevant to the carers and healthcare professionals individually in order to ask some specific questions of the different participant groups. Despite being unable to directly compare the viewpoints from the three groups using statistical analysis, the factors and interpretations of each of the groups produced through the study provided detailed descriptions of the emerging viewpoints. Although the Q-sets were different for each of the groups, the majority of the statements were either the same or very similar allowing cross-group comparisons to be made following the statistical analysis and interpretation of the factors.

Another limitation of the Q-methodological study, which is well documented in the Q-methodology literature, was the time and effort it took to design and develop the Q-set due to the iterative process of reviewing, synthesising and piloting the items in order to be confident that the final Q-set was balanced and representative. The process from the initial review of the academic literature through to having the three finalised Q-sets took three months, which is a significant amount of time in a time-limited project. It is important for future research studies considering the use of Q-methodology to factor in adequate time for Q-set development.

5.4. Conclusion

As this study has highlighted, stroke survivors understand the importance of moving regularly separate to exercise and are generally willing to try and move despite having severe mobility problems. They believed that it was possible to reduce their sedentary behaviour but were unsure about how to. The healthcare professionals supported their view and also believed that it was possible to reduce sedentary behaviour in stroke survivors with severe mobility disabilities. Despite carers being unsure whether reducing sedentary behaviour is possible they provide invaluable support that is acknowledged by both the stroke survivors and the healthcare professionals. There is an obvious need for an intervention or targeted strategies to reduce sedentary behaviour in this specific group of stroke survivors that would be welcomed by the stroke survivors, as this study has identified.

The present Q-methodological study has generated views on sedentary behaviour and physical activity in stroke survivors with severe mobility disability. The Q-study has provided an initial insight into sedentary behaviour in this stroke population and has confirmed that this is an important topic to stroke survivors and also to their carers and healthcare professionals. As highlighted by the systematic review in Chapter Three, sedentary behaviour levels have not been measured in this stroke population. It is not fully known how sedentary these stroke survivors are and how their sedentary time is accumulated. This information would be important to explore in order to help target interventions. More work is also needed to explore with the same participants of this study (i.e. non-ambulatory stroke survivors, carers and healthcare professionals), what the likely process of change of an intervention would be to build upon the findings of the Q-study in order to help develop an intervention that would aim to reduce sedentary behaviour in this stroke population.

In order for an intervention to be developed it would also be important to assess what strategies could be completed by the stroke survivor in order to break-up their sedentary behaviour. As there was a consensus view that doing jobs around the house was physical activity, activities of daily living may be a suitable target for intervention strategies to be based upon. It may be suggested that incorporating activities of daily living that can be completed whilst seated may be suitable to reduce sedentary behaviour in non-ambulatory stroke survivors through increased light-intensity physical activity and energy expenditures instead of regular standing and walking breaks suggested to the general population. This therefore provides support and justification for the second empirical study conducted as part of the project, which aimed to investigate the energy requirements of activities of daily living in stroke survivors with severe mobility disability living at home (described in chapter seven), to assess what activities can raise energy expenditures above the sedentary behaviour threshold.

Chapter 6 - Investigating energy requirements of activities of daily living in stroke survivors with severe mobility disability living at home

6.1. Introduction

In order to help inform guidance for intervention development to reduce sedentary behaviour, it was deemed important to understand what activities and strategies could be used to help reduce sedentary time. A study was conducted that assessed the energy requirements of activities of daily living in stroke survivors with severe mobility disability in their home environment. The chapter first presents a background to energy expenditure measurements in general and then in a stroke population, before describing the methods of the study in detail. The findings are then presented in a case-by-case basis before providing a comparison across all cases. The chapter concludes with a general discussion of the results, the direction of future research and the potential for intervention development before discussing the limitations and issues of feasibility of the methods.

6.2. Background

As the Q-methodology study has highlighted, despite stroke survivors being highly sedentary (Chapter 3 – Systematic review), they understand the importance of regular movement and not sitting for too long without breaks (Chapter 5- Q-methodology results). Along with their family members and healthcare professionals who care for stroke survivors with severe mobility disabilities, there is a strong majority belief that reducing sedentary behaviour in this population is not impossible and a strong will to engage with something that will help them to reduce sedentary time and ultimately improve their health.

While interventions to reduce sedentary behaviour typically promote increased time spent standing and engaged in leisure-based activities, for individuals with severe stroke-related mobility impairment increasing time standing or ambulating may not be an option (Bailey, 2016). As it is believed that an increase in energy expenditure above the 1.5 metabolic equivalents threshold (METs) would result in a break in sedentary behaviour (according to the sedentary behaviour definition explained in Chapter Two), it would be important to determine which activities or strategies require greater than 1.5 METs in these stroke survivors. These could then be adopted by stroke survivors with severe mobility disability to help reduce their sedentary behaviour.

A compendium of activities is available that details the MET values for activities of various intensities, including activities of daily living. The compendium originally produced by Ainsworth and colleagues (1993), with updates available (2011), details MET levels derived from published laboratory and field experiments that have measured the oxygen cost of the specific activities. It was created as a source of information for energy expenditure of different activities and is often used in exercise prescriptions to promote physical activity (Serra et al., 2016). Despite the wealth of information provided by the compendium, it was created for use in able-bodied adults aged between 18-65 years old and therefore may underestimate energy requirements for activities in both older and disabled individuals.
A study by Serra and Colleagues (2016), aimed to measure the energy cost of completing mobility-related activities in stroke survivors and compare these values against the MET values published in the compendium of activities (Ainsworth et al., 2011). Twenty-eight stroke survivors with hemi-paretic gait performed five mobility activities (floor sweeping, stepping in place, over-ground walking, lower speed treadmill walking and higher speed treadmill walking), whilst energy cost monitoring was performed using a portable indirect calorimetry system (COSMED K4b2). The results showed that the MET values published in the compendium overestimated energy expenditure at rest and underestimated energy expenditure during physical activity. Although this study highlighted the need for more applicable energy expenditure measurements for stroke survivors, the study only included stroke survivors who were able to walk and not those with severe mobility disabilities. Therefore future work needs to be more inclusive of stroke survivors with varying levels of stroke severity and associated impairments.

This was also identified by Galea et al. (2015) who, through a systematic review, highlighted the need to not only investigate physical activity levels but also the energy costs of activities in stroke survivors who require assistance to walk, or who walk at very slow speeds. Earlier still, Manns and colleagues (2012) had argued that determining what constitutes light-intensity activity for people with severe mobility disability, in order for interventions to target sedentary behaviour to be developed, should be a research priority. It is therefore important to see what the energy costs of activities of daily living are for stroke survivors, including those with severe mobility disability to assess what activities may have the potential to raise energy expenditure above the 1.5 METs sedentary behaviour threshold.
Verschuren and colleagues (2016), conducted a study to measure and calculate the energy expended by people with stroke during; lying, sitting, standing, walking and

wheelchair propulsion in order to compare the values with the sedentary behaviour definition of 1.5 METs. Twenty-seven stroke survivors, with a range of functional ambulatory classification categories were included in the study. Energy expenditure was measured using an indirect calorimetry system (METAMAX, Cortex Medical) for lying down, supported sitting, unsupported sitting, standing, wheelchair propulsion and walking. The study highlighted the potential overestimation of 1.5METs threshold for sedentary behaviours in stroke survivors, with typical sedentary behaviours (supported and unsupported sitting) being narrowly bound at 1MET. Although this study contributed important evidence to the sedentary behaviour in stroke discussion, no stroke survivors classified as category 2 on the Functional Ambulatory Classification (needing continuous support from at least one person to stand and/or ambulate) (Holden et al., 1984) were included in the study. The activities recorded were also limited to activities during near sedentary behaviours e.g. standing and walking.

As stroke survivors with severe mobility disability are unable to stand or ambulate easily due to their limited lower limb function, it is important to consider whether it is possible for upper extremity activity in people with stroke-related mobility impairments, to reach sufficient intensity to offset the negative effects of sedentary activity (Bailey, 2016). It has been established that most upper-extremity activities (e.g. weight training, bowling, bed making, laundry and moving items) in individuals with spinal cord injury falls into the light-intensity activity category and is classed as a break in sedentary time (Collins et al., 2010). It would therefore be important to see whether this translates to stroke survivors who have severe mobility disability. It may well be that some activities within this category of mobility place energy expenditure above light-intensity and could be incorporated into an intervention to reduce sedentary behaviour.

The purpose of this study was to build upon the work previously conducted by Verschuren and colleagues (2016) and conduct a study to measure energy expenditure in a free living environment. The study aimed to include a range of functional ambulatory classifications (FAC 1, 2 and 3; Figure Three). Measurements were planned to be taken in a natural environment, i.e. in the stroke survivor's home rather than a laboratory study used by Verschuren and colleagues (2016). The study aimed to include a range of activities that were deemed 'normal' activities of daily living that could easily be continued or incorporated into a daily routine if they were to be part of an intervention. The activities included some seated arm activities to test whether the results witnessed in spinal cord injury patients (Collins et al., 2010) could also be observed in stroke survivors with severe mobility disabilities. The study also aimed to reflect upon the feasibility of using portable equipment to take measurements in a natural environment (i.e. stroke survivor's homes or stroke clubs) as this had not been attempted previously. It was also hoped that the study would ultimately help to answer the question, 'what can non-ambulatory stroke survivors do to break sedentary time?'

6.3. Measurement of energy expenditure

Energy expenditure can be measured using a range of approaches including; direct calorimetry, non-calorimetric techniques and indirect calorimetry.

Direct Calorimetry

Direct calorimetry is based on the principle that almost all energy release by metabolism is converted to heat and therefore can be used to calculate energy expenditure (Lagerros and Lagiou, 2007). Direct calorimeters measure the heat lost from the body through whole-room systems. However due to the slow speed of heat exchange, whole-room direct calorimeters are unable to detect acute changes in energy expenditure (Lam and Ravussin, 2016).

Doubly labelled water

This method is often considered the gold standard to estimate total energy expenditure. The participant consumes a quantity of water containing known amounts of the stable isotopes ^2H_2O and $H_2{}^{18}O$. The isotopes distribute throughout the body through bodily fluids and are secreted in the individual's urine. The elimination rates of the isotopes from the body are proportionate to the degree of metabolic CO_2 production. Therefore oxygen uptake and consequently total energy expenditure can be calculated for the study period from the difference in the elimination rates of the two isotopes (Lagerros and Lagiou, 2007). Baseline samples of urine, saliva or blood are collected prior to the administration of the doubly labelled water. Samples of urine, saliva or blood are then collected usually daily over a period of 7-21 days (Levine, 2005). Although this method is safe, precise and can be easily used for energy expenditure assessments in free-living conditions as no monitors have to be worn, it cannot provide information on the nature and intensity of the physical activity, only total energy expenditure. This alongside the fact that the isotopes are very expensive with the method also requiring expensive measurement equipment and specialists to conduct the measurements means that the doubly labelled water method is rarely used in large studies and instead used to validate other methods (Lam and Ravussin, 2016; Lagerros and Lagiou, 2007).

Indirect Calorimetry

As the majority of the body's expended energy is produced through the reaction of oxygen with nutrients, the oxygen consumption and carbon dioxide production, which increases during exercise, is often used to estimate energy expenditure (Lam and Ravussin, 2016). Open-circuit indirect calorimeter systems allow the subject to inspire air with the expired gases then being analysed and can record energy expenditure over several hours or days.

The current study used the Cortex METAMAX 3B portable system to measure energy expenditure. This system uses a mask containing a bidirectional digital turbine that measures volume of oxygen consumption. A sampling tube attached to the turbine allows analysis on the oxygen concentrations using an electrochemical cell and carbon dioxide concentrations using an infrared analyser (Medbø et al., 2002). The built-in sensors allow the device to measure energy expenditure in a free-living environment with the system being portable. It can also sample and store data for up to eight hours for later downloading to a computer, which makes it appropriate for field work.

The Cortex METAMAX 3B is both valid and reliable when measuring cardio-respiratory variables during everyday activities in healthy individuals when tested against the primary criterion Douglas bag method (Macfarlane and Wong, 2012). More recently the Metamax 3b was investigated to assess the test-retest reliability of the portable monitor's equipment during walking in a community setting after stroke (Polese et al., 2015). The study found excellent reliability and concluded that the Metamax 3B was stable during overground walking in subjects in stroke, which is important for the investigation of energy expenditure of subjects after stroke during everyday activity within a community setting. Laboratory experiments using indirect calorimetry often use standardised protocols to control the experiments and any confounding variables that may affect the results. Given the portable nature of the equipment, it is important to ensure that standardised activity protocols are also used to try and control for confounding variables in the community setting. The present study used a standardised activity schedule, which is described in more detail in section 6.5.3.

With this method of indirect calorimetry offering a valid, reliable and pragmatic approach to assessment it was therefore deemed appropriate for use in the current study.

6.4. Aims and Objectives

The aim of this study was to investigate the energy requirements for activities of daily living in stroke survivors with severe mobility disability living at home and assess whether everyday activities induce MET values above those classed as sedentary behaviour. The study also aimed to reflect upon the feasibility of measuring energy expenditure in stroke survivors with severe mobility disability in their home environments.

To categorise physical activities by intensity (i.e. sedentary behaviour, light intensity physical activity, moderate to vigorous physical activity) and the energy costs associated with the activities, metabolic equivalents (METS) are used. METs are defined as multiples of the resting metabolic rate (RMR), with one MET referring to the amount of oxygen consumed at rest, sitting in a chair quietly. This corresponds to an energy expenditure of 4.184 KJ per kg body mass per hour (1kcal per kg body mass per hour) or the approximate oxygen consumption of 3.5ml O_2 per kg body mass, for an average adult (Lagerros and Lagiou, 2007; Jette et al., 1990). While the standard unit of energy in physics is the joule (J), the unit calorie (kilocalorie, kcal) will be used in this chapter.

6.5. Methods

6.5.1. Ethical considerations

The study protocol, information sheets, consent forms and all other relevant study documentation were submitted to and approved by Yorkshire and Humber – Bradford Leeds Research Ethics Committee on 30th October 2017 (REC reference – 17/YH/0358, IRAS ID – 232534). This was part of the Health Research Authority (HRA) approval process which was granted on 9h November 2017 (Appendix M, N and O).

6.5.2. Study Design

An exploratory experimental design was used to investigate the energy requirements for activities of daily living in stroke survivors with severe mobility disability living at home. The study design also included a reflection of the feasibility of conducting these energy expenditure measurements in the target population in their home environments.

6.5.3. Schedule of activities

Participants were asked to complete a standardised schedule of activities, which was created for this study using a mix of activities used in previous studies and some novel activities. The schedule was comprised of activities in which the participants may have normally engaged, that is, no unfamiliar or excessively strenuous activities were included. Participants were only asked to complete activities that were familiar to them and it was created to allow activities to be performed in as uniform manner as possible, using the description in the schedule. Although participants were instructed to perform each activity as they normally would, activities were prescribed to control, as much as possible, for variability in each activity. The activity schedule also included variations of each activity for participants with differing functional ambulatory classifications to ensure that participants were able to complete as many activities as possible. The schedule of activities and instructions for how to complete each activity are detailed in Table Twenty-Eight.

Table 28 Schedule of activities

Activity		Instruction	Duration / Frequency
1	Lying down	Lying down in the supine position with minimal movement	**FAC: 1, 2, 3** Until a plateau in $\dot{V}O_2$ is achieved (Normally 2-4 minutes)
At least 2 minutes rest			
2	Supported sitting	Sitting on a chair with a backrest	**FAC: 1, 2, 3** Until a plateau in $\dot{V}O_2$ is achieved (Normally 2-4 minutes)
At least 2 minutes rest			
3	Unsupported sitting	Sitting unsupported on a chair / stool (no backrest / sitting away from backrest – Ensure that arms are not resting on chair).	**FAC: 1, 2, 3** Until a plateau in $\dot{V}O_2$ is achieved (Normally 2-4 minutes)
At least 2 minutes rest			
4	Standing - static	Static standing with or without help as per their normal performance (including manual assistance of one person or assistive devices)	**FAC: 1, 2, 3** – If unable to do, note on the recording sheet and move to activity 5. 3-5 minutes (until a plateau in $\dot{V}O_2$ is achieved)
At least 2 minutes rest			
5	Arm tasks (1) Dusting	In a seated position with a table in front of them. The table should be at waist height. Movements described below should be completed with a duster in the hand and should mimic the action of dusting. <u>Forward-backward</u> Starting at the mid-point, move duster forward, back to mid-point, move duster backward towards the body, back to mid-point. This is one repetition. <u>Side-to-side</u> Starting at the midpoint, move duster to the left, back to mid-point, move duster to the right, back to mid-point. This is one repetition.	**FAC: 1, 2, 3 -** With both arms or just unaffected arm if unable to use both arms 5 x forward-backward 5x side-to-side 5 x forward-backward 5x side-to-side No break between the sets of repetitions.
At least 2 minutes rest			

Activity		Instruction	Duration / Frequency
6	Body Transfer /Sit-to-stand	**FAC 1, 2 (Unable to stand) -** With or without help as per their normal performance (including manual assistance of a person or assistive devices) Starting from sitting in a chair or on a bed, transfer body to wheelchair (or other way around depending on starting position (chair/bed or wheelchair)). This is one repetition.	**FAC 1, 2 (Unable to stand) -** If unable to do, note on the recording sheet and move to activity 7. 2 repetitions of body transfer (e.g. chair to wheelchair (1 rep), wheelchair back to chair (1 rep))
		FAC 1, 2, 3 (Able to stand) - With or without help as per their normal performance (including manual assistance of a person or assistive devices) Starting from sitting in a chair, stand up straight, hold for 5 seconds before returning to sitting back in the chair. This is one repetition.	**FAC 1, 2, 3 (Able to stand)** 2 repetitions of ‘sit-to-stand’ Allow a rest between repetitions
At least 2 minutes rest			
7	Arm tasks (2) Arm exercises	Seated weighted bicep curl Starting with back of hands resting on legs with weights (0.5 Kg) gripped in hands, bend elbow and bring hand towards chest, return hand to knee. This is one repetition. Seated reach and grab stretch Starting with palms on knees, reach hand above head and grab the air (as if grabbing something above your head), return hand to knees. This is one repetition.	**FAC: 1, 2, 3 -** With both arms or just unaffected arm if unable to use both arms Bicep curls – 2 sets of 10 repetitions (at least 1 minute rest between sets) At least 2 minute rest between bicep curls and reach and grab Reach and grab – 2 sets of 10 repetitions (at least 1 minute rest between sets)
At least 2 minutes rest			

Activity		Instruction	Duration / Frequency
8	Up and go	**FAC 1, 2 (Unable to ambulate - In wheelchair)** From a stationary position, self-propel wheelchair 3m in a straight line at a normal and comfortable pace, turn wheelchair through 180 degrees and return back to starting position (3 m away).	**FAC 1, 2 (Unable to ambulate - In wheelchair)** 2 repetitions of ‘up and go’ Rest of at least 2 minutes in-between each repetition If unable to self-propel wheelchair, note on recording sheet and move to activity 9.
		FAC 2, 3 (Able to ambulate) – With or without help as per their normal performance (including manual assistance of a person or assistive devices) From sitting, stand-up and walk 3 m in a straight line, turn around, walk back to the chair in a straight line and sit down.	**FAC 2, 3 (Able to ambulate)** 2 repetitions of ‘up and go’ Rest of at least 2 minutes in-between each repetition
At least 2 minutes rest			
9	Arm tasks (3) Washing up	Either using participants’ kitchen or washing up bowl (to mimic washing up) on table in front of the participant. Transfer the dishes into the bowl from the side. Wash the dishes with sponge. Remove dishes from bowl and transfer to side. Dry the dishes using a cloth.	**FAC: 1, 2, 3 -** With both arms or just unaffected arm if unable to use both arms 3-5 minutes
At least 2 minutes rest			

Activity		Instruction	Duration / Frequency
10	Wheelchair propulsion / Walking	**FAC 1, 2 (Unable to ambulate - In wheelchair)** Wheel at a pace that is comfortable and 'normal' pragmatically around the home/environment (i.e. around own furniture).	**FAC 1, 2 (Unable to ambulate - In wheelchair)** If unable to self-propel wheelchair, note on recording sheet and end recording session. 3-5 minutes
		FAC 2, 3 (Able to ambulate, no stairs) – With or without help as per their normal performance (including manual assistance of a person or assistive devices) Stand up and begin walking pragmatically (i.e. around the furniture) at a pace that is comfortable and normal.	**FAC 2, 3 (Able to ambulate, no stairs)** 3-5 minutes
		FAC 2, 3 (Able to ambulate including stairs) - With or without help as per their normal performance (including manual assistance of a person or assistive devices) Stand up and begin walking pragmatically (i.e. around the furniture) at a pace that is comfortable and normal. Include an ascension and declension of one flight of stairs as per their normal performance.	**FAC 2, 3 (Able to ambulate including stairs)** 3-5minutes

6.5.4. Recording equipment

Energy expenditure (METs) was measured using indirect calorimetry, using the METAMAX 3B portable system. Participants were asked to try and refrain from eating 2 hours prior to the measurements being taken to ensure that the energy expenditure recorded was of the activities being completed and not affected by digestion. The METAMAX 3B mobile gas analysis system consists of a facemask, a transmitting unit (containing different oxygen and carbon dioxide gas analysers) and a receiving unit. The transmitting unit with facemask and tubing (total weight, 580g – approximately equivalent to a small bag of sugar) was attached to the participants with a harness using Velcro straps (Figure Eighteen). To ensure optimal gas analysis, it was important that the mask fitted correctly. To aid this, different sized masks (medium or large) were available and adjustable Velcro straps were used to ensure a firm fit for each participant. The receiving unit was connected to a laptop computer located within 5 metres of the transmitting unit.

Prior to fitting the equipment to the participant and starting any measurements, the METAMAX 3B was calibrated using reference gases and room air, as per the instructions provided by the manufacturer. This was done outside the home as it required the use of a gas cylinder.

Figure 18 Model wearing facemask and harness

6.5.5. Study Protocol

The four stages of the study are outlined in Figure Nineteen and then described in detail in the subsequent sections.

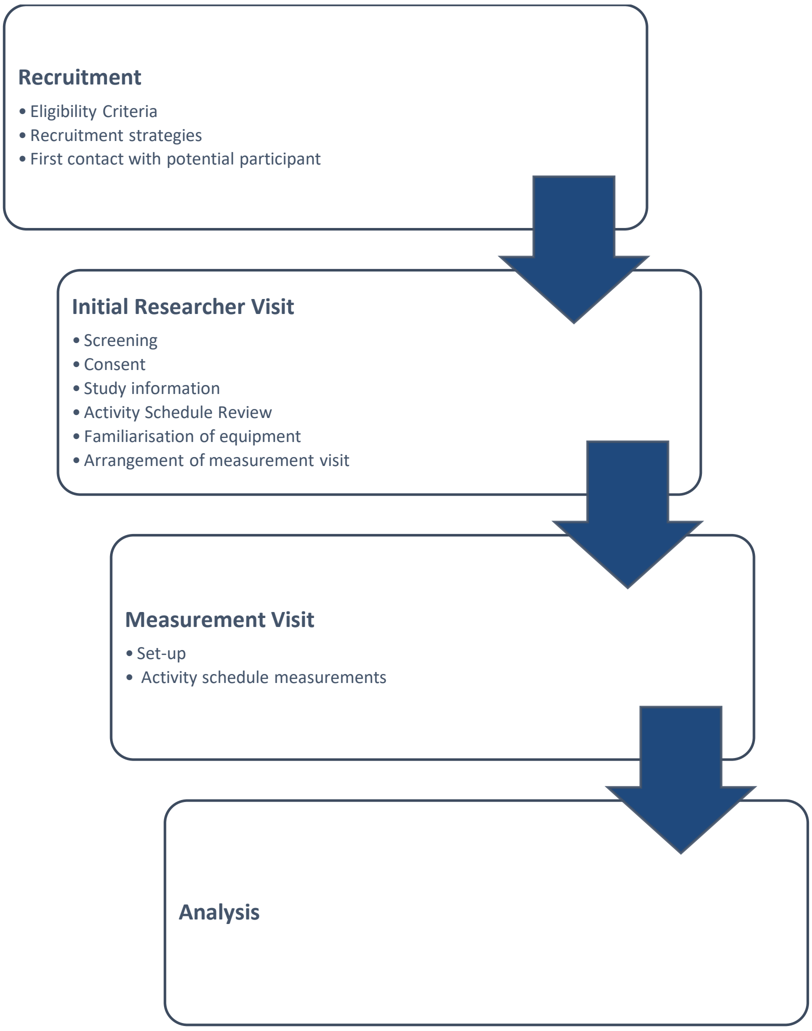


Figure 19 Study protocol

6.5.5.1. Recruitment

Stroke survivors were purposively sampled to enable recruitment of stroke survivors with stroke-related mobility limitation who are classified as categories 1, 2 and 3 on the functional ambulatory classification (Holden et al., 1984). The study aimed to recruit approximately ten stroke survivors. This recruitment target was based upon recruitment figures from the previous Q-methodology study, which found recruiting stroke participants with severe mobility disabilities to be difficult. Ten participants was deemed an acceptable number to achieve the study aims (Section 6.4) whilst being manageable in terms of the recruitment process.

6.5.5.1.1. Eligibility Criteria

The following eligibility criteria were adopted during recruitment of stroke survivors to ensure an appropriate participant group were included in the study.

Inclusion criteria

Stroke survivors were eligible for the study provided they:

- Were aged over 16 years
- Had a confirmed primary diagnosis of stroke
- Had a severe mobility disability (unable to stand or walk without the help of at least one person) . Functional ambulatory classification 1,2 and 3 (Holden et al., 1984)(Figure Three)
- Were returning home/ live at home independently or with support from an informal carer (who may be a spouse, child over 18 years), or other family member
- Were able to understand and follow the instructions for the activity schedule and measurement of energy expenditure.
- Were able to provide informed consent

Exclusion criteria

Stroke survivors were not eligible for the study if any of the criteria below were met:

- Had breathing or respiratory problems (wearing a mask may cause respiratory distress)
- Were pregnant
- Non English speaker

6.5.5.1.2. Recruitment strategies

In order to recruit a sample of stroke survivors with stroke-related mobility limitations who were classified as categories 1,2 and 3 on the functional ambulatory classification (Figure Three), a number of overlapping strategies were adopted. Stroke survivors were identified either through participation in the Q-study (Chapters 4 and 5) or through voluntary organisations.

Recruiting from the Q-methodological study

During the consent process of the Q-methodological study (Chapter 4) participants were asked if they would be happy to be contacted by the researcher regarding participation in future related research studies. All participants who had consented to be contacted again were approached to take part in the present study. Before correspondence was sent out, the survival status and addresses of the stroke survivors were checked using the Summary Care Record on the NHS Spine Portal System. The researcher posted out a covering letter, an information sheet, a consent to researcher contact form and a pre-paid reply envelope. The letter explained that the stroke survivor had been contacted because they had previously given permission to be contacted about related future research studies. If the potential participant was interested in taking part in the study they were asked to complete the consent to researcher contact form and return it directly to the researcher using the pre-paid reply envelope.

Recruitment through voluntary organisations

Stroke survivors with severe mobility disabilities who matched the inclusion criteria were identified by voluntary organisations (stroke clubs) and provided with a study information pack. The information pack contained an invitation letter from the researcher, an information sheet, a consent to researcher contact form and a pre-paid reply envelope. Similar to the ‘recruiting from the Q-methodological study’ method described before, if the potential participants were interested in taking part in the study they were asked to return the consent to researcher contact form to the researcher. Additionally, voluntary organisations were also able to advertise the research study in their office/clubs, on their websites and/or via social media.

6.5.5.1.3. First contact with potential participant

The consent to researcher contact forms allowed the participant to specify their preferred method of initial contact (telephone, email, written). Once the consent to researcher contact forms were received, the researcher made contact with either the stroke survivor or carer according to their preferences. During the initial contact, the researcher explained the study in full and answered any questions that the stroke survivor or carer had. The researcher outlined what participation in the study would involve (i.e. completing a schedule of activities that are normal and not unfamiliar whilst wearing some equipment to measure energy expenditure) and explained the anticipated outcome of the study (i.e. no direct benefit to the stroke survivor) but that the study would help to understand the energy requirements for movement and activities of daily living after stroke and the that the information generated may contribute to the development of an intervention to reduce sedentary behaviour in stroke survivors with severe mobility disability. The researcher also explained that during the initial visit, the stroke survivor would be asked some screening questions to confirm that they were suitable to take part in the study.

If the stroke survivor was happy to proceed, a suitable date and time for an initial visit at home was agreed. The researcher also made the stroke survivor aware that they could have a carer, family member or friend present at the initial visit.

6.5.5.2. Initial researcher visit

6.5.5.2.1. Screening

During the initial researcher visit, the researcher confirmed the potential participant's eligibility using the eligibility criteria and determined their level of ambulation using the Functional Ambulation Classification (FAC) (Figure Three).

As participants were required to wear a portable gas analysis system (Metamax 3B, Cortex Medical) consisting of a facemask and receiver worn on the chest using a harness, it was important that participants were able to understand what taking part in the study would involve and were able to comprehend the instructions for wearing the equipment and carrying out the battery of activities. It was also important to establish that the participants had the capacity to understand what participation in the study would mean for them and that they could make an informed decision about whether they would like to participate. To help establish whether participants understood and would be able to complete the study, the researcher used the (6 CIT) (Brooke and Bullock, 1999) (Appendix G) and Frenchay Aphasia Screening Test (FAST) (Enderby et al., 1986) (Appendix H) to screen potential participants for any cognitive impairment and/or language deficits that may have made them unsuitable for inclusion in the study). Details of the screening tools and the procedure to assess capacity are detailed in Chapter 4, as they were also used for screening potential participants in the Q-methodological study (Section 4.6.2.1.3).

6.5.5.2.2. Consent

Stroke survivors were fully supported to provide informed consent during the initial researcher visit. The researcher encouraged the participant to ask questions and also asked the participant questions to ensure that they understood what was being asked of them. Written consent was obtained after eligibility had been confirmed and the purpose of the study had been explained in full. Each point of the consent form was read out loud to the potential participant before it was signed to ensure that any questions were answered and that the potential participant was happy to proceed.

6.5.5.2.3. Study information

Once consent had been taken, the participants were asked for some demographic data including; height (cm), weight (Kg) and age, which was recorded onto the data recording sheet. This information was required by the MetaSoft software package in order for accurate energy expenditure measurements to be taken during the second visit. Unfortunately due to the difficulty of taking measurements in individuals with severe mobility limitations and with the lack of specialist equipment, the researcher recorded the weight and height that the participant and carer reported. Although the researcher could not guarantee that the measurements were accurate, as the software required the information to allow energy expenditure measurements to be calculated, it was decided that an estimate would be sufficient.

Participants were also asked to complete the Nottingham Extended Activities of Daily Living Scale (Nouri and Lincoln, 1987) (Appendix Q) to assess the participants' level and frequency of everyday activities in the previous few weeks. Again all of the information was collected onto the recording sheet.

6.5.5.2.4. Activity schedule review

Following the consent process, through discussions with the participant and drawing on the stroke survivor's functional ambulatory classification, the researcher determined which activities and variations of the activities on the activity schedule (Table Twenty-Eight) would be assigned to the participant to complete during the measurement visit. The researcher explained to the stroke survivor what would happen during the measurement visit and explained what activities would be completed. During the discussion, the researcher clarified that the stroke survivors would not be asked to do anything that they do not usually do and that carers, family members or friends should be present at the measurement visit to help with the tasks as per their normal execution of the activities (e.g. help to stand or walk).

6.5.5.2.5. Familiarisation of equipment

Participants were given the opportunity to try wearing the equipment during the initial visit to become familiar with wearing the facemask and harness/transmitter box. The equipment may have felt unfamiliar to them so it was deemed important that the participants had time to try the equipment on and become familiarised before the measurement visit.

6.5.5.2.6. Arrangement of measurement visit

If the stroke survivor was happy to proceed, a suitable date and time for the second appointment (measurement visit) was made (within three weeks of the initial visit). As participants were asked to refrain from eating two hours prior to the energy expenditure measurements, a suitable time was arranged to coincide with the participant’s usual routine (i.e. proximity to mealtimes).

6.5.5.3. Measurement Visit

The measurement visit took between 2 hours and 2.5 hours to set-up, explain and complete the activity schedule including recording measurements. The timescale allowed participants to take breaks at any time during the activity schedule and measurements of energy expenditure. Two researchers were present during the measurement visit (NC and MP), to allow one to be focused on the participant and help them with the activities and another to monitor the recordings on the software.

6.5.5.3.1. Set-up

Prior to fitting the equipment to the participant and starting any measurements, the METAMAX 3B was set-up and calibrated as per the instructions provided by the manufacturer, including syncing the equipment to the software on a portable laptop. Before testing, participants were fitted with the equipment and allowed a minimum of three minutes to again acclimatise to wearing the METAMAX 3B equipment. It is important to note that the tubes connecting the mask to the transmitting unit did not impact the participants’ movement and therefore their performance of the activities in the schedule.

6.5.5.3.2. Activity Schedule Measurements

Once the participants were comfortable and happy with wearing the equipment the researcher proceeded to begin the activity schedule measurements. The researcher (NC) initiated the recording by starting the recording on the laptop. MetaSoft software was used to measure minute ventilation, oxygen uptake ($\dot{V}o_2$) and carbon dioxide production. The researcher (NC) monitored the recordings and once the oxygen uptake became stable, after around 60 seconds, the first activity of the schedule was started. As the software took a continuous recording, the researcher (NC) added makers and notes on to the recording to highlight when an activity started and stopped and to indicate the repetitions and breaks.

The first planned activity of the activity schedule to be measured was lying down in the supine position with minimal movement. This is usually measured in order to provide a value of resting energy expenditure which can then be used to compare the energy consumption for other activities and calculate the metabolic equivalent for each activity. However, due to the restricted mobility of the participants, only one participant was able to lie-down in the supine position and one was only able to lie semi-supine on a recliner chair. All participants were able to perform the second activity on the activity schedule, supported sitting at rest. Therefore for the purpose of this study, the oxygen consumption value recorded for supported sitting at rest was used as the resting energy expenditure for all four participants.

Once resting energy expenditure had been recorded, the participants continued to work through the activities on their prescribed schedule of activities. The assisting researcher (MP) supported the participants to complete each of the activities by explaining the activities and reading the detailed instructions from the activity schedule. The activity schedule included a minimum of 2 minute rest breaks between each activity to allow time for the participant to rest and to ensure a return-to-baseline value before the next activity was completed.

Throughout the measurement visit, the researcher (MP) continuously asked the participant if they were ok. As the participants were advised not to speak during the measurements, they were informed that a ‘thumbs up’ action should be used to indicate that they were feeling ok and happy to continue and ‘thumbs down’ action to indicate that they were in discomfort or wanting to stop for a break. Participants were able to remove the mask during ‘rest’ periods to have a break from wearing the mask if they wished to do so. They were also allowed drinks of water during the rest periods between activities.

Participants were asked to rate their perceived rate of exertion during the activity, immediately after completing each activity, using the modified Borg Rating of Perceived Exertion Scale (Borg, 1982) (See Figure Twenty). Participants were asked to indicate how they felt during each activity, on the scale of 0-10 by pointing to the level of exertion on the printed scale. This was collected to allow a comparison of the participants’ perceived exertion against the measured energy requirements for each activity.

Once the activity schedule was completed, the researcher (NC) stopped the equipment recording on the laptop and both researchers (NC and MP) removed the facemask and transmitter from the participant.

After each use of the equipment, the facemask, turbine and straps were sterilised in a solution of sterilised fluid and water for at least 30 minutes to maintain hygiene. Additionally, following the data recording visit, the transmitter unit battery pack needed to be recharged to ensure that an adequate battery supply was available for the next measurement visit, and ensured that the equipment was sterilised ready for the next participant.

1-10 Borg Rating of Perceived Exertion Scale	
0	**Rest**
1	**Really Easy**
2	**Easy**
3	**Moderate**
4	**Sort of Hard**
5	**Hard**
6	
7	**Really Hard**
8	
9	**Really, Really Hard**
10	**Maximal: Just like my hardest race**

Figure 20 Modified BORG Rating of Perceived Exertion Scale

6.5.5.4. Data analysis

The data generated by the study were analysed with the support of Professor Karen Birch (Reader in Exercise Science at the University of Leeds and Academic Supervisor) and Dr Gemma Lyall (Research Fellow in Exercise Physiology at the University of Leeds). Data were anonymised before being analysed.

Second by second expired air analyses data was measured by the METAMAX and recorded onto the MetaSoft software during the measurement visit. The data produced in MetaSoft was anonymous and only identifiable using the allocated unique study ID number. The anonymous data were exported to Microsoft Excel for analysis. Outliers were removed using two standard deviations from the mean from the time period of data where the $\dot{V}o_2$ level plateaus. Where the time period of an activity was not long enough to reach a plateau, the mean of the whole time of the activity was used to calculate two standard deviations from the mean to remove major outliers.

The mean and standard deviation of oxygen uptake for each task was assessed. In order to calculate the mean oxygen uptake for the activities, each task should have been performed for a period of time long enough for the data to be stable and therefore a ‘plateau’ in values to be observed. A plateau was able to be achieved in activities that were continuous and could be maintained for a period typically between two and five minutes (dependent of the activity) and included lying down, supported sitting, unsupported sitting, static standing, washing up and wheelchair propulsion.

For the remaining four activities; dusting, sit-to-stand, arm exercises and up and go, the period of time for the activities were very short and therefore unable to observe a plateau. Instead, $\dot{V}o_2$ values continued to increase following the task during the recovery period with subsequent peaks also being observed. To account for the delay in recording oxygen consumption from muscle activity by mouth measurements, the 25 seconds immediately following the completion of the task was included in the activity time to produce the peak value. Additionally, to determine the total energy consumption of the activity, the excess post exercise oxygen consumption (EPOC) during the recovery phase and the peak values for the task were combined to capture the energy consumption for the short time period activity and the recovery phase. It is important to note that the peak value was used as a representative value of mean oxygen uptake for the tasks in these activities that were unable to observe a plateau.

In order to calculate the metabolic equivalents of tasks (METs) for each of the activities performed, the recorded value of supported sitting at rest (ml/kg/min) was taken as the resting oxygen uptake value (i.e. 1 MET) for each of the participants, instead of the 3.5 ml/kg/min standard value (Lagerros and Lagiou, 2007; Jette et al., 1990). The oxygen uptake values recorded for each of the activities were then divided by the participants' resting oxygen uptake value to calculate the MET value for the activity.

6.6. Findings

6.6.1. Results

As this study aimed to evaluate the feasibility of the methods including the activity schedule, a large sample size was not required. The study aimed to recruit ten participants but only four consented and completed the study. The majority of the participants from the Q-methodological study were invited to take part in the present study with all four of the participants being recruited through this method. A group of five potential participants from the South East of England were excluded from being invited due to their location as it was unfeasible to conduct the study there due to logistics and practicalities. This is further discussed in section 6.7.1.1. One participant from the Q-methodology study was unable to be invited due to respiratory problems that were disclosed during the Q-methodology interview. This was in line with the eligibility criteria, with individuals with breathing or respiratory problems being excluded as wearing the mask may have caused respiratory distress. Voluntary organisations (stroke clubs) were also involved in the recruitment procedure with suitable stroke survivors within their organisations being handed an information pack with details of the study. No stroke survivors were recruited through this method.

All four participants who consented and participated in the study had previously taken part in the Q-methodology study (See Chapters 4 and 5) and agreed to be contacted about the present study. Characteristics of the four participants are detailed in Table Twenty-Nine. Equal number of males and females were included with an average age of 66.5 years old (SD=7.42) with a time since stroke ranging from one year to ten years six months post-stroke. Two participants, E02 and E04 were categorised as level one on the Functional Ambulation Classification denoting an inability to ambulate. The other two participants, E01 and E03, were categorised as level two therefore requiring continuous manual contact of at least one person during ambulation on level surfaces to support body weight and/or maintain balance (Holden et al., 1984). The FAC level assigned to the participants reflects the activities from the activity schedule that each of the participants were able to complete, with E01 and E03 both able to complete the majority of the activity schedule. Participants were also asked prior to any energy measurement being taken to complete the Nottingham Extended Activities of Daily Living Score (Nouri and Lincoln, 1987) (Appendix Q) to assess the participants' level and frequency of everyday activities in the previous few weeks. All four participants scored less than 10 out of a maximum possible score of 22 indicating a very low level of independence.

The results of the four participants are first presented case-by-case (sections 6.6.1.1 – 6.6.1.4) before a comparison across cases is presented (section 6.6.1.5).

Table 29 Participant Characteristics

	E01	**E02**	**E03**	**E04**
Gender	Male	Female	Male	Female
Age (years)	58	76	65	67
Height (cm)	177.8	163	180	168
Weight (Kg)	114.3	64	98	117
Time since stroke	2 years 2 months	1 year 2 months	7 years	1st - 10 years 6 months 2nd – 5 months
Level of Ambulation (Functional Ambulatory Classification)	2	1	2	1
Nottingham extended Activities of Daily Living score	3	2	7	3

Table 30 Relative (ml/kg/min, (*SD*)), and absolute (L/min, *(SD)*) mean oxygen uptake values, relative MET values and rating of perceived exertion (RPE) for static activities

	E01				**E02**				**E03**				**E04**			
	Relative	Absolute	METs	RPE	Relative	Absolute	METs	RPE	Relative	Absolute	METs	RPE	Relative	Absolute	METs	RPE
Lying down	1.85 *(0.39)*	0.21 *(0.04)*	1.00	3					3.49 *(0.35)*	0.35 *(0.05)*	1.12	0				
Supported sitting	1.85 *(0.38)*	0.21 *(0.04)*	1.00	3	2.98 *(0.48)*	0.19 *(0.03)*	1.00	1	3.11 *(0.59)*	0.31 *(0.08)*	1.00	2	1.77 *(0.75)*	0.21 *(0.09)*	1.00	1
Unsupported sitting	2.91 *(1.34)*	0.33 *(0.15)*	1.57	3	3.89 *(0.75)*	0.25 *(0.05)*	1.31	2	3.56 *(0.52)*	0.35 *(0.05)*	1.14	2	2.26 *(1.06)*	0.26 *(0.12)*	1.28	2
Standing - static	4.91 *(1.97)*	0.56 *(0.22)*	2.65	5					4.84 *(0.92)*	0.47 *(0.10)*	1.56	3				

Table 31 Relative (ml/kg/min, (*SD*)) and absolute (L/min, *(SD)*) mean oxygen uptake values and relative MET values for peak and peak + EPOC and the rating of perceived exertion (RPE) for non-static activities

			Dusting		**Sit-to-stand**		**Arm exercises**		**Up and Go**		**Washing Up**		**Wheelchair Propulsion**	
			Relative	Absolute	Relative	Absolute	Relative	Absolute	Relative	Absolute	Relative	Absolute	Relative	Absolute
E01	Peak	Mean O_2 uptake	3.87 *(1.48)*	0.45 *(0.17)*	4.12 *(1.73)*	0.47 *(0.20)*	2.66 *(1.07)*	0.30 *(0.12)*	4.84 *(1.61)*	0.53 *(0.25)*	3.52 *(1.25)*	0.41 *(0.15)*		
		METs	2.09		2.23		1.44		2.62		1.90			
	RPE		7		8		8		10		9			
	Peak + EPOC	Mean O_2 uptake	3.52 *(1.37)*	0.41 *(0.14)*	2.92 *(0.99)*	0.34 *(0.11)*	2.29 *(0.83)*	0.26 *(0.10)*	4.80 *(1.39)*	0.55 *(0.16)*				
		METs	1.90		1.58		1.24		2.59					
E02	Peak	Mean O_2 uptake	3.98 *(0.99)*	0.25 *(0.06)*	5.04 *(1.84)*	0.32 *(0.12)*	3.59 *(0.80)*	0.24 *(0.04)*			4.54 *(1.06)*	0.29 *(0.07)*	9.41 *(1.41)*	0.60 *(0.09)*
		METs	1.34		1.69		1.20				1.52		3.16	
	RPE		3		4		2				2		8	
	Peak + EPOC	Mean O_2 uptake	3.46 *(0.83)*	0.22 *(0.06)*	4.79 *(1.39)*	0.31 *(0.09)*	3.16 *(0.75)*	0.20 *(0.05)*					7.10 *(2.34)*	0.46 *(0.14)*
		METs	1.16		1.61		1.06						2.38	
E03	Peak	Mean O_2 uptake	3.82 *(0.63)*	0.37 *(0.06)*	5.25 *(3.39)*	0.51 *(0.33)*	3.85 *(1.49)*	0.38 *(0.15)*	8.17 *(2.31)*	0.78 *(0.24)*	5.14 *(1.28)*	0.50 *(0.13)*		
		METs	1.23		1.69		1.24		2.63		1.65			
	RPE		2		4		2		5		2			
	Peak + EPOC	Mean O_2 uptake	3.22 *(0.88)*	0.32 *(0.09)*	4.06 *(1.81)*	0.40 *(0.18)*	3.35 *(1.22)*	0.33 *(0.12)*	7.59 *(2.49)*	0.74 *(0.24)*				
		METs	1.04		1.31		1.08		2.44					
E04	Peak	Mean O_2 uptake	2.87 *(1.34)*	0.34 *(0.16)*			2.82 *(0.70)*	0.29 *(0.13)*			2.88 *(0.86)*	0.34 *(0.10)*		
		METs	1.63				1.59				1.63			
	RPE		2				4				3			
	Peak + EPOC	Mean O_2 uptake	2.14 *(0.78)*	0.28 *(0.12)*			2.27 *(1.00)*	0.27 *(1.00)*						
		METs	1.21				1.28							

6.6.1.1. Participant E01

Participant E01 was a 58 year old male stroke survivor with a FAC category of 2. The participant moved small distances around his home using a tetrapod walking stick and the help of his wife (full-time carer). The gentleman was able to complete all of the activities except for walking. As previously discussed, the participant was only able to lie semi-supine on a recliner chair which may therefore explain why his recorded energy expenditure value for lying down was comparable to the value recorded during supported sitting at rest.

Mean resting energy consumption for E01 was 1.85 ml/kg/min (SD = 0.38). Figure Twenty-One displays the relative energy expenditure, relative MET values and perceived exertion levels for each of the activities performed. The values are also listed in Tables Thirty and Thirty-One. All of the non-rest activities (See Table Thirty-One) except for Arm exercises, had relative MET values exceeding 1.5 METs for both the peak period and the total activity period (peak + EPOC). Interestingly these activities included dusting and washing up which are activities that are completed whilst sitting without the need for standing or travelling (dusting used 2.09 METs and washing up used 1.90 METs). In the case of this participant, they would be able to break up their sedentary behaviour by incorporating some arm activities into their day including washing up and dusting. It is also important to note that although both dusting and sit-to-stand activities had relatively short activity periods and therefore only short ‘peak’ times, the short activity time and recovery period still produced a MET value over 1.5, therefore taking them out of sedentary behaviour. This suggests that even short time periods of the activities with the potential to increase energy expenditure may have the potential to reduce sedentary behaviour in stroke survivors with severe mobility problems.

The ratings of perceived exertion provided by the participant for each activity increased in value as the activities were completed in order on the schedule. This finding is quite unusual as the perceived exertion recorded by the participant did not match the energy requirements for the tasks, which reflected the complexity of the activities. For example, washing up was described as being an RPE score of 9 (Really, really hard) whilst sit-to-stand was rated as 8 on the RPE scale, however sit-to-stand required more oxygen and therefore more energy to complete than washing up. This may be explained by an accumulative fatigue and muscular discomfort that gradually increased as the activities were completed, with sit-to-stand being the sixth activity and washing up being the last activity (ninth) to be completed. The only exception was the eighth activity, the up and go, which scored the highest rating of perceived exertion of 10 (Maximal: Just like my hardest race).This activity, however, did use the second greatest amount of energy after static standing and would therefore match the level of perceived exertion. It is also important to consider how participants use the RPE scale to describe their feelings of exertion. Often RPE scores reflect the muscular effort rather than the energy requirements, with a strong muscular contraction being deemed really hard. For example the strong contraction of the arm muscles during the washing up task may have felt more difficult than the full body movement involved in the sit-to-stand task for participant E01.

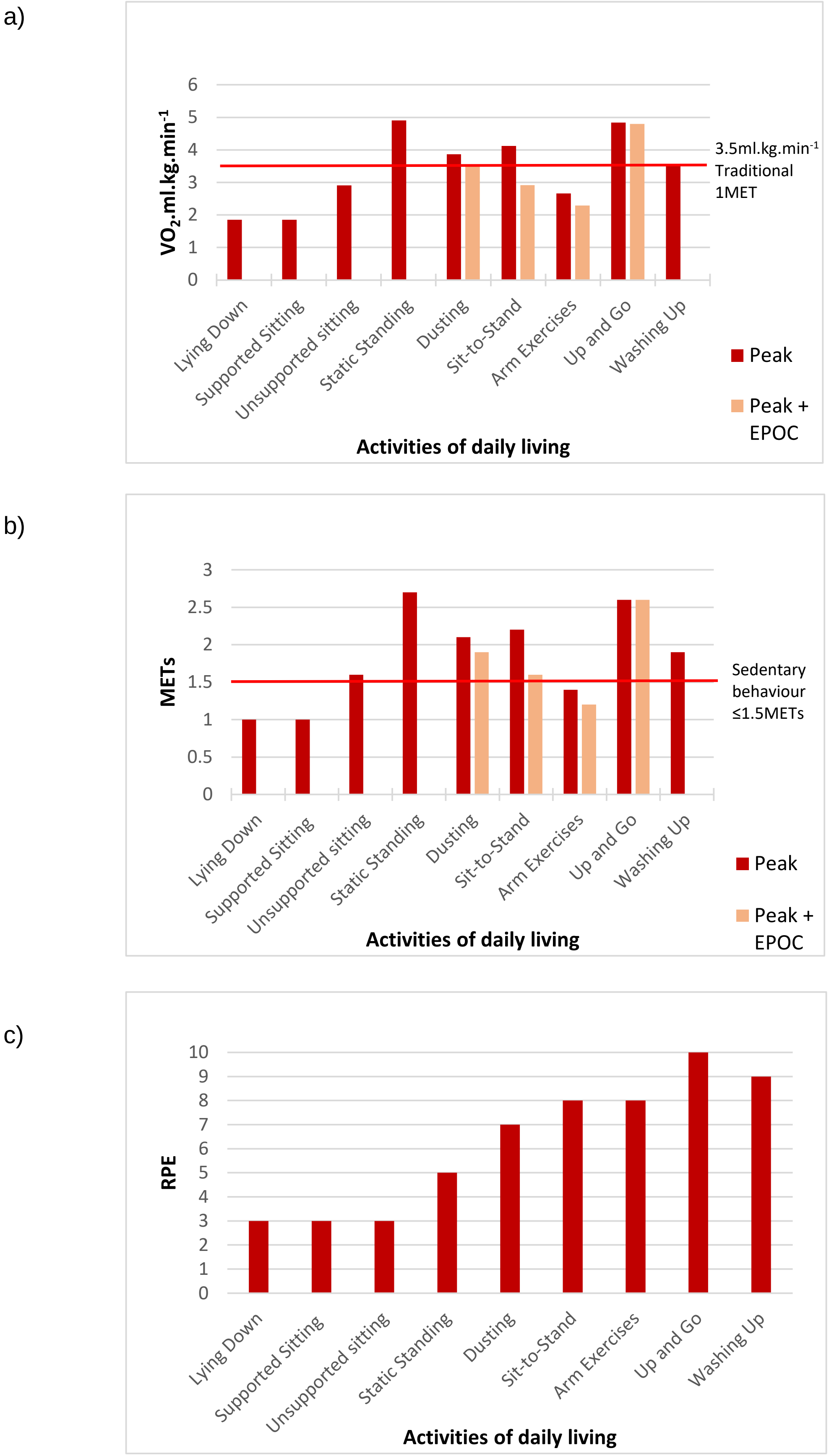


Figure 21 Participant E01's a) Oxygen uptake (ml.kg.min^{-1}) b) Energy expenditure (METs) c) Perceived exertion (RPE) for each of the activities performed

6.6.1.2. Participant E02

Participant E02 was a 76 year old female with a FAC category of 1 (unable to ambulate). The participant spent the majority of the day sat in a manual wheelchair and required the help of formal carers to transfer her from bed to wheelchair in the morning and back again in the evening. The participant was able to complete seven out of the ten activities on the activity schedule. Due to her limited mobility, she was unable to complete the static standing and Up and Go activities. With the participant being unable to get into or out of bed without the help of the formal carers and the difficulty of timing the measurement visits to compliment the carers' visits, she was unable to complete the lying down activity.

Although wheelchair propulsion listed as activity ten (wheelchair propulsion/walking) was attempted by the participant, she was unable to complete the activity as per the written instructions; 'wheel at a pace that is comfortable and 'normal' pragmatically around the home/environment (i.e. around own furniture)'. As she was unable to use her arm to self-propel her wheelchair as a result of hemiplegia following the stroke, the participant instead used her unaffected leg and a rocking motion of her body to self-propel her wheelchair. Although the movement was an unconventional method of wheelchair propulsion and not as described in the instructions, it was deemed important to capture the energy consumption for the activity as it was her method of travelling around her home that she does on a daily basis and was therefore more meaningful for the participant than the standardised instructions.

Mean resting energy consumption for E02 was 2.98 ml/kg/min (SD=0.48). Figure Twenty-Two displays the relative energy expenditure, relative MET values and perceived exertion levels for each of the activities performed by E02. The values are also listed in Tables Thirty and Thirty-One. Three activities had relative MET values exceeding 1.5 METs for the peak period (sit-to-stand (1.69 METs), washing up (1.52 METs) and wheelchair propulsion (3.16 METs)), two of which also had MET values exceeding 1.5 METs for the total activity period (peak + EPOC) (sit-to-stand (1.61 METs) and wheelchair propulsion (2.38 METs)). Interestingly, for this participant wheelchair propulsion used 3.16 METs which equates to moderate intensity physical activity and therefore most definitely breaks their periods of sedentary behaviour. Although this activity only reached a moderate intensity level, the fact that she rated the activity at point 8 on the RPE scale indicates the difficulty that patients with severe mobility disabilities following stroke have in conducting activities in their daily lives.

The participant rated washing up as level 2 on the RPE scale indicating the activity was ‘easy’. Although the MET value for washing up was 1.52 METs and therefore above the threshold for sedentary behaviour, the low rating of perceived exertion highlights the potential for the participant to increase their energy consumption for activities by pushing themselves during the activity to increase the intensity. This is supported by the results for the dusting activity, with the participant using 1.34 METs but also only perceiving the activity as 3 on the perceived exertion scale. The participant could try to increase the intensity of the activity to try and increase the energy consumption and ultimately raise the METs required for the activity. In the case of dusting they may be able to increase the intensity enough to raise the METs above 1.5 and therefore break up their sedentary behaviour.

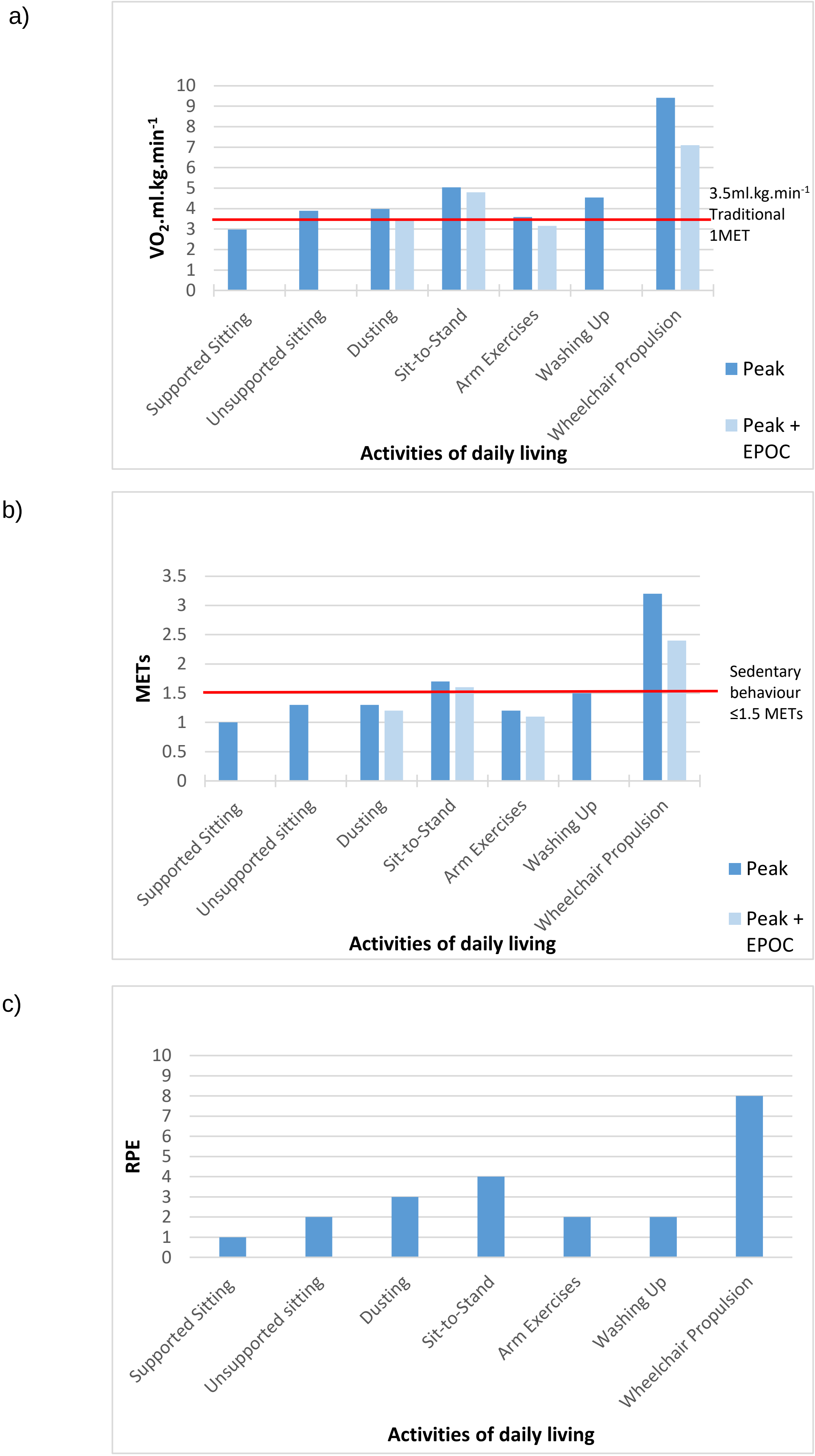


Figure 22 Participant E02's a) Oxygen uptake ($\dot{V}O_2$ ml.kg.min^{-1}) b) Energy expenditure (METs) c) Perceived exertion (RPE) for each of the activities performed

6.6.1.3. Participant E03

Participant E03 was a 65 year old male who was 7 years post-stroke. He had a FAC level of 2, as he required continuous manual contact of at least one person during ambulation to maintain his balance and support his body weight. Of the four participants, E03 scored the highest on the NEADL with a score of 7. Although this is still a relatively low score indicating a low level of independence, participant E03 had had stroke related mobility disabilities for the longest period of time compared to the other three participants. This suggests that with time comes an adaptation to living with physical disabilities and regaining independence. Participant E03 had regular physiotherapy sessions through a private neurophysiotherapy practice which included hydrotherapy. He also completed daily exercise sessions with his wife and carers to maintain his strength and movement.

Mean resting energy consumption for E03 was 3.11 ml/kg/min (SD=0.59). Figure Twenty-Three displays the relative energy expenditure, relative MET values and perceived exertion levels for each of the activities performed by E03. The values are also listed in Tables Thirty and Thirty-One. Four activities during the peak period had relative MET values that exceeded 1.5 METs (static standing (1.56 METs), sit-to-stand (1.69 METs), up and go (2.63 METs) and washing up (1.65 METs)), with washing up being the only activity that was completed whilst sitting and not involving standing or travelling. Up and go was the only activity that also had a relative MET value exceeding 1.5 METs for the total activity period (peak + EPOC) with a value of 2.44 METs. The 2.63 METs required by E03 to complete the Up and Go task is at the higher end of the light intensity physical activity (LIPA) classification on the activity spectrum, with 3 METs being the threshold for moderate intensity physical activity.

Participant E03 perceived all of the activities as fairly easy with all of the activities being rated as a level 5 or below on the rating of perceived exertion scale. Even for the activities that exceeded 3.5 METs; static standing, sit-to-stand and Up and Go, the participant did not feel that they were very taxing with RPE scores of 3, 4 and 5 respectively. This suggests the potential for pushing the intensity of the activities to enable greater energy consumption without too much more effort from the participant. As dusting and arm exercises were both rated as 2 on the RPE scale, if the participant was to push the intensity of the activities it may increase the energy consumption enough to raise the MET values over 1.5 (from 1.23 METs for dusting and 1.24 METs for the arm activities).

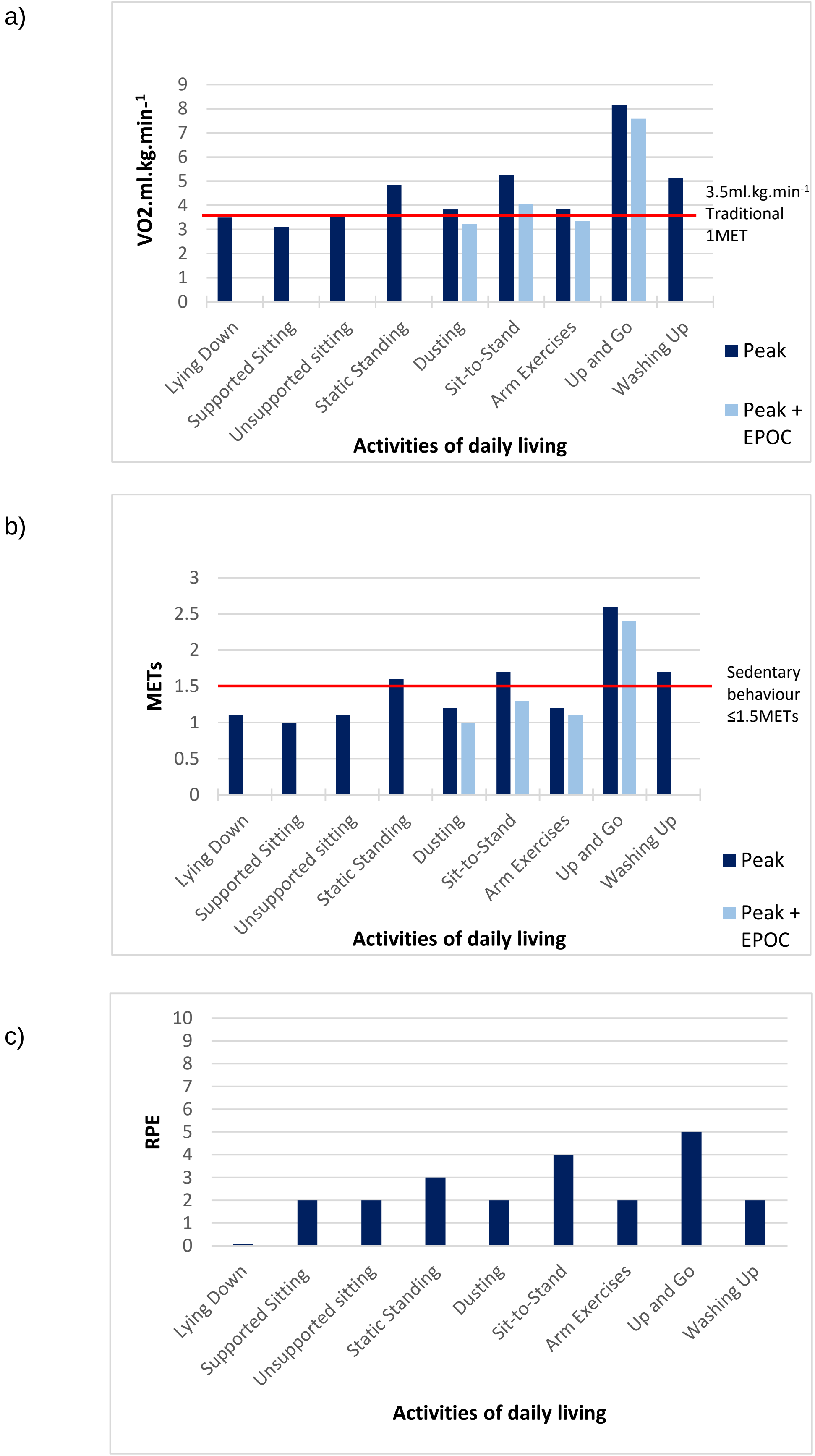


Figure 23 Participant E03's a) Oxygen uptake ($\dot{V}O_2$ ml.kg.min^{-1}) b) Energy expenditure (METs) c) Perceived exertion (RPE) for each of the activities performed

6.6.1.4. Participant E04

Participant E04 was a 67 years old female stroke survivor who had had her first stroke over ten years ago with a second stroke occurring only five months ago. It was this second stroke that caused the severe mobility disabilities leaving the participant chair bound and unsafe to move without trained carers and a hoist. Formal carers transferred the participant from her bed in the morning to her chair and back again at night and also to use the toilet throughout the day. As she was unable to move without her formal carers she was categorised as level 1 on the functional ambulatory classification and was limited by the activities that she could complete from the activity schedule. Only five of the ten activities on the activity schedule were attempted, all of which were completed in a sitting position.

Mean resting energy consumption for E04 was 1.77 ml/kg/min (SD=0.75). Figure Twenty-Four displays the relative energy expenditure, relative MET values and perceived exertion levels for each of the activities performed by E04. The values are also listed in Tables Thirty and Thirty-One. All activities not at rest (i.e. Dusting, arm exercises and washing up) consumed enough energy to exceed the 1.5 METs sedentary behaviour threshold (Dusting 1.62 METs, arm exercises 1.59 METs, washing up 1.63 METs). Interestingly, although both dusting and arm exercises used more than 1.5METs for the peak activity period, the total activity (peak + EPOC) did not with respective MET values of 1.21 METs and 1.28 METs. This proposes that in order to increase the total energy expenditure of these activities the focus should be on increasing the intensity and duration of the activity instead of relying on the excess post exercise oxygen consumption (EPOC).

Although the relative MET values for the three arm-based activities only just managed to exceed 1.5 METs, relatively low ratings of perceived exertion were scored by the participant for the activities. Similarly to participants E02 and E03, there is therefore potential for the intensity of the activities to be increased in order to increase the energy consumption without the task being too demanding for the participant to complete.

As this participant was unable to stand or ambulate without help from her formal carers, the results indicating the suitability of arm-based activities as a possible mechanism for breaking her periods of sedentary behaviour was very positive.

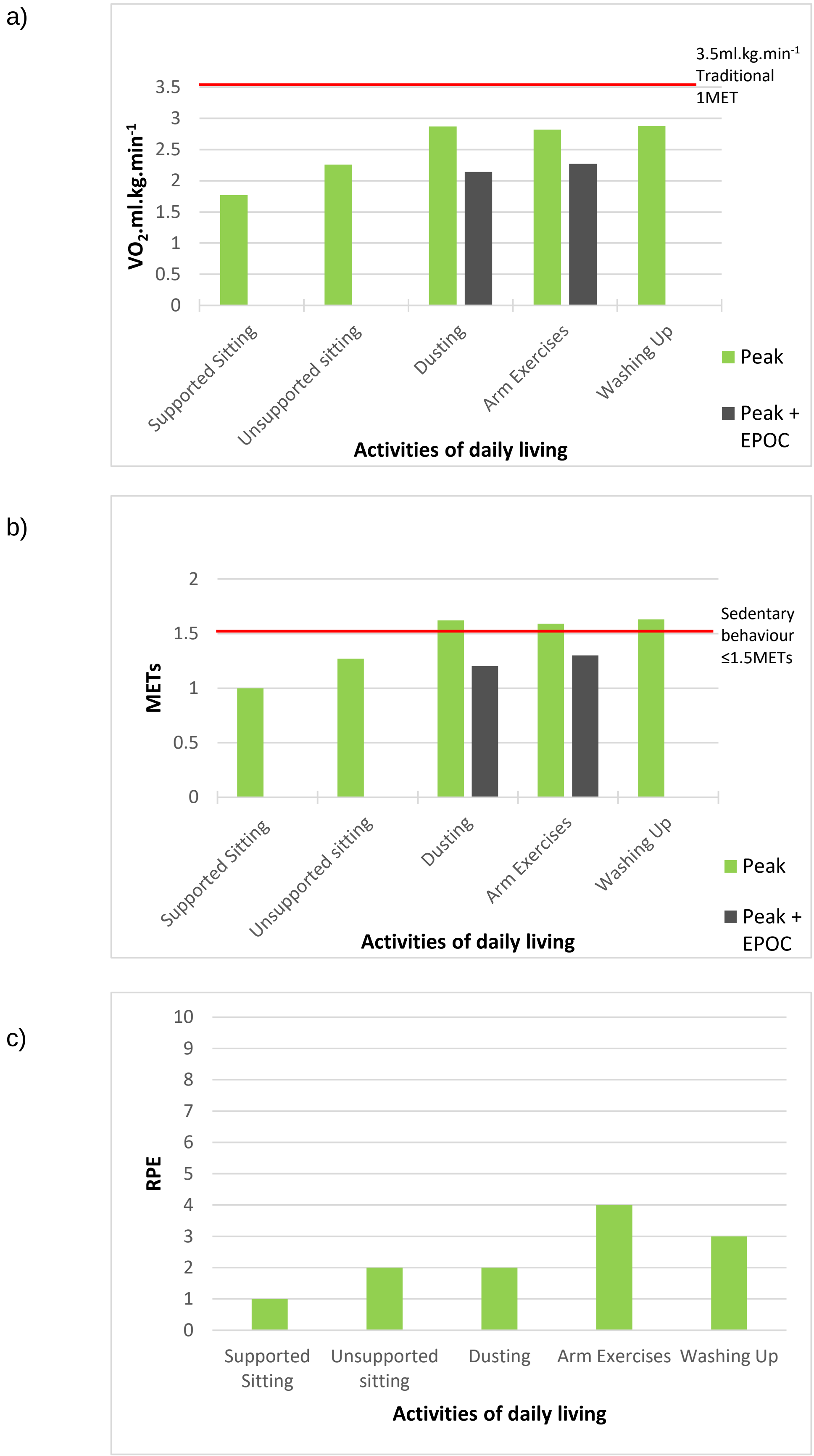


Figure 24 Participant E04's a) Oxygen uptake ($\dot{V}o_2$ ml.kg.min^{-1}) b) Energy expenditure (METs) c) Perceived exertion (RPE) for each of the activities performed

6.6.1.5. Energy expenditure comparisons between participants

The energy expenditure data collected from the study varied between the participants with the mean resting energy consumption ranging from 1.77 ml/kg/min (SD=0.75) for participant E04 and 3.11 ml/kg/min (SD=0.59) for participant E03. Due to this variation and the small sample it was deemed unsuitable to combine the data in order to infer conclusions. However, despite the variations in data across the four participants, as displayed in Figure Twenty-Five, definite patterns were observed in relation to each of the activities measured.

As discussed in a previous section, participants E01 and E04 both had lower relative energy expenditure values than the other two participants. This could potentially be explained by their high Body Mass Indexes (36 and 41 respectively). As the relative oxygen consumption value is the volume of oxygen consumed relative to the individual's body mass (kg), their values would be lower. In relation to the metabolic equivalents value recorded for each activity that they performed, the MET values were either comparable to those of participants E02 and E03 or were higher than these two participants.

All four participants recorded higher values for unsupported sitting compared to supported sitting (rest). Although an increase in $\dot{V}o_2$/kg/min values would be predicted, the observed values were quite high with participants E01 and E02 using more energy for unsupported sitting compared with arm exercises and E01 requiring enough energy to exceed the 1.5 METs sedentary behaviour low intensity physical activity threshold. Through observations of the participants during the measurement visit it was noted that during the unsupported sitting activity, participants tended to lean forward tucking their arms underneath them to ensure that they were not inadvertently leaning or resting on the chair. It could be suggested that the positioning of the participants, with them leaning forward may have raised the diaphragm and restricted lung expansion ultimately affecting their breathing.

As anticipated, the activities that involved 'travelling' i.e. wheelchair propulsion and Up and Go, used the most energy as illustrated in Figure Twenty-Five. Participant E02 used three times the volume of oxygen consumption at rest to complete the wheelchair propulsion activity. These two activities were followed by static standing and sit-to-stand which also required a significant amount of energy to complete. Again these findings were unsurprising as they both involved a standing posture and the use of the lower limbs and would similarly require an increased amount of energy expenditure in healthy participants. In contrast, the high energy expenditure values recorded for the washing up task were unexpected especially as the task was completed while sitting down. These results suggest that some arm activities may be able to break sedentary behaviour in stroke patients who are unable to stand or ambulate.

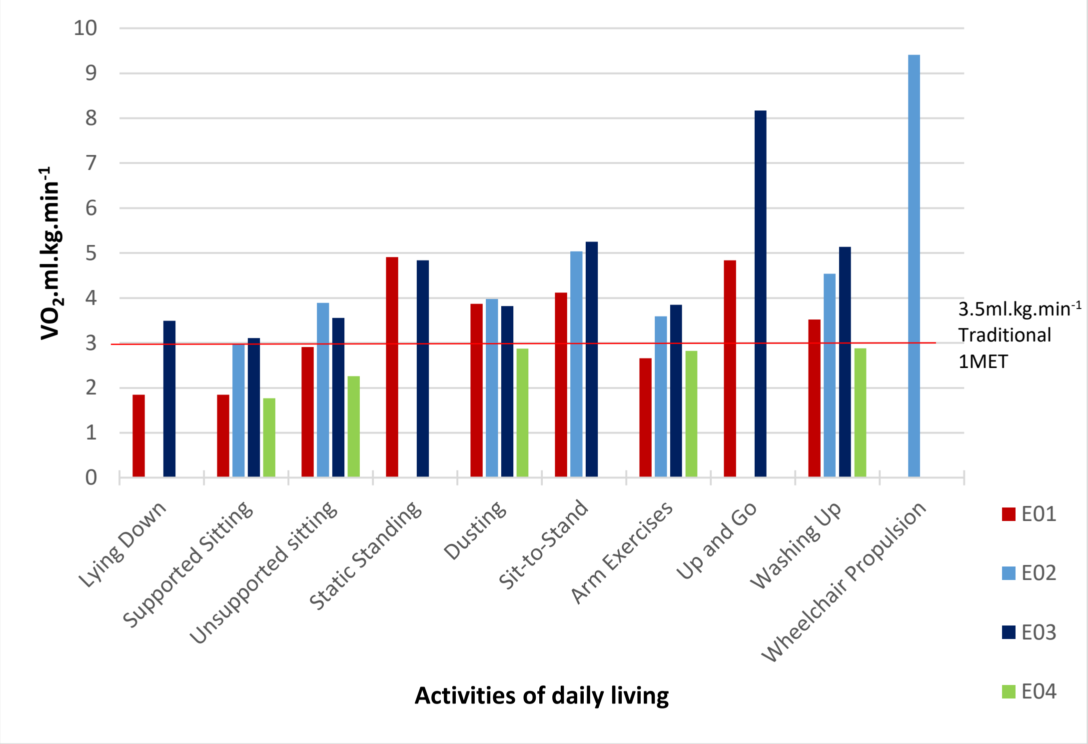


Figure 25 Oxygen uptake ($\dot{V}o_2$ml.kg.min-^{1}) comparisons across activities and participants

In order to compare the energy expenditures of the activities between the four participants, metabolic equivalents (METs) were calculated using the individuals' resting energy expenditure values. The threshold between activities categorised as sedentary behaviour and light-intensity physical activity of 1.5 METs was exceeded by all activities that involved standing, walking and travel (Figure Twenty-Six). This finding was to be predicted as the participants had to take a lot of thought and effort to initially plan the activity and then to execute it. As these participants did not stand or walk as often as healthy individuals or even at all, a large amount of energy was required to perform these activities. This was reflected in the data with the participants requiring between 1.56 METs and 2.65 METs for standing and healthy individuals only requiring 1.3 METs for standing 'quietly' increasing to 1.8 METs for standing while 'fidgeting' (Ainsworth et al., 2011). For these participants simply standing up raised their energy expenditure enough to be categorised as light-intensity physical activity unlike healthy individuals.

Unsurprisingly wheelchair propulsion by participant E02 required the largest amount of energy to compete the task. At 3.16 METs this activity is classified as moderate-intensity physical activity and is reflected by the sharp increase in the rating of perceived exertion scored by the participant (RPE 8) compared to the other activities (See Figure Twenty-Seven).

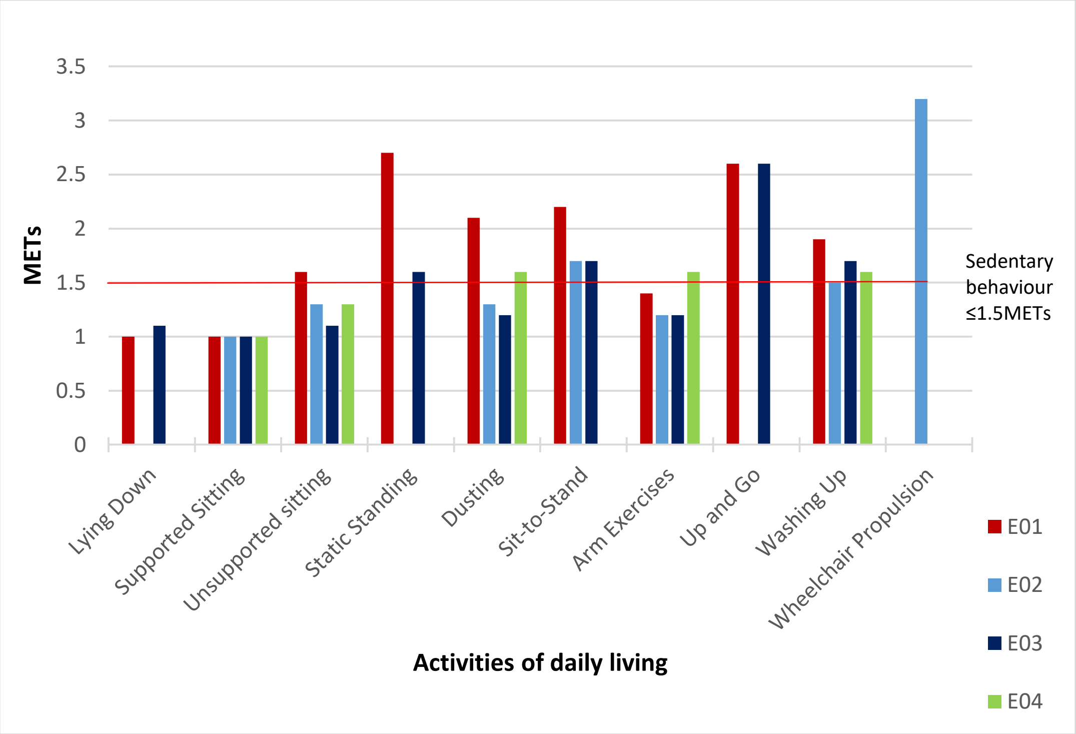


Figure 26 Energy expenditure (METs) comprisions across activities and participants

As can be seen in Figure Twenty-Six, all four participants reached 1.5 METs for washing up with a range of 1.52 – 1.90 METs. This result is particularly surprising as the activity was completed in a seated position and mimicked the action of washing up using a washing up bowl and plastic plates and cutlery in the absence of water. In the compendium of activities for healthy individuals, washing dishes whilst standing requires 1.8 METs to complete (Ainsworth et al., 2011). The values recorded for these stroke survivors were similar to those recorded by Ainsworth and colleagues (2011) despite the present sample being unable to stand and having to complete the activity sitting down. If the action of placing items into the washing up bowl, mimicking cleaning them and then removing them to dry using a tea towel required at least 1.5METs, the addition of water and water resistance to actually wash the dishes would increase the intensity of the activity and ultimately the energy required. The activity would also be affected by the use of plastic plates and cutlery, with the extra weight of crockery predicted to also increase the intensity of the activity. Although these results are a promising indicator that washing up whilst sitting down may be one way in which sedentary behaviour can be broken up in these participants, the practicalities of being able to wash dishes with water away from the sink may be challenging. All participants, except E01 scored washing up as either 2 or 3 on the RPE scale (Figure Twenty-Seven). This indicates that the participants did not find the task very challenging and there is therefore the potential for the intensity of the activity to be increased. This could be done through the addition of water, heavier crockery and potentially a longer activity time in order to push the activity and increase the energy requirement of the task. As the RPE scores were relatively low there is scope to increase the intensity whilst ensuring that the task is still acceptable for the participants.

Two other promising results from the study were the energy expenditures required for the other arm activities; dusting and arm exercises. Energy expenditures for dusting ranged between 1.23 METs and 2.09 METs with two of the four participants exceeding 1.5 METs (See Figure 8). Although healthy individuals require more energy for dusting or polishing furniture at 2.3 METs (Ainsworth et al., 2011), similar to washing up the activity was completed whilst standing with engagement of the lower limb muscles therefore obviously requiring more energy. Similarly, the energy expenditure for arm exercises ranged from 1.20 METs and 1.59 METs (Figure Twenty-Six). Although a comparable value for healthy individuals of 3.0 METs has been published as part of the original compendium of physical activities (Ainsworth et al., 1993), the activity was classed as a conditioning exercise of weight lifting with a light to moderate effort. With this activity also likely to have been completed while standing, the values are therefore difficult to compare with the values from the present study.

Like the majority of the activities performed, with the rating of perceived exertions mainly scoring 4 or below on the RPE scale (except E01) there is potential to increase the intensity of both arm activities whilst making them still acceptable to the stroke survivors (Figure Twenty-Seven). In order to standardise the activity, participants were ask to move the duster in a series of backwards-forwards and side-to-side movements with the intensity being low and the movement being slow and controlled. This activity could be intensified with a more vigorous movement of the duster and not restricted to forward-backward and side to side movements.

During the arm exercises activity, the participants used a light hand weight of 0.5kg for the bicep curls. To increase the intensity of the activity heavier weights could be used whilst keeping correct form in the movement i.e. not using a weight too heavy to perform the movement safely and correctly. For the reach and grab exercise, participants were asked to 'reach their hand above their head and grab the air'. With this exercise being at a light effort level, participants could be encouraged to reach as far as they can up in the air without causing themselves pain or discomfort.

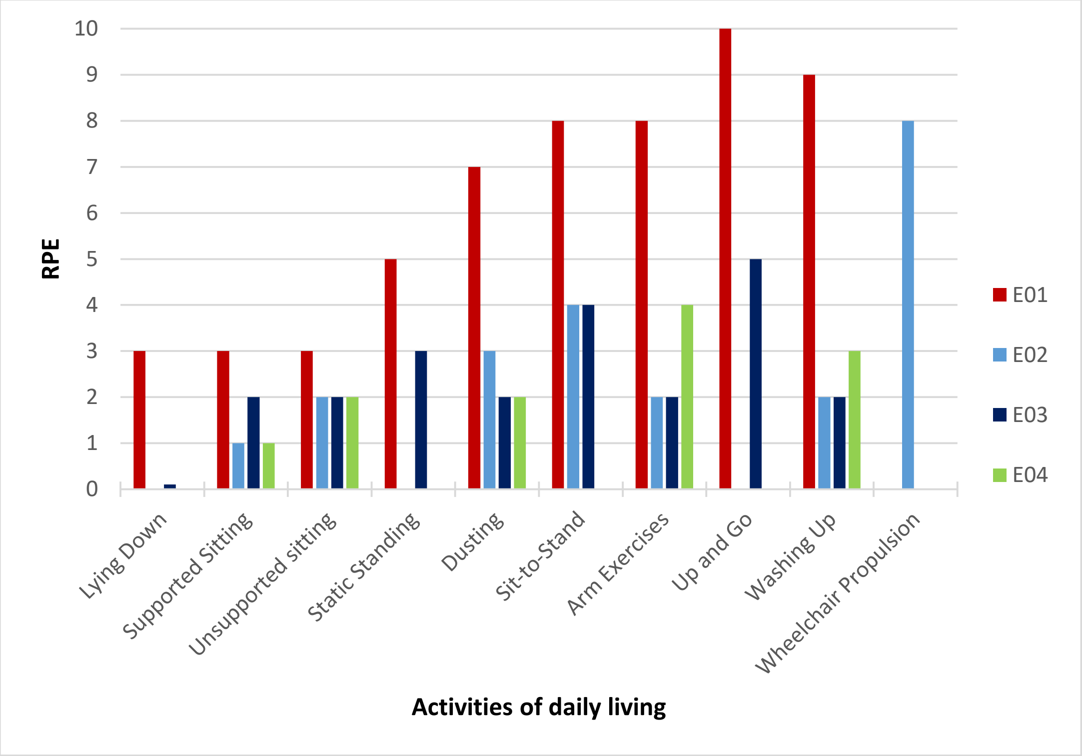


Figure 27 Rating of Perceived Exertion comparisons across activities and participants

6.7. Discussion

Due to the study only requiring a small number of participants in order to assess the feasibility of the methodology, and a difficulty in recruiting participants to the study, only four stroke survivors took part. Given the small sample and the high variation in participant characteristics (i.e. weight) and ability (i.e. activities able to perform as per the instructions), the study was unable to combine results and draw meaningful conclusions. However, from the limited data that was produced, promising results were found with patterns emerging, as described in Section 6.6.1.5

It has often been questioned whether the standard oxygen consumption value equivalent to 1 MET, 3.5 ml/min/kg, is appropriate for everyone. Byrne and colleagues (2005) found that the standard value for 1 MET significantly overestimated the average $\dot{V}o_2$ value for rest, on average by 35%, and was affected by age, body weight and body composition. Similarly, another study (Kwan et al., 2004) found that age had an independent effect on energy expenditure, with the 3.5 ml/min/kg significantly overestimating the energy expenditure in elderly people (65-89 years old). The lower resting metabolic rates (RMR) compared to the standard value observed in the present study are supported by two previous studies that also found that mean RMR was significantly lower in stroke survivors compared to healthy individuals. Compagnat and colleagues (2018) reported a mean RMR of 3.08 ml/min/kg whilst Serra and colleagues observed a mean RMR of 2.99 ml/min/kg. It is therefore important when planning to measure energy costs in stroke survivors to ensure that a measurement of the individuals' resting energy expenditure is taken in order to calculate a personal MET value, which can then be used to calculate METs for different activities.

One of the aims of this study was to investigate the potential for arm activities to raise energy expenditure high enough to break sedentary behaviour. This follows evidence, that most upper-extremity activities (e.g. weight training, bowling, bed making, laundry and moving items) in individuals with spinal cord injury fall into the light-intensity activity category and can therefore be classed as breaks in sedentary time. Surprisingly, in the present study, all four participants reached 1.5 METs for washing up, two out of four exceeded 1.5 METs for dusting and the energy expenditure for arm exercises ranged from 1.20 METs and 1.59 METs. Given the relatively low rating of perceived exertion scores reported for these activities (2 – 4 RPE), there is potential for the activities to be scaled to a higher intensity level whilst making them still acceptable to the stroke survivors. This therefore could potentially be a strategy for reducing sedentary behaviour by raising energy expenditure above 1.5 METs. It is also important to note that despite these activities lasting for only a short period of time, the 'peak' activity time and the time for recovery (Peak + EPOC) still produced promising results of close to or exceeding 1.5 METs. This suggests that short time periods might be enough to break sedentary time. However, future work needs to be conducted to assess how long breaks in sedentary behaviour need to be in order to produce a beneficial physiological effect. This is especially important given the findings of a recent study (Janssen et al., 2017) suggesting frequent short bouts of light intensity physical activity does not have a significant effect on post-prandial plasma glucose and insulin in people with stroke (English et al., 2018b). The same study however also reported decreased systolic blood pressure in stroke survivors following short bouts of light intensity activity, suggesting a physiological benefit of short breaks in sedentary behaviour (English et al., 2018a).

Although Serra and colleagues (2016) found mobility related activities (floor sweeping, stepping in place, over-ground walking, and lower and higher speed treadmill walking) were around 1.25 to 1.5 times greater when measured in stroke survivors compared to the activity compendium METs (Ainsworth et al., 2011), the current study wasn’t able to compare the majority of activities with those listed on the compendium. Some of the measured activities including dusting and washing dishes produced similar or slightly lower values of energy expenditure compared to healthy controls listed in the activity compendium. As the activities completed by the healthy individuals would have been completed whilst standing, therefore engaging the lower limb muscles, the fact that the stroke survivors achieved similar results whilst sitting suggests a higher requirement of energy expenditure in stroke survivors. In order to produce greater comparisons between energy expenditure values of stroke survivors and healthy individuals, future work is needed to measure the energy costs of activities using an identical activity schedule (i.e. activities completed in sitting position) and instructions for both groups of participants.

Of the activities that were measured in both the present study and the study by Verschuren and colleagues (2016), higher recorded energy expenditure values were observed in the present study. Unsupported sitting was reported as being between 1.05 METs and 1.13 METs compared to 1.14 METs and 1.57 METs in the present study. Similarly, standing was recorded as 1.26 to 1.60 METs by Verschuren et al., whereas the present study found standing to fall between 1.56 METs and 2.65 METs. Wheelchair propulsion also required a significantly higher MET value for the present study (3.16 METs) compared to the 2016 study (1.7 METs – 1.93 METs). The higher recorded values for unsupported sitting, standing and wheelchair propulsion observed in the present study may be explained by the difference in study design. The same activities may require additional energy when completed in a natural home environment compared to a controlled laboratory environment. Additionally participants in the present study had more severe mobility problems (FAC 1 and 2) compared to Verschuren et al. (2016) that had participants with FAC levels 1 and 3. The difference in the participants’ mobility limitations may have contributed to the observed difference in energy expenditures with individuals with more severe mobility disabilities requiring more energy to complete the same activities.

The majority of activities were rated at a level five (out of ten) or below by the participants (except E01 who consistently scored significantly higher across all activities) on the BORG rating of perceived exertion scale (Borg, 1982). These low scores indicate that the stroke survivors found the activities acceptable. The easier and more enjoyable an activity is the more likely that stroke survivors will engage and participate in the activity regularly. This is important for intervention development as potential activities to break-up sedentary time that are included in the intervention are more likely to be adhered to if they are acceptable to the participant. As these activities posed no difficulty or burden on the participants in the study, they could be considered future strategies to reduce sedentary behaviour. The low scores also suggest that the stroke survivors may be willing to increase the intensity of the activity This is important as some activities, including dusting and arm exercises, were close to reaching 1.5 METs, and with an increase in the activity intensities there is a potential that they could push them over the sedentary behaviour threshold. Further research is therefore required to assess what the energy expenditures of different intensities of activities are. This would help to identify the required level of intensity to achieve a MET value greater than 1.5 METs (sedentary behaviour threshold). It would also be important to assess the ratings of perceived exertion for the differing intensities to ensure that any proposed activity is still acceptable to the stroke survivor despite the increase in intensity.

Sedentary behaviours are defined as any waking behaviour, while in a sitting or reclining posture, characterised by low energy expenditure (≤1.5 METs) (Tremblay et al., 2017). Given the definition being comprised of two concepts; energy expenditure and posture, current debates exist around whether increasing energy expenditure or altering posture (i.e. standing) is important for reducing sedentary behaviour (Magnon et al., 2018). Thoughts surround whether the positive physiological effects of reducing sedentary behaviour are primarily driven by increases in energy expenditure, changes in postural allocation or a combination of both (Mansoubi et al., 2015). The beneficial effects of interrupting prolonged periods of sitting are well documented, with studies highlighting reductions in postprandial glucose and insulin responses (Thorp et al., 2014; Dunstan et al., 2012b) and reductions in systolic blood pressure (English et al., 2018a). Although the experimental evidence of health benefits of breaking-up sedentary behaviour is extremely important, all of the study protocols include breaking-up sitting time with periods of standing or ambulation. If postural allocation is the key factor in reducing sedentary behaviour to observe a beneficial physiological response, the question should be asked; is it possible for non-ambulatory individuals who are unable to stand-up or walk to get the same beneficial response? In a study by McCarthy and colleagues (2017), it was found that performing short bouts of arm ergometry during prolonged sitting attenuated postprandial blood glucose and insulin levels, despite remaining in a seated posture. As the results could not be contributed to postural change, further investigation is required to identify the possible mechanisms for the observed postprandial glycaemia. Muscle activation, increases in energy expenditure and increases in blood flow have been suggested by the study author as possible contributory factors. These clinically significant results highlight the opportunity for individuals who are unable to weight-bear or ambulate, including stroke survivors, to reduce their sedentary behaviour (McCarthy et al., 2017).

The purpose of this study was to not only find activities that have potential health benefits through reducing sedentary behaviour, but that are also functional and meaningful. This is important as to ensure that the activities are acceptable for the stroke survivors, with activities with more functional relevance potentially being adhered to more. Some functional activities may also improve the stroke survivors' quality of life through increased levels of independence, a sense of achievement and purpose e.g. helping with daily cleaning activities. It is important to note that even if increasing energy expenditure is not enough to break sedentary behaviour and produce physiological changes, the results of encouraging and supporting stroke survivors to participate in activities of daily living and improve their independence may be enough of a benefit.

6.7.1. Limitations and issues of feasibility

One of the aims of the present study was to reflect upon the feasibility of measuring energy expenditure of activities of daily living in stroke survivors with severe mobility disability in a free-living environment. Previous studies had measured energy expenditures of activities in stroke survivors but had conducted the testing in a laboratory setting (Serra et al., 2016; Verschuren et al., 2016). However, in order to assess potential activities that these stroke survivors could incorporate into their daily routine as part of an intervention to reduce sedentary behaviour it was deemed important to try and take measurements in a natural setting. This next section will discuss aspects relating to feasibility including practical aspects, data analysis and outputs produced.

6.7.1.1. Methods and Equipment

As this study involved the use of equipment that participants were required to wear in order to take some physiological measurements some stroke survivors may have felt uncomfortable in agreeing to take part in an unfamiliar study. Unlike the Q-methodology study whereby individuals are used to or are aware of an interview, the present study may have been perceived as invasive especially by these stroke survivors who may have spent months in hospital receiving invasive treatment. It was important for the stroke survivors to trust and have a rapport with the researchers in order to feel comfortable and confident to take part. It would be important, if replicating this study to ensure face-to-face contact with potential participants when trying to recruit so an honest conversation of what the study would involve takes place early. This would also allow a relationship to develop between the participant and researcher which is essential to build trust and ensure successful consent and participation.

The study protocol required that at least two study visits should be made for each participant, one to explain the study, obtain consent and go through the activity schedule and the second to measure energy expenditure. Through trialling this structure within the study it was deemed important for the two visits to be used. The first visit allowed rapport and trust to be built between the participants and the researchers with in-depth discussions around what the study would involve, informed consent completed and a personalised plan created of the activity schedule ready for the second visit. As the preparation work was completed during the first visit, both the researchers and participants knew what was to happen during the second visit, allowing the measurement period to be completed smoothly and timely. Having two visits per participant, although time intensive, was essential to allow the measurement visit to run as quickly and smoothly as possible. This is important as it limited the time the participants were required to wear the equipment (No longer than 1 hour 20 minutes) and provided a structured plan to work to and ultimately reduced the burden on the participant.

While the chief investigator was the only researcher to attend the initial visit, two researchers were present during the measurements visits. Again, this was essential to allow one researcher to monitor the recording data on the laptop, add markers and comments to the continuous data recording to indicate the start and stop of each activity and take overall control of the data collection visit, while the second researcher was able to be patient focused providing continuous direction and support through the completion of the activity schedule. The patient focused researcher was able to monitor the participants and regularly check that they were able to continue. They also had an important role in asking the participants how they perceived their rate of exertion during the activity by holding up a laminated Borg Rating of Perceived Exertion Scale (Borg, 1982) for them to point at.

It was also important for two researchers to be present during the measurement visit to enable the set-up and calibration of the equipment prior to starting the energy expenditure measurements. Set-up of the equipment involved calibration using reference gases and room air and as this required the use of a gas cylinder, the calibration procedure was completed outside of the participants' home. As one of the processes involved calibration against room air, it was important for the equipment to be protected from air disturbances i.e. wind, breath. Calibration of the equipment was therefore completed in the car outside the participants' house. Although the three step-process was easy to follow, the limited space within the car made the process more difficult, especially when using the Hans Rudolph 3L syringe for volume calibration.

During the initial researcher visit, study information was collected including demographic data (i.e. height, weight and age), which was required by the software in order for accurate energy expenditure. Participants were also asked to complete the Nottingham Extended Activities of Daily Living Scale (Nouri and Lincoln, 1987), in order to assess the participants' level and frequency of everyday activities in the weeks previous to the study. Upon reflection following the study, it would also be important to have an indication of other factors that may affect energy expenditure values or the participants' capability for completing each of the activities. Future studies should assess mobility aids used by the stroke survivors and spasticity levels as these will affect how they perform the activities of daily living. Although walking aid use was not formally assessed in the present study, the researcher (NC) made field notes during each of the research visits and noted what mobility aids they used generally and for the individual activities. It would also be important to record medications used by the participants to be aware of potential effects on the energy expenditure measurements. Similarly, co-morbidities might also be interesting to document in order to understand the factors that might affect energy expenditure in these stroke survivors. Medication was recorded in the study by Verschuren et al. (2016) and both medication and co-morbidities was recorded in the 'test-retest reliability' study of the Metamax 3b equipment by Polese et al. (2015).

One of the main barriers to the conduct of the study related to the mask worn by the participants. To ensure optimal gas analysis it was important for the mask to fit correctly with no air leaks. Two different sized masks were available (medium or large) and adjustable Velcro straps were used to ensure a firm fit. The initial set-up of the recording equipment and fitting of the mask was found to be quite difficult especially in relation to finding a balance between making the mask fit tightly and ensuring the participants remained comfortable. Participants often initially commented that the mask felt uncomfortable with the straps being tight. However, following a period of time to allow familiarisation of wearing the equipment (typically 3-4 minutes), participants tolerated wearing the mask well. Some of the participants required regular breaks from wearing the mask (typically 1 minute) and although it was aimed to allow these during the rest periods between the activities they sometimes had to be taken during rest periods immediately following an activity where the measurements were of importance (e.g. peak + EPOC). Although these unplanned breaks were not ideal for measurement purposes, it was important to allow the participants to take breaks when they needed them.

Continuing with the notion of equipment, participants were overall very accepting of the transmitter unit and wearing it using the Velcro strap harness. The additional weight of the transmitter unit (580g – approximately equivalent to a small bag of sugar), was again no problem to the participants with none commenting on having to wear the equipment.

The maintenance procedures of the equipment between measurements (see section (6.5.5.3.2) limited the number of participants that could be measured during a day and ultimately prevented visits being conducted with participants from a stroke club in the South East of England. From experience during the Q-methodology study, these participants lived quite far from one another, therefore the practicalities of arranging visits whilst also allowing time for sterilisation of equipment and recharging of batteries between visits was deemed unfeasible. As previously discussed, it was extremely important for each participant to receive two visits, one initial set-up meeting and a second measurement visit. For this group of participants it would have been difficult to arrange these multiple visits, unless they had been pre-arranged at no more than two participants a day. This would have required two researchers to spend a minimum of three days in this location which was beyond the capacity of the researcher in the PhD programme.

6.7.1.2. Activity Schedule

During the design of the study, discussions took place regarding the structure of the schedule of activities including activities to include, how these could be standardised and what order they should appear in the schedule. In order to reduce the burden to the participants, consideration was given to the types of activities included with the final activity schedule being composed of normal activities in which the participants might engage (i.e. no unfamiliar or excessively strenuous activities). The order of the activities was also considered, with activities using the same part of the body being spread out within the order to allow each part of the body time to rest and minimise muscle fatigue. Routine breaks were also included throughout the activity schedule with rest periods of at least 2 minutes between each activity.

One of the main limitations of the study was the length of the activity schedule and the time it took to complete the energy expenditure measurements. Participants E01 and E03 both managed to complete nine out of the ten activities but took around 1 hour 10 minutes to complete the schedule. Participant E02 also took around 1 hour 10 minutes to fully complete seven of the activities and E04 required 40 minutes to perform five activities. Although the participants were able to complete the activity schedule and wear the equipment for the time required, a few factors highlighted the issue of the activity schedule being too long for one visit. Participants looked visibly more tired at the end of the study following the completion of the activities. Participant E01's ratings of perceived exertion increased with each activity completed with the washing up task scoring 9 out of 10 on the RPE scale. This was incongruent with the other participants with ratings of perceived exertion fluctuating with difficulty of the activity e.g. higher RPE scores for sit-to-stand, up and go and wheelchair propulsion. This could potentially be explained by participant E01's increasing fatigue as the activity schedule was completed causing perceived exertion to increase.

Routine two minute breaks were scheduled between each of the activities to allow the participants a rest period before having to undertake the next activity in their schedule. Often an activity would also include a rest period e.g. sit-to-stand and arm task, that were included in order to measure the energy expenditure during the recovery phase following the immediate activity. Participants were keen for the measurement to finish as soon as possible and as a result often indicated during the between-activity rest period that they were ready to continue onto the next activity. This again suggests that the activity schedule was too much for one visit, and if it was broken into multiple visits these important breaks could remain in order to ensure full recovery to resting energy expenditure following the activity. It would be important for future studies to break the measurement visit into more than one session to reduce the burden and fatigue of the participants and to achieve more accurate results with oxygen consumption reverting to resting levels between each activity.

In a couple of instances, the order of the activities had to be changed for logistical and practical reasons. After participant E03 lay down in bed to complete the first activity, he then used the bed to complete the third activity in the schedule, unsupported sitting, instead of the scheduled activity, supported sitting. The decision to swap the two activities was made for a practical reason as it reduced the number of transfers needed from wheelchair to bed and vice versa, therefore reducing the burden on the participant and his levels of fatigue. It is important to be aware for future studies that it may be practical to swap the order of activities rather than keep to the schedule. However it is also important to note that the activity schedule was designed with consideration regarding the order with activities using the same body part being spread out throughout the schedule. Therefore if the order is to be changed, thought should be given as to whether the activities in the new order use similar parts of the body and therefore may cause muscle fatigue. Activities should be ordered to allow each part of the body time to rest.

It was deemed important to create an activity schedule with prescribed instructions in order to standardise the activities and to produce results that could be compared across the participants. However this study highlighted the issue that stroke survivors with severe mobility problems have when having to complete an activity in a certain way. Throughout the measurement visits, the standardised instructions were followed where possible. However when a participant wasn’t able to complete the activity as prescribed but could instead do it in a way that was relatable to their day-to-day living, it was deemed important to still record the energy expenditure required for that activity. An example of this was participant E02 and wheelchair propulsion. As the lady had hemiplegia affecting one of her arms, she was unable to propel her wheelchair in a conventional way (i.e. pushing the wheels using her hands). During the initial visit when discussing the activity schedule and deciding what activities were able to be attempted, the participant asked whether she could complete her method of travelling around her house in her wheelchairs. Although the movement was an unconventional method of wheelchair propulsion and not as described in the instructions, it was deemed important to capture the energy consumption for the activity as it was her method of travelling around her home that she does on a daily basis and was therefore more meaningful for the participant than the standardised instructions. So although it is important to try and standardise the instructions, it is also very important for the activities to be as meaningful for the participants as possible, even if it means a deviation from the activity schedule. Activities that are more meaningful to the participants would be more likely adhered to if part of an intervention to reduce sedentary behaviour than an activity that does not resemble a typical activity of daily living for the individual.

6.7.1.3. Data analysis

As this study aimed to test the feasibility of measuring energy expenditure for activities of daily living in a free-living environment, only a small number of participants were planned to be recruited. Due to the difficulties with recruiting to the study, as explained previously, only four participants were recruited to take part. With only four sets of data, the analysis was unable to combine and draw any conclusions from the collected data. Although no general inferences could be made, patterns did emerge from the data in relation to the energy expenditure for different activities of daily living. Overall the data showed promising results and it would therefore be important to collect more data in order to generate conclusions. This is important to understand what energy is required to complete activities of daily living in stroke survivors with severe mobility disabilities and determine what activities require enough energy to break sedentary time.

Once the data was collected and before any analysis could be commenced, the data had to be ‘cleaned’ to remove any outliers. During the study it was noted that the stroke survivors had constant small ‘fidgeting’ movements. This meant that the data was ‘noisy’ with what appeared to be lots of anomalous data points. Even once the data had been cleaned, the ‘noisy’ data made it difficult to identify plateaus in energy expenditure data points for the activities that allowed a plateau to be observed e.g. lying down, sitting, washing up. It was also often difficult to determine whether a data point was a ‘peak’ value or an anomalous data point especially in the activities with short time periods where spikes were frequently observed. It would be important to remind participants in future studies to focus on the activity being completed and to keep additional movements to a minimum. It would also be interesting to understand how additional data sets affect the clean-up and analysis and whether more data would give a clearer indication of what constitutes a ‘peak’ value and what constitutes an anomalous data point.

Typically in studies examining energy expenditure using indirect calorimetry, the mean oxygen consumption of activities is calculated from the plateau observed in the data. A plateau is achieved in activities that are continuous and that can be maintained for a period of typically between two and five minutes to allow the data to become stable. As described in Section 6.5.5.4, a plateau was able to be achieved in six out of the ten activities including; lying down, supported sitting, unsupported sitting, static standing, washing up and wheelchair propulsion. For the remaining four activities; dusting, sit-to-stand, arm exercises and up and go, the period of time for the activities were very short and therefore unable to observe a plateau. Due to the delay in recording oxygen consumption from muscle activity by mouth measurements, $\dot{V}o_2$ values continued to increase following the task during the recovery period with subsequent peaks also being observed. To account for this delay, it was decided to include the 25 seconds immediately following the completion of the task in the activity time to produce the Peak value. It was also deemed important to determine the total energy consumption of the activity, with the excess post exercise oxygen consumption (EPOC) during the recovery phase and the peak values for the task being combined to capture the energy consumption for the short time period activity and the recovery phase. Future studies should aim to include activities whereby data values can become stable and plateau to aid analysis of the data. However, it is important to note that participants, who have physical disabilities like those who took part in the present study, will have limitations to not only what activities they are able to complete but also to the length of time that they can complete the activity for. Data sets of future studies should be carefully examined to determine what period of time following the task should be included in the peak value.

6.8. Conclusion

This study has showed that recording measurements of energy expenditure in a natural environment is feasible in stroke survivors with severe mobility disability. It has also observed promising results in relation to the potential use of activities of daily living, including arm activities as strategies to reduce sedentary behaviour in non-ambulatory stroke survivors.

Chapter 7 - Discussion and Conclusions

7.1. Introduction

The thesis investigated sedentary behaviour in stroke survivors who have a severe mobility disability and are living at home. The study included systematic reviews of the evidence, exploration of perspectives on sedentary behaviour in this population and an investigation of the energy requirements for activities of daily living in their home environment. This work will inform future research to guide intervention development to reduce sedentary behaviour in stroke survivors with severe mobility disability.

This chapter provides a synthesis of the key findings from each of the sub-studies, locating the work in the existing literature. Implications for policies and practice related to sedentary behaviour in community-dwelling stroke survivors with severe mobility disability are then considered with recommendations for future research being highlighted, before critically evaluating the strengths and limitations of the research.

7.2. Summary of Key Findings

An initial review of the literature during the planning stages of this research indicated that limited research had been published in relation to sedentary behaviour and stroke survivors with severe mobility disabilities. The 2014 systematic review by English and colleagues confirmed that stroke survivors were highly sedentary compared to healthy adults. It also acknowledged the exclusion of non-ambulatory stroke survivors from the review.

The purpose of the mixed-methods systematic review described in Chapter two was to assess the effectiveness, appropriateness and acceptability of interventions to reduce sedentary behaviour in disabled people. This review was deemed necessary as little was known about sedentary behaviour and the stroke population with severe mobility disabilities. It was hoped that by drawing on the wider literature, it would allow any interventions or components of interventions that could potentially translate into the stroke population to be identified. The review highlighted the limited published research investigating sedentary behaviour in individuals with a physical disability with only six randomised controlled studies and one qualitative study being identified at the time of conducting the review (2016). Due to the lack of available evidence, a meta-synthesis to aggregate the findings from the two parallel syntheses (RCTs and Qualitative studies) could not be undertaken. Since undertaking the review, there has been an increase in research into sedentary behaviour and pre-existing health conditions and disability. This is evidenced by two interventions (English et al., 2016c) that were identified and included in the systematic review of physical activity and sedentary behaviours in people with stroke living in the community (Chapter Three), that were not published before the searches were run in April 2016. This interest in reducing sedentary behaviour in stroke survivors is continued with another intervention to reduce sedentary behaviour recently being published (Ezeugwu and Manns, 2018). These studies have shown that interventions to reduce sedentary behaviour in the stroke population are feasible and acceptable with promising initial results in aiming to reduce sedentary behaviour in stroke survivors. A Cochrane systematic review currently being undertaken (Saunders et al., 2018) will identify interventions aimed at reducing sedentary behaviour in stroke survivors and help to understand the efficacy of such interventions. Despite the increase in interventions aimed at reducing sedentary behaviour in stroke survivors, all are targeted at ambulatory stroke survivors, again highlighting the gap in research knowledge explored by the thesis. Similarly, a commensurate increase in qualitative studies exploring sedentary behaviour in chronic disease (Weedon et al., 2019), disability (Aminian et al., 2019) and stroke (Hall et al., 2019; Ezeugwu et al., 2017; Nicholson et al., 2016) have been undertaken and published, which will be discussed in the following paragraphs.

English and colleague's systematic review, published in 2014, was a significant piece of work that highlighted the substantial amount of time that stroke survivors spend being sedentary. However, with the searches being conducted two years prior to publication it was predicted that a number of newer research studies would available. This was confirmed through the systematic review described in Chapter Three. The update of the 2014 review found 20 additional studies reported in 24 articles, confirming the significant increase in research interest into sedentary behaviour and stroke survivors. A similar review published in July 2017 (Fini et al., 2017) described physical activity across the various stages following stoke (acute, subacute, chronic). These two complementary systematic reviews (Chapter Three; Fini et al. (2017)) exploring physical activity and sedentary behaviour levels after stroke, both highlighted that stroke survivors display significantly lower levels of physical activity compared to healthy controls and are highly sedentary, with the majority of their waking hours spent in sedentary behaviours. An examination of the inclusion and exclusion criteria of the 44 studies included in the systematic review (Chapter Three) confirmed that stroke survivors with severe mobility disability are still being excluded from research studies with none of the 44 studies included in the review including stroke survivors who were unable to walk short distances independently (Functional Ambulatory Classifications 1,2,3; Figure Three) as was found by the original review (English et al., 2014). Although the increase in studies exploring physical activity and sedentary behaviour provides a great wealth of information, this review confirmed the importance of more in-depth investigations of the experiences, views and capabilities of stroke survivors with severe mobility disability in relation to reducing sedentary behaviour.

The Q-methodological study (Chapters Four and Five) explored the perspectives of 17 stroke survivors, 12 informal carers and 20 healthcare professionals in relation to sedentary behaviour and movement in stroke survivors with severe mobility disability. This is the first study to address these issues in stroke survivors with severe mobility disability and the first to do so using Q-methodology. A consistent finding across the three participant groups was the general lack of knowledge and understanding around the topic of sedentary behaviour. This was also a common finding to other studies exploring sedentary behaviour in stroke survivors (Hall et al., 2019; Ezeugwu et al., 2017). Although through the informal discussions it was gauged these participants have a general understanding that everyone should move regularly and not sit for too long, statements relating to sedentary behaviour were typically sorted neutrally (middle of the grid), perhaps indicating that they did not have a strong view on the definition one way or another. Another possible explanation for the placement of these statements could be that although they do believe defining sedentary behaviour might be important at some level, it is less important to them than the other statements presented to them in the forced choice sorting process. The commentary provided by the participants, especially the healthcare professionals, indicated that they did have some uncertainty about the formal SBRN definitions. Despite the Sedentary Behaviour Research Network's work to agree a standard scientific definition for sedentary behaviour (Tremblay et al., 2017), the media often portrays sedentariness as a lack of physical activity rather than the agreed scientific definition. More work is needed to publicise the definition and help make everyone from patients to healthcare professionals aware of what sedentary behaviour is, what the health effects are and what can be done to reduce it. As will be described in more detail in the next section, the imminent publication of UK guidelines on sedentary behaviour will hopefully help to raise awareness of sedentary behaviour and ultimately help the UK population to reduce their sedentary behaviour.

Overall there was a majority view across the three participant groups that reducing sedentary behaviour is important for stroke survivors. A significant number of barriers that affect how much they move throughout the day, including; fatigue, confidence and fear of falls, which are common to most stroke survivors (Hall et al., 2019; Ezeugwu et al., 2017; Nicholson et al., 2016), were clearly evident in the stroke survivors with severe mobility disability in this study. Despite acknowledgment of these barriers within the study, there was a general consensus that reducing sedentary behaviour in these stroke survivors is not impossible but may be very difficult. The findings from the Q-methodological study support the need for strategies to reduce sedentary behaviour that are suitable for stroke survivors with severe mobility disabilities to be identified in order for an intervention to reduce sedentary behaviour to be developed.

The commentary of the stroke survivors and carers through the Q-Methodology study indicated how they had adapted to and coped with the stroke survivor’s limitations on mobility and activities and to some extent the strategies that they had adopted to ‘keep moving’ and try to reduce sedentary behaviour. These findings highlight the valuable resource of information that this group of stroke survivors, carers and stroke specific healthcare professionals with who they come into contact with can provide. Much can be learned from these participants which would help to develop meaningful interventions to reduce sedentary behaviour that could be tailored to meet the needs of this group of stroke survivors.

While the Q-methodology study presented in the thesis is the first study to explore sedentary behaviour in stroke survivors with severe mobility disability, it is important to acknowledge another study that has included this stroke survivor population in research. Lloyd et al. (2018a) designed and tested the feasibility of a physical activity programme for non-ambulatory stroke survivors. To inform the design of the physical activity programme, interviews were conducted with non-ambulatory stroke survivors and their carers to explore their views on physical activity in relation to their needs, goals, barriers and motivators (Lloyd et al., 2018b). Although the focus of the qualitative studies differ (exercise and severe mobility disability), similar findings were observed, perhaps as a result of their shared severe physical problems following their stroke. Both studies identified the difficulty in adapting to life after stroke, with both physical and lifestyle changes occurring. Additionally, both studies highlighted the limited knowledge around how to help stroke survivors who are unable to ambulate independently to engage in physical activity and increase their movement, both supporting the need for interventions and strategies that are tailored to this specific stroke population. Both studies also explored the views of carers and recognised the importance of the carer in supporting the stroke survivors in engaging in physical activity and reducing sedentary behaviour. They also acknowledged the impact that the stroke has on the carer with them expressing a loss of identity i.e. from a family member to a carer. Despite the differing focus of the two studies, the results indicate that non-ambulatory stroke survivors have similar barriers and facilitators when trying to target physical activity or sedentary behaviour.

In order to determine what activities stroke survivors with severe mobility disabilities are able to complete that may increase their energy expenditures above the sedentary behaviour – physical activity threshold, an exercise physiology study; described in Chapter Six, was conducted. Using portable indirect calorimetry the energy requirements for different activities of daily living were measured in the stroke survivors’ home environment. With the limited number of existing studies that measured energy expenditure in this population of stroke survivors all being conducted in a laboratory setting (Verschuren et al., 2016), this study was the first to measure energy expenditure in the stroke survivors home environment in a small proof of concept study. Although the study highlighted the challenges of conducting the study in stroke survivors’ homes, it also demonstrated that it was feasible to use portable indirect calorimetry in a home environment in stroke survivors with severe mobility disability.

The study identified that higher energy expenditure was required for activities of daily living in stroke survivors with severe mobility disability compared to healthy adults. While the findings from the present study (Chapter Six) and those published by Verschuren et al. (2016) both demonstrated that higher energy expenditure values are required for activities in stroke survivors compared to healthy adults (Ainsworth et al., 2011), the findings from the present study observed higher recorded energy expenditure values than those published by Verschuren et al. (2016). This possibly suggests that activities undertaken in a natural environment require more energy to complete compared to activities undertaken and controlled in a laboratory environment. The findings from this study were also significant in demonstrating the possibility that it may be possible to incorporate seated functional tasks involving the upper limb in reducing sedentary behaviour, with the arm activities requiring energy expenditure greater than 1.5 metabolic equivalents (sedentary behaviour threshold) to complete. These findings are consistent with those observed in individuals with spinal cord injury (Collins et al., 2010) and provides support to the argument that upper extremity activity in people with stroke-related mobility impairments may be sufficient to offset the negative effects of sedentary activity (Bailey, 2016). Although the next steps for research are discussed in Section 7.3.2, it would be important to assess whether these activities with shorter time periods produce a beneficial physiological effect. This is especially important given the findings of a recent study (English et al., 2018b) suggesting that frequent short bouts of LIPA do not have a significant effect on post-prandial plasma glucose and insulin but does reduce systolic blood pressure in people with stroke (English et al., 2018a). Despite the encouraging results from the four case studies, work is needed to optimise data collection, including the activity schedule, to produce more meaningful data (i.e. average oxygen consumption for activities) in order to allow comparisons and conclusions to be made and help to identify strategies for the reduction of sedentary behaviour.

7.3. Implications

7.3.1. Implications for policies and practice

The research presented in the thesis is a novel investigation in an area where to date there has been very little consideration of the experiences, views and needs of this group of stroke survivors with severe mobility disability. It has provided a significant insight into the area of sedentary behaviour and stroke survivors with severe mobility disability and has provided an important baseline for continued work in the area with the overall aim of developing an intervention to reduce sedentary behaviour in this population. With the topic showing future promise with the identification of future research directions highlighted through the thesis, significant recommendations will become more evident as future research is conducted. Publication of the findings from the systematic review of physical activity and sedentary behaviour after stroke (Chapter Three), the Q-methodological study and the energy requirements of activities of daily living study will help inform future research and could contribute to the 2020 update of the ISWP National Clinical Guideline for Stroke.

It was highlighted through the research that a lack of knowledge and understanding around sedentary behaviour and the associated definitions exists within healthcare professionals and patient groups. Although this matter has already been discussed throughout the thesis, it is important to note that in order for clinical practitioners to increase their focus on and ensure that sedentary behaviour reduction is included in rehabilitation from an early stage following a stroke and continued through long-term; more work is needed to raise health professionals' awareness. More work is needed to not only clarify definitions in order for a better understanding of the concept of sedentary behaviour but to increase awareness of the detrimental health effects of sitting for long periods without breaks. Awareness needs to be targeted at both the general public as well as healthcare professionals to ensure they have a better understanding and consider it in their clinical practice. Consideration should be made as to how this can be achieved, with different forms of information likely to be required for the two target populations; general public and healthcare professionals. In order to reach the general population, a national advertising campaign would help to increase awareness of sedentary behaviour and provide simple strategies that can be easily implemented in everyday life. This campaign could coincide with the imminent release of the UK sedentary behaviour guidelines. In order to increase awareness in the healthcare professional population, it would be important to target and involve the relevant societies, colleges and associations related to the healthcare professionals (i.e. Chartered Society of Physiotherapists, Royal College of General Practitioners, Royal College of Nursing, Royal College of Occupational Therapists) in order to raise awareness and provide information in a way that will ensure that it is visible and easily accessible to healthcare professionals.

Following an increase in knowledge about the high prevalence of sedentary behaviour and its detrimental health effects, Australia and Canada were the first countries to develop guidelines for sedentary behaviour. The Canadian Sedentary Behaviour Guidelines focus on Children and Youth (Tremblay et al., 2011) whilst the Australian Guidelines are provided for early years, young people and adults (18-64 years old) (Australian Government - Department of Health, 2014). While current guidance in the UK is targeted at physical activity, numerous evidence briefings and Chief Medical Officers Reports (Davies et al., 2011; Public Health England, 2014; British Heart Foundation, 2012) have been published that provide guidance and recommendations for physical activity and sedentary behaviour. The momentum caused by the increase in interest and evidence indicating the importance of reducing sedentary behaviour has led to an update of the UK sedentary behaviour guidelines (Davies et al., 2011) that are due to be released in 2019. While the updated UK sedentary behaviour guidelines will hopefully allow better public knowledge of sedentary behaviour and the importance of trying to limit their sitting time, these guidelines will be focused on the general public and not specifically tailored to individuals with disabilities or health conditions. As highlighted by the 'Everybody active, every day' Public Health England report (Public Health England, 2014), although guidance can be applied to individuals with disabilities and long-term health conditions, they need to be tailored to the individual taking into account their needs and capabilities.

Recommendations targeted at the reduction of sedentary behaviour in stroke survivors is currently included in the National Clinical Guideline for Stroke (Intercollegiate Stroke Working Party, 2016) with the aim to reduce time spent sitting for long periods. The guidance only states that 'stroke survivors should aim to be active every day and minimise the amount of time spent sitting for long periods'. Inclusion of recommendations to minimise the amount of time spent sitting in the guidance is important, however more detail is required in order to make it easier for healthcare professionals to encourage and implement in their everyday clinical practice. The common view of the healthcare professional participants in the Q-methodology study was that it was important for guidelines to recommend the reduction of sedentary behaviour. However, despite this, the majority of participants were unaware that it already formed part of the current guidelines. This is unsurprising given that the guidance does not use the terminology 'sedentary', is very vague and doesn't provide details on how this can be achieved unlike the recommendations for physical activity. It is therefore important for an increased awareness of the changes to guidelines specifically in relation to reducing sitting time. This would hopefully ensure that sedentary behaviour reduction is included in rehabilitation practice and becomes part of the healthcare professionals' thoughts when considering plans for rehabilitation of stroke survivors.

The general consensus from participants in the Q and energy studies conducted, that reducing sedentary behaviour in stroke survivors with severe mobility disability is possible, with an acknowledgement of the difficulty involved, has highlighted the need for strategies and interventions to be developed. Further research is required to determine what is required to break sedentary behaviour and have a health benefit and match it to what the stroke survivors are capable of doing. The outcomes of which, will likely effect guidance and clinical practice in future. It will be important for guidance in future to include more detailed strategies or recommendations that healthcare professionals can use and incorporate into their daily practice, instead of the current guidance that simply states ‘reduce sitting for long periods’. Current guidance does not help healthcare professionals to understand what can be done to reduce sedentary behaviour, especially in stroke survivors who are non-ambulatory and unable to stand. Due to the complex nature of sedentary behaviour reduction in non-ambulatory stroke survivors future guidance may have to be broken down into strategies for ambulatory and strategies for non-ambulatory stroke survivors. This would provide information on what each group of stroke survivors can specifically do to reduce their sedentary behaviour. As already briefly discussed, The National Clinical Guideline for Stroke (Intercollegiate Stroke Working Party, 2016) currently provides recommendations for increasing physical activity and explains that physical activity programmes should be individualised during rehabilitation. As the current recommendations for reducing sedentary behaviour is minimal within the guidance, it would be important for some key strategies that could be easily implemented to be included, as is currently available for physical activity. It would also be important for recommendations to suggest the tailoring of strategies to reduce sedentary behaviour as each stroke survivor will have different levels of ability, motivation and barriers affecting their movement.

Implementation of evidence based practice is well documented as being an extremely difficult process with an average of 17 years being identified as the time it takes for new research evidence to become embedded into usual care (Morris et al., 2011; Balas and Boren, 2000). Clinicians often do not have the knowledge, resources or skills to translate the findings from a research trial and apply these to their clinical practice (Lynch et al., 2018). Given the poor uptake of evidence based practice and the significant delays of translation into clinical practice, including in stroke rehabilitation (Lynch et al., 2018), significant attempts to better understand the research to practice gap is occurring through implementation science. It is defined as; “the scientific study of methods to promote the systematic uptake of research findings and other evidence-based practices into routine practice, and, hence, to improve the quality and effectiveness of health services” (Eccles and Mittman, 2006). One strategy to help improve implementation focuses on the dissemination of research findings, which should be targeted at specific clinical journals to allow the greatest chance of being read by clinicians. It is also suggested that articles that can be used to guide how to apply the new evidence or implement the clinical guidelines into clinical settings should be published alongside the research evidence (Lynch et al., 2018). Although it is important to disseminate research findings through publication of journal articles, additional channels should be considered in order to reach healthcare professionals and policy makers. Dissemination plans could also consider the use of news and media (radio, television, newspapers) and social media (Twitter, Facebook, blogs) in order to publicise research findings to the target audience (Brownson et al., 2018).

In order for interventions or strategies to reduce sedentary behaviour in stroke survivors with severe mobility disability to be included into everyday clinical practice it would be important for future research and intervention development to have a dedicated implementation plan to ensure that the impact of the research is greater than simply publishing the results. Although there are calls for more research funding to be made available for implementation science, another strategy that could be adopted by funding bodies i.e. National Institute for Health Research (NIHR), is the mandatory inclusion of an implementation plan as part of their application process. Currently funders typically require information about the dissemination plan for the research, but this could be altered to also require information about knowledge translation. This would ensure that healthcare professionals and researchers consider how they intend to implement their research findings into clinical practice from the early stages of planning the research so as to ensure that it is considered during the whole research programme.

It should also be noted that future interventions and guidance should ensure that reduction of sedentary behaviour should be approached with a multi-disciplinary involvement. The idea of The Q-methodology study highlighted the importance for all healthcare professionals to be actively aiming to reduce sedentary behaviour from the acute team to the rehabilitation team and continued by the community-based staff once the stroke survivor is discharged home. There should also be a strong consideration of how the family, friends and carers can be involved early on in the rehabilitation process in order for continued support once therapy input is stopped. Similarly this research has highlighted how important it is for the stroke survivor to take some responsibility not only for their rehabilitation but also in the goal to reduce their sedentary behaviour. Without their willing and motivation, reducing their sedentary time will be even more difficult for the healthcare professionals and family, friends and carers to encourage.

The energy expenditure of activities of daily living study, described in Chapter Six, highlighted the increased energy requirements for activities of daily living compared to healthy individuals. These findings are important to be shared with healthcare professionals in order to raise awareness of the stroke survivors' capacity in terms of their energy levels. Practitioners should be mindful that simple tasks and exercises do require increased levels of energy and therefore may not be as easy to complete as they may think. This may also explain the considerable problem of fatigue following stroke, with stroke survivors' lack of energy possibly contributing to their extreme tiredness.

7.3.2. Implications for future research

As has been discussed throughout the thesis, one of the main outcomes of the research is the knowledge that stroke survivors, carers and healthcare professionals believe that it is important to try and reduce sedentary behaviour in stroke survivors with severe mobility disability. With an intervention and strategies to reduce sedentary behaviour being welcomed by stroke survivors it is now important for further research to be conducted in order for an intervention to be developed.

Although stakeholders were included in the Q-methodology study including stroke survivors, informal carers and healthcare professionals further research may be required to gauge the views of all possible individuals who may be involved in an intervention. To ensure that during the intervention design and development process that the correct and most appropriate individuals are included, more groups of people should be involved. One of the limitations of the Q-methodology study conducted for this thesis was the absence of medical and nursing staff as a result of availability to dedicate time to participate in the study. With a majority view that aiming to reduce sedentary behaviour should be a multidisciplinary team approach including all healthcare professionals who help to care for a stroke survivor in their journey following their stroke. It is also important to consider when the intervention may take place. If the intervention should start within the hospital prior to the stroke survivor's discharge home it would be important to include medical and nursing staff from the acute/rehabilitation wards. With an intervention likely to continue once a stroke survivor is discharged home in the community it would be important for more community based staff who provide care to the stroke survivor to be approached including General Practitioners (GPs) and community nursing teams. Careful consideration during the planning and design stages of intervention development is therefore required to ensure the most appropriate stakeholders are involved.

Similarly to implementation science, discussed in the previous section, in order to optimise the uptake of strategies to reduce sedentary behaviour in clinical practice the involvement of stakeholders during intervention development is vital. A co-production approach that involves all stakeholders, allows all involved to identify the potential barriers to implementation and consider strategies and solutions that could be adopted to help overcome the problems in their specific areas i.e. local clinical practice (Stewart et al., 2019). An intervention that has been co-produced with patients, family members, healthcare professionals, clinical management and policy makers helps to design interventions that produce sustainable changes in behaviour (Giné-Garriga et al., 2019).

In order for strategies that can reduce sedentary behaviour in this stroke population to be suggested and incorporated into any future interventions, more research is required to establish what these strategies would look like. The study exploring energy expenditures for activities of daily living described in Chapter Six, provided promising results for potential ideas for strategies. Although some activities that were completed by the stroke survivors were found to raise their oxygen consumption levels higher than the sedentary behaviour – light physical activity threshold (1.5 METs), further work is required to determine the effects of these activities. Future research suggestions have been highlighted and described in detail in Chapter Six. Overall, work is required to determine whether the activities identified in the study as having potential to reduce sedentary behaviour, including some arm activities (e.g. washing up) produce the same health benefits of standing to reduce sedentary behaviour. More work is also required to examine the optimum dosing of the activity ‘breaks’ in sitting. As some of the activities measured were short in duration it would be important to assess how long an activity would need to be completed for before it can be classed as a ‘break’ in sedentary behaviour with the health benefits. As the study confirmed the feasibility of the methods of recording energy expenditure in the stroke survivors’ homes it would also be important for more stroke survivors to be recruited and participate in a similar study for conclusions to be generated to gauge what can reduce sedentary behaviour. Ultimately the next steps in the research field of sedentary behaviour in stroke survivors with severe mobility disability is to examine what can be done that makes a difference, i.e. has a beneficial health effect. These potential strategies should then be matched to what is deemed acceptable and achievable to the stroke survivor to ensure that any intervention has the highest chance of compliance and commitment from stroke survivors and their family, friends and carers.

7.4. Strengths and Limitations/ Challenges of the thesis

The research presented in this thesis provides a novel contribution to both the stroke and sedentary behaviour research fields. Evidenced by the systematic reviews, previous work and research had excluded the stroke population with severe mobility disabilities. With the increased research interest in sedentary behaviour and the emergence of health consequences it was important and timely to investigate sedentary behaviour in a population who have an increased risk of poor health outcomes and complex care needs.

One of the main strengths of the research presented in the thesis is the opportunity given to this group of stroke survivors, who have to date been excluded, to have a voice, allowing their experiences, views and needs to be heard in relation to movement and their rehabilitation. Additionally, the strong engagement received from the participants, especially the stroke survivors, confirmed the importance of the research and provided a significant insight into the area of sedentary behaviour and stroke survivors with severe mobility disability. It has provided an important baseline for continued work in the area with the overall aim of developing an intervention to reduce sedentary behaviour in this population.

By initially investigating this research topic, this research provided the stroke survivors with the opportunity to comment on how they have adapted and managed following their stroke and to comment on what they perceived was important and possible for them to achieve. All of the stroke survivors who were recruited expressed their enjoyment of taking part in the research and were also grateful for being allowed the opportunity to talk about their experiences and perspectives. Often participants would express how they were thankful that someone was not only taking an interest in them and their condition but that the researcher was able to listen to them. Stroke survivors and their informal carers often report feeling abandoned by health services following their stroke (Lloyd et al., 2018b; Pindus et al., 2018), therefore the opportunity to participate in the present research made the stroke survivors and carers feel included.

It is important to note that although this study aimed to include this excluded stroke population, the process of recruiting stroke survivors with severe mobility disability was difficult and time consuming. Often severe mobility disabilities are the result of a severe stroke and are accompanied by a range of other severe health problems. Severe communication problems and cognitive impairments are common in stroke survivors with severe mobility limitations. These associated problems often limit an individual’s opportunity for involvement in research due to their inability to understand, consent to take part and participate. Through discussions with healthcare professionals and academic supervisors it was predicted that recruitment of the target stroke population who met the eligibility criteria would be difficult.

Even with the comprehensive and complex recruitment strategy, recruiting both stroke survivors with severe mobility disabilities and their informal carers was extremely difficult. This resulted in small sample sizes for both participant groups with seventeen stroke survivor participants and twelve informal carers. Larger sample sizes would have allowed more detailed and potentially stronger factors (viewpoints) to be discovered in the Q-methodology study (Chapters Four and Five) and comparisons and conclusions to be made in the study of energy expenditure (Chapter Six). However, for the purpose of the present research the sample sizes achieved were sufficient for the proposed aims. The Q-methodology study produced interesting and valuable results and despite the relatively small numbers of participants, three clear and justified factors (viewpoints) were identified for both of the participant groups. Similarly, one of the aims of the energy expenditure of activities of daily living study was to reflect upon the feasibility of the methodology with stroke survivors with severe mobility disability in their home environment, which the sample size adequately achieved.

Another strength of the research presented in the thesis was the involvement of stakeholders during the Q-methodology study. With this research possibly leading to an intervention it was important that all individuals who could potentially be involved in the design, delivery and target of the intervention should be included in the study. Medical Research Council guidance states that all stakeholders should be involved in every stage of the intervention development process from development to feasibility/piloting, evaluation and implementation (MRC, 2008). Although intervention development was not part of the current research, as the aim of the research was to understand whether an intervention to reduce sedentary behaviour in stroke survivors with severe mobility disability was needed and whether it would be acceptable and achievable, it was deemed important to include all stakeholders. It is likely that any intervention that could be developed in the future would involve both informal carers and healthcare professionals involved in the stroke survivors' care. It was therefore important to include not only the target stroke survivor population but also family, friends and carers who provide regular support and healthcare professionals to gauge their thoughts and perspectives on the topic of sedentary behaviour. The importance of co-production in intervention design and involvement of stakeholders was discussed in a previous section.

The inclusion of healthcare professionals in the Q-methodological study provided an opportunity to explore their knowledge from their experiences of working with and treating these stroke survivors. They were able to provide advice on the potential capabilities of stroke survivors with severe mobility disability and highlighted the common barriers to increasing physical activity and movement in this stroke population. Although 20 healthcare professionals were recruited and participated in the study, none represented medical or nursing staff. Participants were comprised of physiotherapists, occupational therapists and therapy assistants from private, acute and community teams. The study planned to recruit a range of healthcare professions including doctors, nurses and therapy staff. However recruitment of this participant group was limited by the staff who were able and available to take part, with therapy staff finding it easier to schedule time for participation in the research within their therapy schedules. Having a more representative sample that included nursing staff and doctors would have allowed a greater understanding of the rehabilitation of the stroke survivors. It would be important for future work to include a range of professions by planning recruitment and data collection strategies that would ensure the inclusion of all professionals involved in the care of stroke survivors.

The combination of systematic reviews, a Q-methodology study and an exercise physiology study in a multi-component design strengthened the research project by providing a holistic approach to exploring sedentary behaviour in stroke survivors with severe mobility disability. With the research project presented in this thesis being the first to explore sedentary behaviour in this specific stroke population it was important to use a multi-component design to ensure that different aspects of sedentary behaviour were explored. The systematic reviews allowed an exploration of the available evidence and provided support for the two empirical studies. The current typical position in reducing sedentary behaviour is to regularly 'stand up' in order to reduce sedentary time, however, for stroke survivors who have severe mobility problems that limit their ability to stand this may not be possible. The energy expenditure study was therefore important to understand and determine what activities and strategies other than standing, these stroke survivors could do in order to reduce their sedentary time. Despite their distinct aims and methods, the three components of the research presented in this thesis combine to create a holistic view of sedentary behaviour in stroke survivors who are unable to ambulate independently.

As the research presented in the thesis was the first to investigate sedentary behaviour in a stroke population with severe mobility disability, the outputs are limited by the scope of the research aims. This research has only explored the surface of the research field of sedentary behaviour in non-ambulatory stroke survivors and as such only presents an insight into the topic. In order for further conclusions to be made and future intervention development, significant further research is required, as highlighted by the thesis.

7.5. Conclusion

This thesis has presented a novel research project examining sedentary behaviour in stroke survivors with severe mobility disability. It has introduced the topic of sedentary behaviour generally and more specifically in a stroke population, and provided the rationale for the research. Existing literature surrounding sedentary behaviour and disability generally and sedentary behaviour and physical activity of stroke survivors was examined (Chapters Two and Three). The thesis then explored the perspectives and experiences of stroke survivors with severe mobility disability, informal carers and healthcare professionals involved in their care in relation to sedentary behaviour, movement and exercise following stroke using Q-methodology (Chapters Four and Five). It has also reflected upon the feasibility of measuring energy expenditure in a community setting with stroke survivors with severe mobility disability in an exercise physiology study. The study also assessed the energy requirements of activities of daily living including arm activities (e.g. washing up and dusting) that hoped to identify activities that could form part of an intervention to reduce sedentary behaviour. A summary of the key findings was then presented, followed by a discussion of the implications of the research for policy and practice, before the implications for future research were discussed. Finally, an assessment of the strengths, limitations and challenges of the research was presented.

Overall, this research provides support for the inclusion of severe stroke in research. Given the prevalence of stroke and over 22% of stroke survivors being left with severe disabilities (Royal College of Physicians Sentinel Stroke National Audit Programme (SSNAP), 2018), it is important for them to be considered and included in research. The present research has demonstrated that it is possible to include stroke survivors with severe mobility disability in research studies and highlighted the rewarding nature of including these stroke survivors as they provide a valuable insight into a significant proportion of stroke survivors. Despite the significant mobility problems faced by these stroke survivors, the majority view of all participants (stroke survivors, informal carers and healthcare professionals) was reducing sedentary behaviour is important and possible. Although they were unsure what could be done in order to reduce sedentary behaviour in this non-ambulatory population, the energy expenditure study (Chapter Six) has highlighted the potential of some activities of daily living that could potentially be adopted as strategies in a future intervention.

This research project has established the importance of research in this previously neglected stroke population and has identified the next stages of research required to design and develop strategies and interventions to reduce sedentary behaviour in stroke survivors with severe mobility disabilities.

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Appendices

Appendix A MEDLINE Search Strategy – Mixed Methods Systematic Review Sub-Review 1

1 Disabled Persons/ (35272)
2 Amputees/ (2671)
3 Persons With Hearing Impairments/ (1852)
4 Mentally Ill Persons/ (5517)
5 Mental disorders/ (141173)
6 Visually Impaired Persons/ (1895)
7 Spinal Cord Injuries/ (30837)
8 Disability Evaluation/ (38924)
9 "International Classification of Functioning, Disability and Health"/ (255)
10 disabilit*.tw. (113934)
11 disabled.tw. (18689)
12 impair*.tw. (481753)
13 amput*.tw. (31840)
14 Mobility Limitation/ (2961)
15 mobility limitation*.tw. (514)
16 Dependent Ambulation/ (124)
17 dependent ambulation.tw. (3)
18 non ambulatory.tw. (411)
19 nonambulatory.tw. (702)
20 Wheelchairs/ (3893)
21 wheelchair*.tw. (4916)
22 "Recovery of Function"/ (36791)
23 exp Paraplegia/ (12265)
24 paraplegia.tw. (9612)
25 Quadriplegia/ (7395)
26 quadriplegia.tw. (2227)
27 exp Hearing Loss/ (58759)
28 hearing loss.tw. (31255)
29 exp Blindness/ (22088)
30 blindness.tw. (19198)
31 exp Vision Disorders/ (63430)
32 vision disorder*.tw. (425)
33 (mental* adj3 (ill* or disorder*)).tw. (50480)
34 functional limitation*.tw. (4055)
35 activity limitation*.tw. (1981)
36 or/1-35 (1011152)
37 sedentary lifestyle/ (4370)
38 sedentar*.tw. (18968)
39 ((chair or sitting or car or automobile or auto or bus or indoor or in-door or screen or computer) adj time).tw. (1458)
40 low energy expenditure.tw. (114)
41 "sitting less".tw. (9)
42 (sitting adj3 behavio?r).tw. (97)
43 ((television adj watch*) or tv watch*).tw. (467)
44 Television/ (12160)
45 Computers/ (49253)
46 screen time.tw. (701)
47 inactivit*.tw. (9515)

48 low activ*.tw. (7323)
49 bed rest.tw. (4118)
50 chair rise*.tw. (247)
51 "computer use".tw. (1133)
52 "couch potato".tw. (35)
53 "screen based".tw. (386)
54 "car use".tw. (68)
55 "non exercise".tw. (437)
56 physic* inactiv*.tw. (5045)
57 ((light or low) adj physical activ*).tw. (1276)
58 ((decreas* or reduc*) adj5 (sedentary or sit* or "physical* inactiv*")).tw. (26077)
59 or/37-58 [sedentary behaviour] (128917)
60 qualitative*.tw. (154583)
61 interview/ (25997)
62 narrative*.tw. (16748)
63 (personal adj2 experience*).tw. (12032)
64 interview*.tw. (231137)
65 exp qualitative research/ (26406)
66 (survey* or questionnaire* or "focus group*").tw. (673793)
67 theme*.tw. (42845)
68 "Surveys and Questionnaires"/ (339950)
69 Focus Groups/ (19762)
70 or/60-69 [qualitative studies filter] (1095722)
71 36 and 59 and 70 [Disability and sedentary and qualitative] (1244)

Appendix B MEDLINE Search Strategy - Mixed Methods Systematic Review Sub-Review 2

1 Disabled Persons/ (35102)
2 Amputees/ (2658)
3 Persons With Hearing Impairments/ (1844)
4 Mentally Ill Persons/ (5497)
5 Mental disorders/ (140731)
6 Visually Impaired Persons/ (1887)
7 Spinal Cord Injuries/ (30697)
8 Disability Evaluation/ (38755)
9 "International Classification of Functioning, Disability and Health"/ (251)
10 disabilit*.tw. (113009)
11 disabled.tw. (18613)
12 impair*.tw. (477791)
13 amput*.tw. (31742)
14 Mobility Limitation/ (2899)
15 mobility limitation*.tw. (500)
16 Dependent Ambulation/ (123)
17 dependent ambulation.tw. (3)
18 non ambulatory.tw. (410)
19 nonambulatory.tw. (701)
20 Wheelchairs/ (3873)
21 wheelchair*.tw. (4894)
22 "Recovery of Function"/ (36516)
23 exp Paraplegia/ (12245)
24 paraplegia.tw. (9581)
25 Quadriplegia/ (7370)
26 quadriplegia.tw. (2223)
27 exp Hearing Loss/ (58597)
28 hearing loss.tw. (31118)
29 exp Blindness/ (22024)
30 blindness.tw. (19084)
31 exp Vision Disorders/ (63239)
32 vision disorder*.tw. (424)
33 (mental* adj3 (ill* or disorder*)).tw. (50149)
34 functional limitation*.tw. (4008)
35 activity limitation*.tw. (1949)
36 or/1-35 (1004822)
37 sedentary lifestyle/ (4262)
38 sedentar*.tw. (18758)
39 ((chair or sitting or car or automobile or auto or bus or indoor or in-door or screen or computer) adj time).tw. (1415)
40 low energy expenditure.tw. (114)
41 "sitting less".tw. (9)
42 (sitting adj3 behavio?r).tw. (96)
43 ((television adj watch*) or tv watch*).tw. (458)
44 television/ (12094)
45 computers/ (49204)
46 screen time.tw. (669)
47 inactivit*.tw. (9422)
48 low activ*.tw. (7268)
49 bed rest.tw. (4103)
50 chair rise*.tw. (244)
51 "computer use".tw. (1124)
52 "couch potato".tw. (34)

53 "screen based".tw. (379)
54 "car use".tw. (67)
55 "non exercise".tw. (431)
56 "physic* inactiv*".tw. (4973)
57 ((light or low) adj physical activ*).tw. (1261)
58 ((decreas* or reduc*) adj5 (sedentary or sit* or "physical* inactiv*")).tw. (25940)
59 or/37-58 [sedentary behaviour] (128269)
60 randomi?ed controlled trial.pt. (410079)
61 controlled clinical trial.pt. (90300)
62 randomi?ed.ab. (367122)
63 placebo.ab. (156359)
64 drug therapy.fs. (1833352)
65 randomly.ab. (217155)
66 trial.ab. (316830)
67 groups.ab. (1373167)
68 or/60-67 [RCT filter] (3487409)
69 36 and 59 and 68 [combined 3 concepts SB D RCT] (1939)
70 (exp child/ or exp infant/ or exp adolescent/) not ((exp child/ or exp infant/ or exp adolescent/) and (exp aged/ or exp adult/)) (1628678)
71 (child* or infant* or school* or young or youth* or adolescen* or teen*).ti. (941865)
72 70 or 71 [non adult studies] (1878656)
73 69 not 72 [sedentary behaviour and disability with RCT filter adults only] (1810)

Appendix C English et al. (2014) Systematic Review Search Strategy

Medline search

1. exp *Stroke/
2. exp *Brain Injuries/
3. exp *Parkinson Disease/
4. exp *Multiple Sclerosis/
5. exp *Spinal Cord Injuries/
6. exp *Postpoliomyelitis Syndrome/
7. exp *Guillain-Barre Syndrome/
8. 1 or 2 or 3 or 4 or 5 or 6 or 7
9. exp *Motor Activity/
10. exp *Locomotion/
11. exp *Walking/
12. exp *Energy Metabolism/
13. exp *Physical Exertion/
14. exp *Exercise/
15. exp *Exercise Therapy/
16. exp *Physical Fitness/
17. exp *Resistance Training/
18. exp *Leisure Activities/
19. exp *Sedentary Lifestyle/
20. exp *Health Behavior/
21. exp *Monitoring, Ambulatory/
22. exp *Actigraphy/
23. step*.mp.
24. pedomet*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier]
25. accelerom*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier]
26. inclinom*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier]
27. 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26
28. 8 and 27
29. limit 28 to (english language and humans)
30. 9 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26
31. 8 and 30
32. limit 31 to (english language and humans)
33. 9 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 24 or 25 or 26
34. 8 and 33
35. limit 34 to (english language and humans)
36. limit 35 to (english language and humans and "all adult (19 plus years)")
37. concussion.mp. [mp=title, abstract, original title, name of substance word, subject heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier]
38. 36 not 37
39. activity monitor*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier]

40. 12 or 13 or 19 or 21 or 22 or 24 or 25 or 26 or 39
41. 8 and 40
42. limit 41 to (english language and humans)

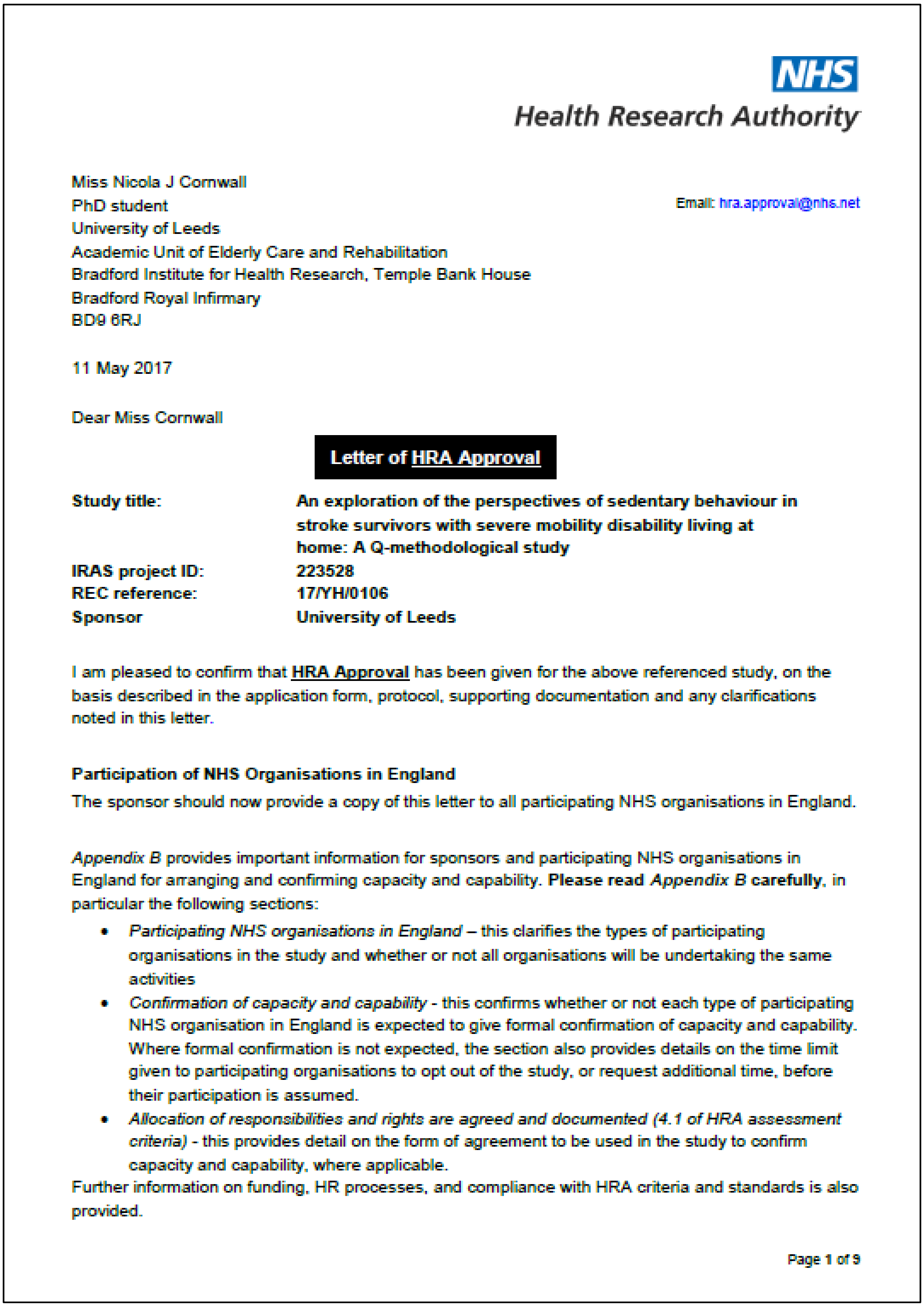
Limits – adults, humans, English, use explode and focus for all headings

Appendix D MEDLINE Search Strategy – Update of English et al. (2014) Systematic Review

1 stroke/ (76030)
2 (stroke* or post stroke or poststroke or post-stroke).tw. (165593)
3 1 or 2 [stroke] (177701)
4 sedentary lifestyle/ (5092)
5 sedentar*.tw. (20232)
6 ((chair or sitting or car or automobile or auto or bus or indoor or in-door or screen or computer) adj time).tw. (1685)
7 low energy expenditure.tw. (123)
8 "sitting less".tw. (12)
9 (sitting adj3 behavio?r).tw. (106)
10 ((television adj watch*) or tv watch*).tw. (501)
11 Television/ (12462)
12 Computers/ (49635)
13 screen time.tw. (833)
14 inactivit*.tw. (9988)
15 low activ*.tw. (7487)
16 bed rest.tw. (4253)
17 chair rise*.tw. (273)
18 "computer use".tw. (1189)
19 "couch potato".tw. (37)
20 "screen based".tw. (424)
21 "car use".tw. (73)
22 "non exercise".tw. (468)
23 physic* inactiv*.tw. (5396)
24 ((light or low) adj physical activ*).tw. (1390)
25 exp Monitoring, Ambulatory/ (24546)
26 exp Actigraphy/ (2274)
27 pedomet*.tw. (1781)
28 accelerom*.tw. (8415)
29 inclinom*.tw. (497)
30 activity monitor*.tw. (2280)
31 or/4-30 [sedentary behaviour] (141096
32 3 and 31 [stroke and sedentary behaviour] (2396)
33 exp animals/ not humans.sh. (4313283)
34 32 not 33 [human only studies] (2269)
35 remove duplicates from 34 (2165)

Appendix E Letter of HRA Approval – Q-Methodology Study

Please note two amendments were submitted for review – one substantial amendment to add two additional sites for recruitment (Amendment date: 01/02/18) and one non-substantial amendment to extend the recruitment period (Amendment date:21/03/18).



NHS
Health Research Authority

Miss Nicola J Cornwall
PhD student
University of Leeds
Academic Unit of Elderly Care and Rehabilitation
Bradford Institute for Health Research, Temple Bank House
Bradford Royal Infirmary
BD9 6RJ

Email: hra.approval@nhs.net

11 May 2017

Dear Miss Cornwall

Letter of HRA Approval

Study title:	**An exploration of the perspectives of sedentary behaviour in stroke survivors with severe mobility disability living at home: A Q-methodological study**
IRAS project ID:	**223528**
REC reference:	**17/YH/0106**
Sponsor	**University of Leeds**

I am pleased to confirm that **HRA Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

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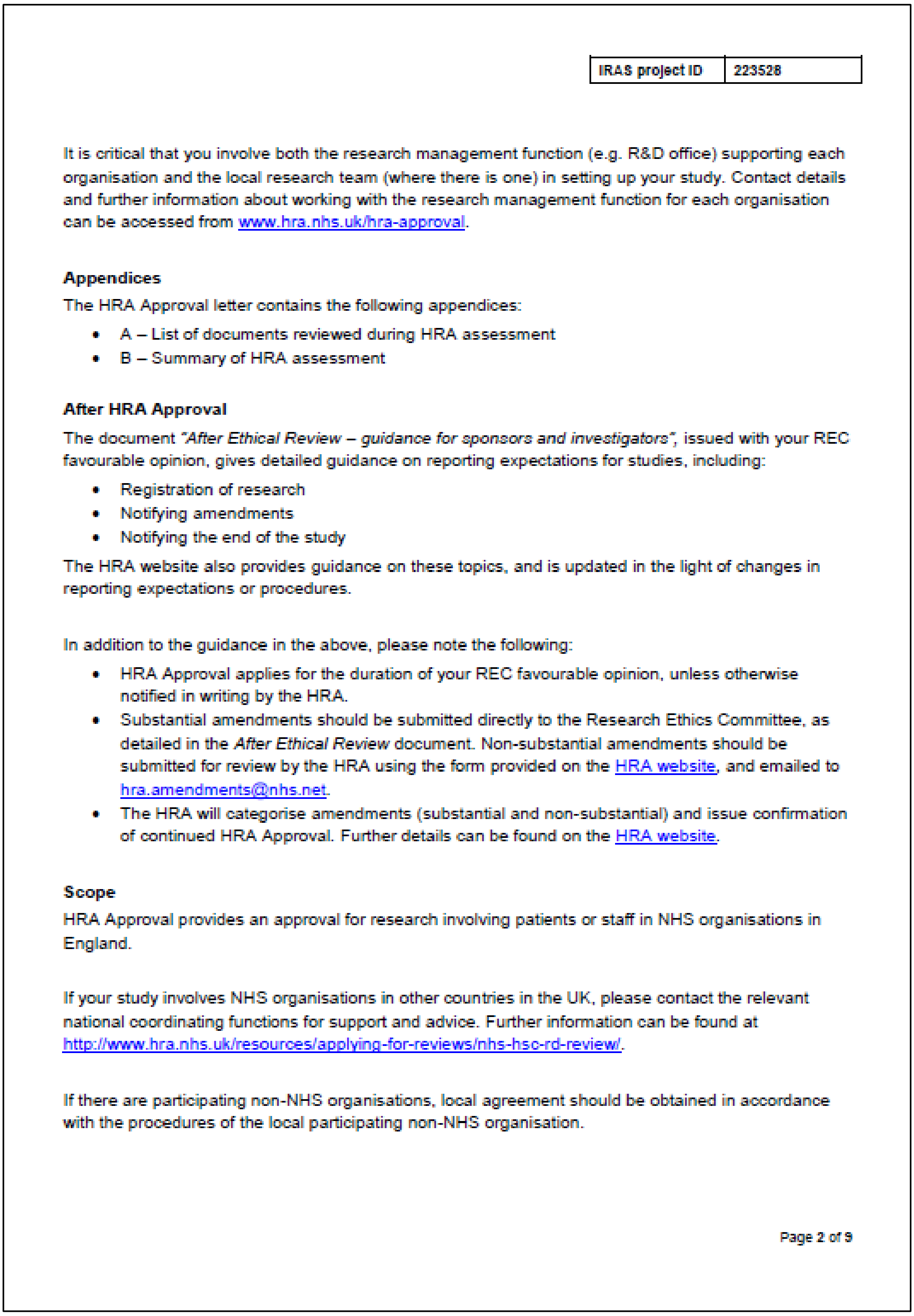


It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from www.hra.nhs.uk/hra-approval.

Appendices

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

After HRA Approval

The document *"After Ethical Review – guidance for sponsors and investigators"*, issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

In addition to the guidance in the above, please note the following:

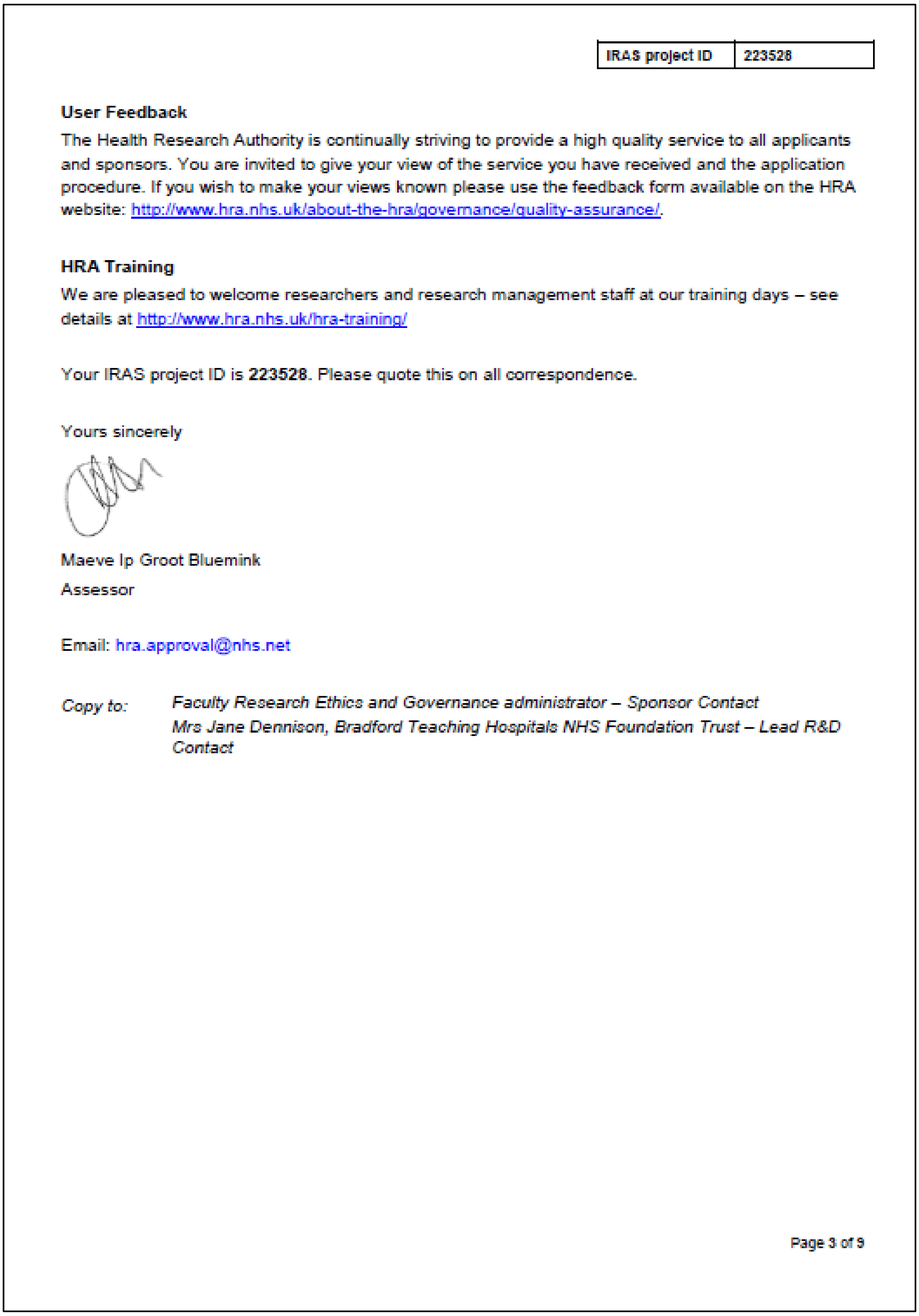
- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the HRA website, and emailed to hra.amendments@nhs.net.
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the HRA website.

Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.



IRAS project ID	223528

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/.

HRA Training

We are pleased to welcome researchers and research management staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

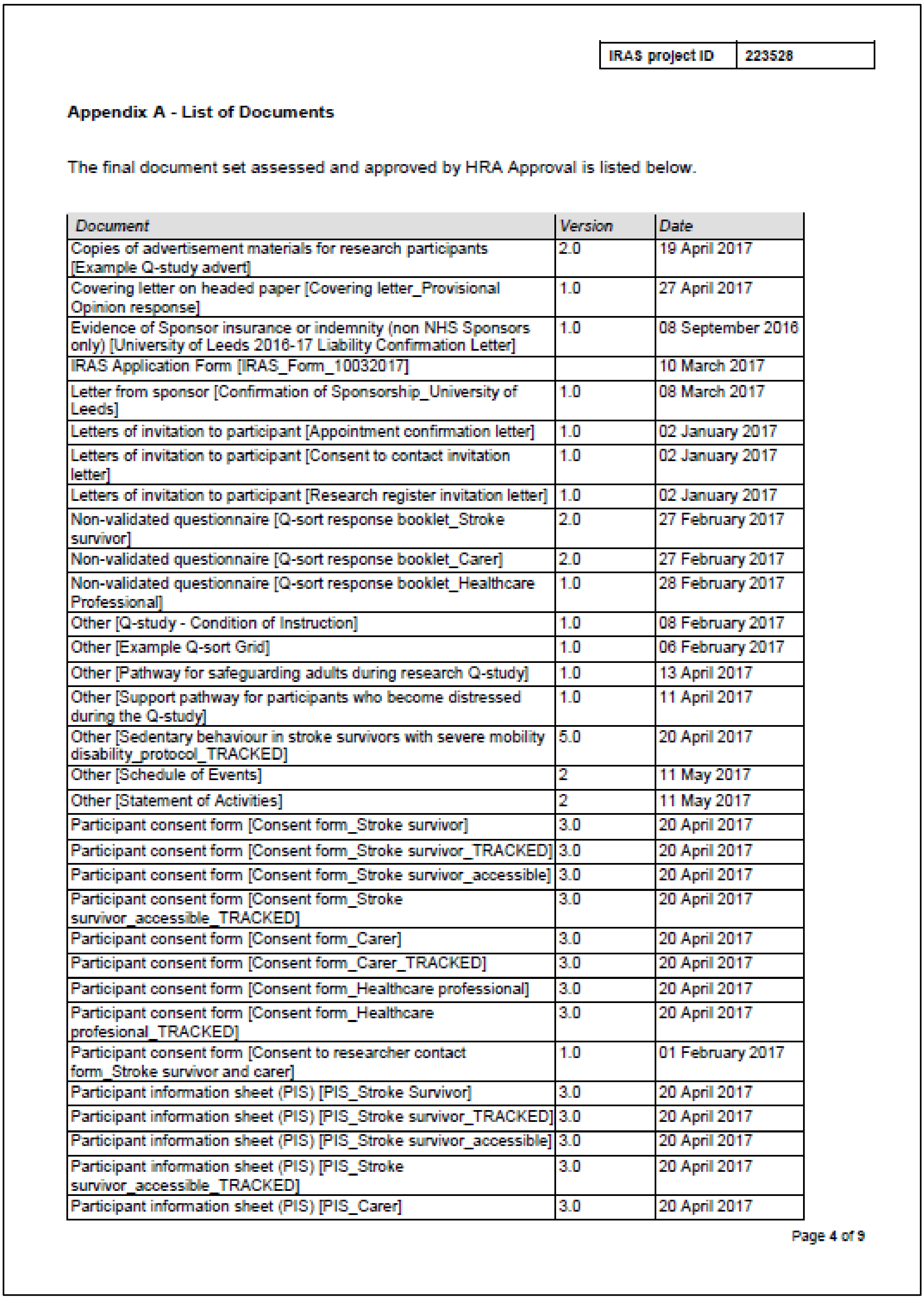
Your IRAS project ID is **223528**. Please quote this on all correspondence.

Yours sincerely

Maeve Ip Groot Bluemink
Assessor

Email: hra.approval@nhs.net

Copy to:	*Faculty Research Ethics and Governance administrator – Sponsor Contact* *Mrs Jane Dennison, Bradford Teaching Hospitals NHS Foundation Trust – Lead R&D Contact*



IRAS project ID	223528

Appendix A - List of Documents

The final document set assessed and approved by HRA Approval is listed below.

Document	*Version*	*Date*
Copies of advertisement materials for research participants [Example Q-study advert]	2.0	19 April 2017
Covering letter on headed paper [Covering letter_Provisional Opinion response]	1.0	27 April 2017
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [University of Leeds 2016-17 Liability Confirmation Letter]	1.0	08 September 2016
IRAS Application Form [IRAS_Form_10032017]		10 March 2017
Letter from sponsor [Confirmation of Sponsorship_University of Leeds]	1.0	08 March 2017
Letters of invitation to participant [Appointment confirmation letter]	1.0	02 January 2017
Letters of invitation to participant [Consent to contact invitation letter]	1.0	02 January 2017
Letters of invitation to participant [Research register invitation letter]	1.0	02 January 2017
Non-validated questionnaire [Q-sort response booklet_Stroke survivor]	2.0	27 February 2017
Non-validated questionnaire [Q-sort response booklet_Carer]	2.0	27 February 2017
Non-validated questionnaire [Q-sort response booklet_Healthcare Professional]	1.0	28 February 2017
Other [Q-study - Condition of Instruction]	1.0	08 February 2017
Other [Example Q-sort Grid]	1.0	06 February 2017
Other [Pathway for safeguarding adults during research Q-study]	1.0	13 April 2017
Other [Support pathway for participants who become distressed during the Q-study]	1.0	11 April 2017
Other [Sedentary behaviour in stroke survivors with severe mobility disability_protocol_TRACKED]	5.0	20 April 2017
Other [Schedule of Events]	2	11 May 2017
Other [Statement of Activities]	2	11 May 2017
Participant consent form [Consent form_Stroke survivor]	3.0	20 April 2017
Participant consent form [Consent form_Stroke survivor_TRACKED]	3.0	20 April 2017
Participant consent form [Consent form_Stroke survivor_accessible]	3.0	20 April 2017
Participant consent form [Consent form_Stroke survivor_accessible_TRACKED]	3.0	20 April 2017
Participant consent form [Consent form_Carer]	3.0	20 April 2017
Participant consent form [Consent form_Carer_TRACKED]	3.0	20 April 2017
Participant consent form [Consent form_Healthcare professional]	3.0	20 April 2017
Participant consent form [Consent form_Healthcare profesional_TRACKED]	3.0	20 April 2017
Participant consent form [Consent to researcher contact form_Stroke survivor and carer]	1.0	01 February 2017
Participant information sheet (PIS) [PIS_Stroke Survivor]	3.0	20 April 2017
Participant information sheet (PIS) [PIS_Stroke survivor_TRACKED]	3.0	20 April 2017
Participant information sheet (PIS) [PIS_Stroke survivor_accessible]	3.0	20 April 2017
Participant information sheet (PIS) [PIS_Stroke survivor_accessible_TRACKED]	3.0	20 April 2017
Participant information sheet (PIS) [PIS_Carer]	3.0	20 April 2017

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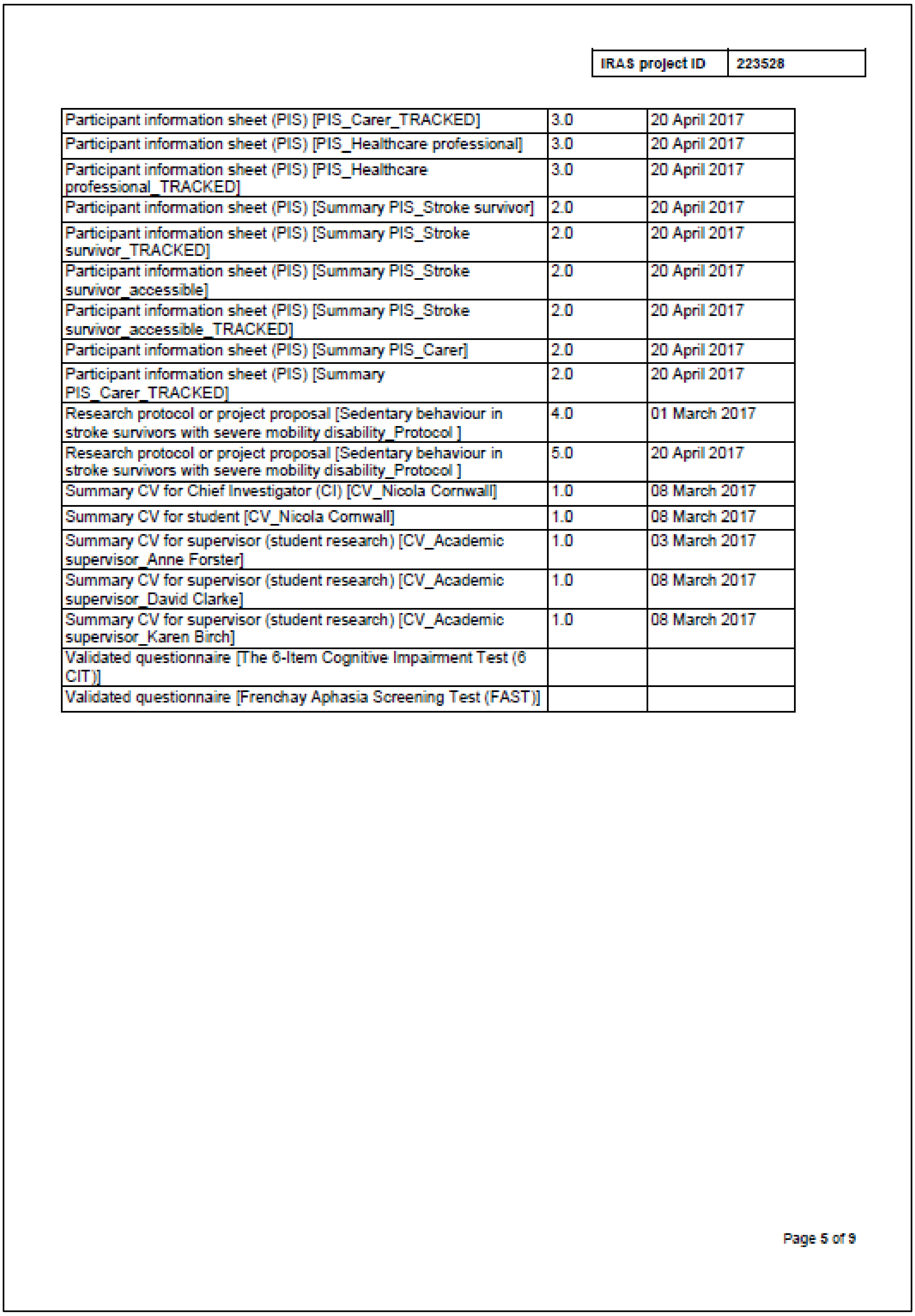
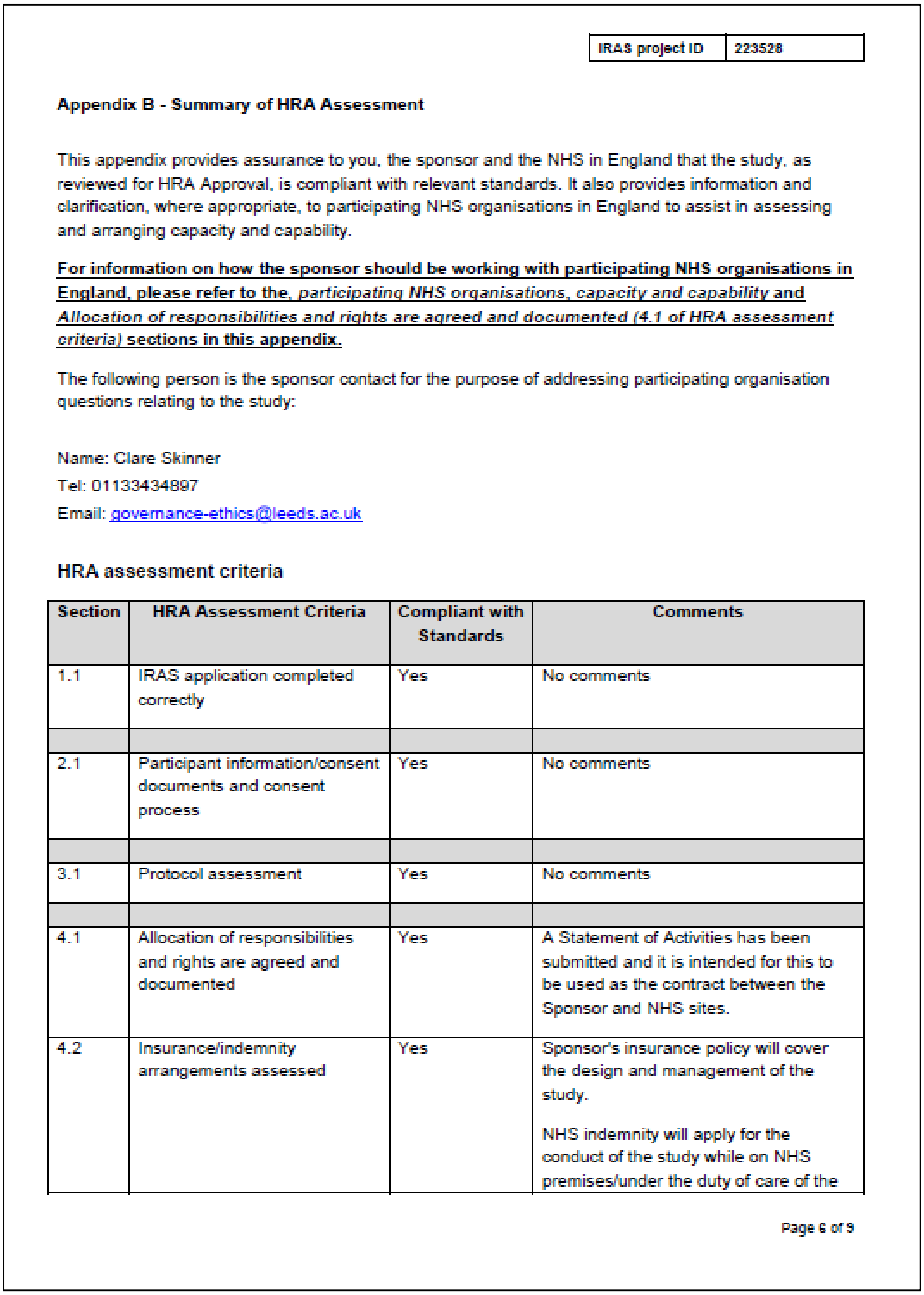


IRAS project ID	**223528**

Participant information sheet (PIS) [PIS_Carer_TRACKED]	3.0	20 April 2017
Participant information sheet (PIS) [PIS_Healthcare professional]	3.0	20 April 2017
Participant information sheet (PIS) [PIS_Healthcare professional_TRACKED]	3.0	20 April 2017
Participant information sheet (PIS) [Summary PIS_Stroke survivor]	2.0	20 April 2017
Participant information sheet (PIS) [Summary PIS_Stroke survivor_TRACKED]	2.0	20 April 2017
Participant information sheet (PIS) [Summary PIS_Stroke survivor_accessible]	2.0	20 April 2017
Participant information sheet (PIS) [Summary PIS_Stroke survivor_accessible_TRACKED]	2.0	20 April 2017
Participant information sheet (PIS) [Summary PIS_Carer]	2.0	20 April 2017
Participant information sheet (PIS) [Summary PIS_Carer_TRACKED]	2.0	20 April 2017
Research protocol or project proposal [Sedentary behaviour in stroke survivors with severe mobility disability_Protocol]	4.0	01 March 2017
Research protocol or project proposal [Sedentary behaviour in stroke survivors with severe mobility disability_Protocol]	5.0	20 April 2017
Summary CV for Chief Investigator (CI) [CV_Nicola Cornwall]	1.0	08 March 2017
Summary CV for student [CV_Nicola Cornwall]	1.0	08 March 2017
Summary CV for supervisor (student research) [CV_Academic supervisor_Anne Forster]	1.0	03 March 2017
Summary CV for supervisor (student research) [CV_Academic supervisor_David Clarke]	1.0	08 March 2017
Summary CV for supervisor (student research) [CV_Academic supervisor_Karen Birch]	1.0	08 March 2017
Validated questionnaire [The 6-Item Cognitive Impairment Test (6 CIT)]		
Validated questionnaire [Frenchay Aphasia Screening Test (FAST)]		

Page **5** of **9**



IRAS project ID	223528

Appendix B - Summary of HRA Assessment

This appendix provides assurance to you, the sponsor and the NHS in England that the study, as reviewed for HRA Approval, is compliant with relevant standards. It also provides information and clarification, where appropriate, to participating NHS organisations in England to assist in assessing and arranging capacity and capability.

For information on how the sponsor should be working with participating NHS organisations in England, please refer to the, *participating NHS organisations, capacity and capability* and *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* sections in this appendix.

The following person is the sponsor contact for the purpose of addressing participating organisation questions relating to the study:

Name: Clare Skinner
Tel: 01133434897
Email: governance-ethics@leeds.ac.uk

HRA assessment criteria

Section	HRA Assessment Criteria	Compliant with Standards	Comments
1.1	IRAS application completed correctly	Yes	No comments
2.1	Participant information/consent documents and consent process	Yes	No comments
3.1	Protocol assessment	Yes	No comments
4.1	Allocation of responsibilities and rights are agreed and documented	Yes	A Statement of Activities has been submitted and it is intended for this to be used as the contract between the Sponsor and NHS sites.
4.2	Insurance/indemnity arrangements assessed	Yes	Sponsor's insurance policy will cover the design and management of the study. NHS indemnity will apply for the conduct of the study while on NHS premises/under the duty of care of the

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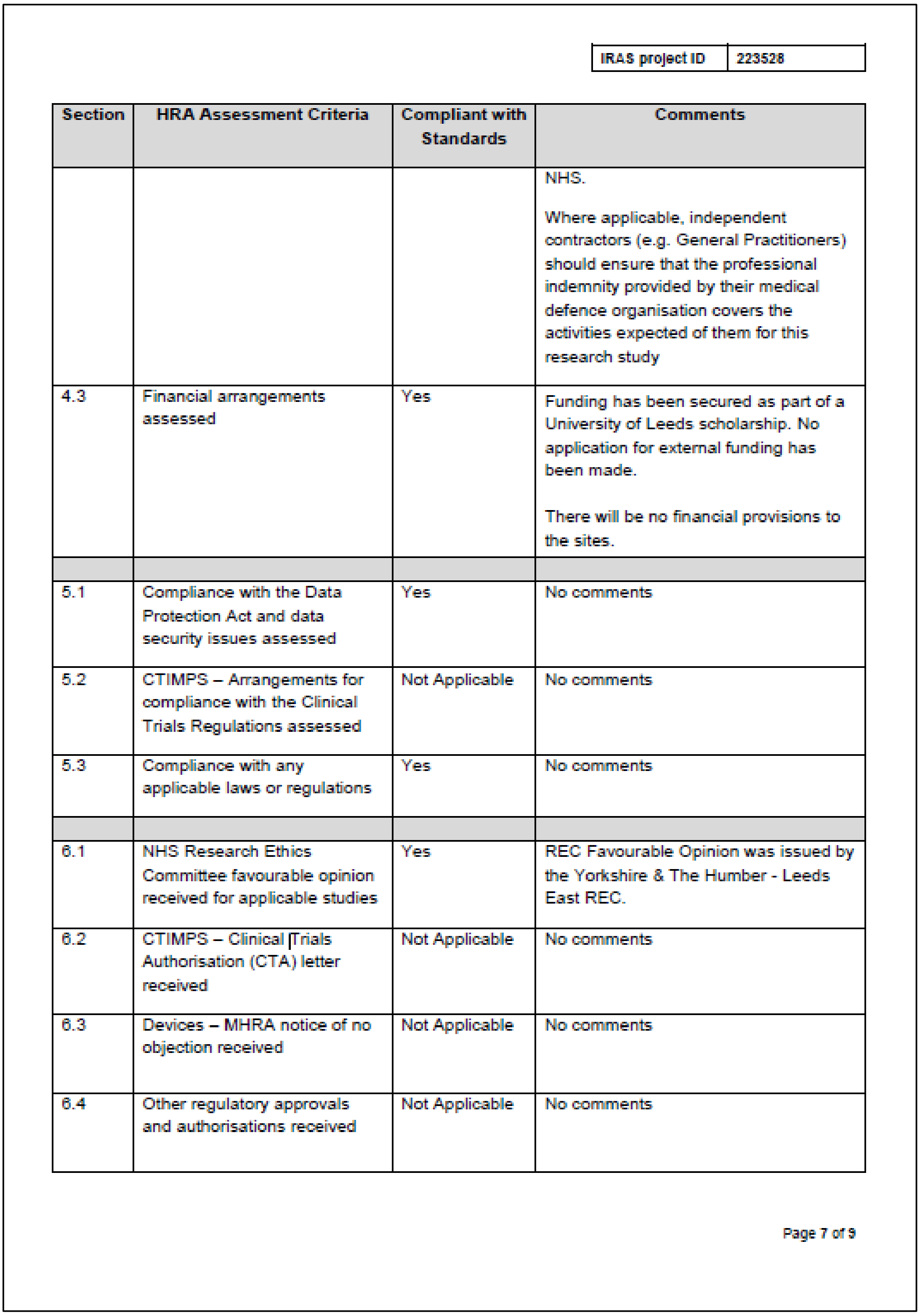
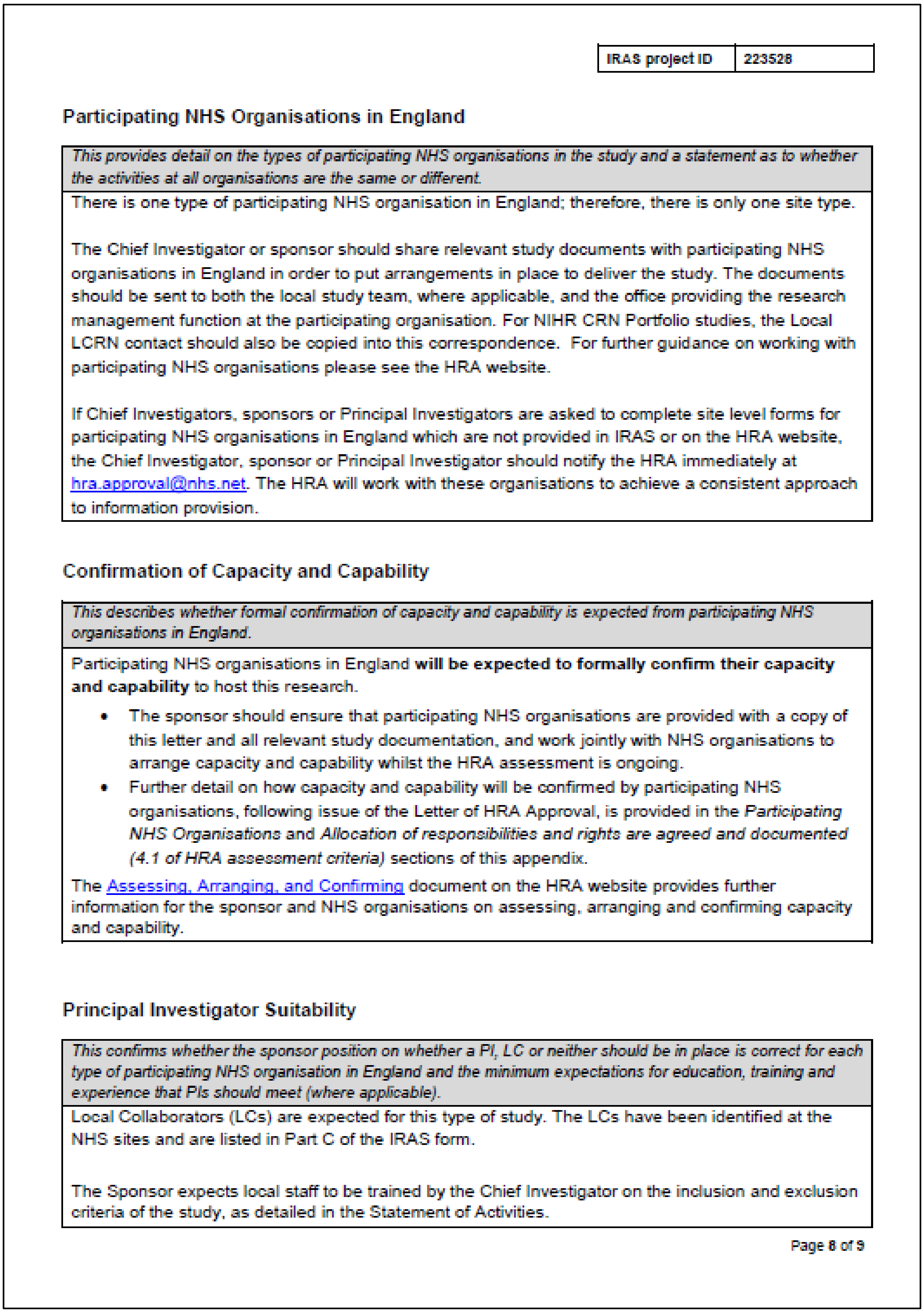


IRAS project ID	223528

Section	HRA Assessment Criteria	Compliant with Standards	Comments
			NHS. Where applicable, independent contractors (e.g. General Practitioners) should ensure that the professional indemnity provided by their medical defence organisation covers the activities expected of them for this research study
4.3	Financial arrangements assessed	Yes	Funding has been secured as part of a University of Leeds scholarship. No application for external funding has been made. There will be no financial provisions to the sites.
5.1	Compliance with the Data Protection Act and data security issues assessed	Yes	No comments
5.2	CTIMPS – Arrangements for compliance with the Clinical Trials Regulations assessed	Not Applicable	No comments
5.3	Compliance with any applicable laws or regulations	Yes	No comments
6.1	NHS Research Ethics Committee favourable opinion received for applicable studies	Yes	REC Favourable Opinion was issued by the Yorkshire & The Humber - Leeds East REC.
6.2	CTIMPS – Clinical Trials Authorisation (CTA) letter received	Not Applicable	No comments
6.3	Devices – MHRA notice of no objection received	Not Applicable	No comments
6.4	Other regulatory approvals and authorisations received	Not Applicable	No comments



Participating NHS Organisations in England

This provides detail on the types of participating NHS organisations in the study and a statement as to whether the activities at all organisations are the same or different.

There is one type of participating NHS organisation in England; therefore, there is only one site type.

The Chief Investigator or sponsor should share relevant study documents with participating NHS organisations in England in order to put arrangements in place to deliver the study. The documents should be sent to both the local study team, where applicable, and the office providing the research management function at the participating organisation. For NIHR CRN Portfolio studies, the Local LCRN contact should also be copied into this correspondence. For further guidance on working with participating NHS organisations please see the HRA website.

If Chief Investigators, sponsors or Principal Investigators are asked to complete site level forms for participating NHS organisations in England which are not provided in IRAS or on the HRA website, the Chief Investigator, sponsor or Principal Investigator should notify the HRA immediately at hra.approval@nhs.net. The HRA will work with these organisations to achieve a consistent approach to information provision.

Confirmation of Capacity and Capability

This describes whether formal confirmation of capacity and capability is expected from participating NHS organisations in England.

Participating NHS organisations in England **will be expected to formally confirm their capacity and capability** to host this research.

- The sponsor should ensure that participating NHS organisations are provided with a copy of this letter and all relevant study documentation, and work jointly with NHS organisations to arrange capacity and capability whilst the HRA assessment is ongoing.
- Further detail on how capacity and capability will be confirmed by participating NHS organisations, following issue of the Letter of HRA Approval, is provided in the *Participating NHS Organisations* and *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* sections of this appendix.

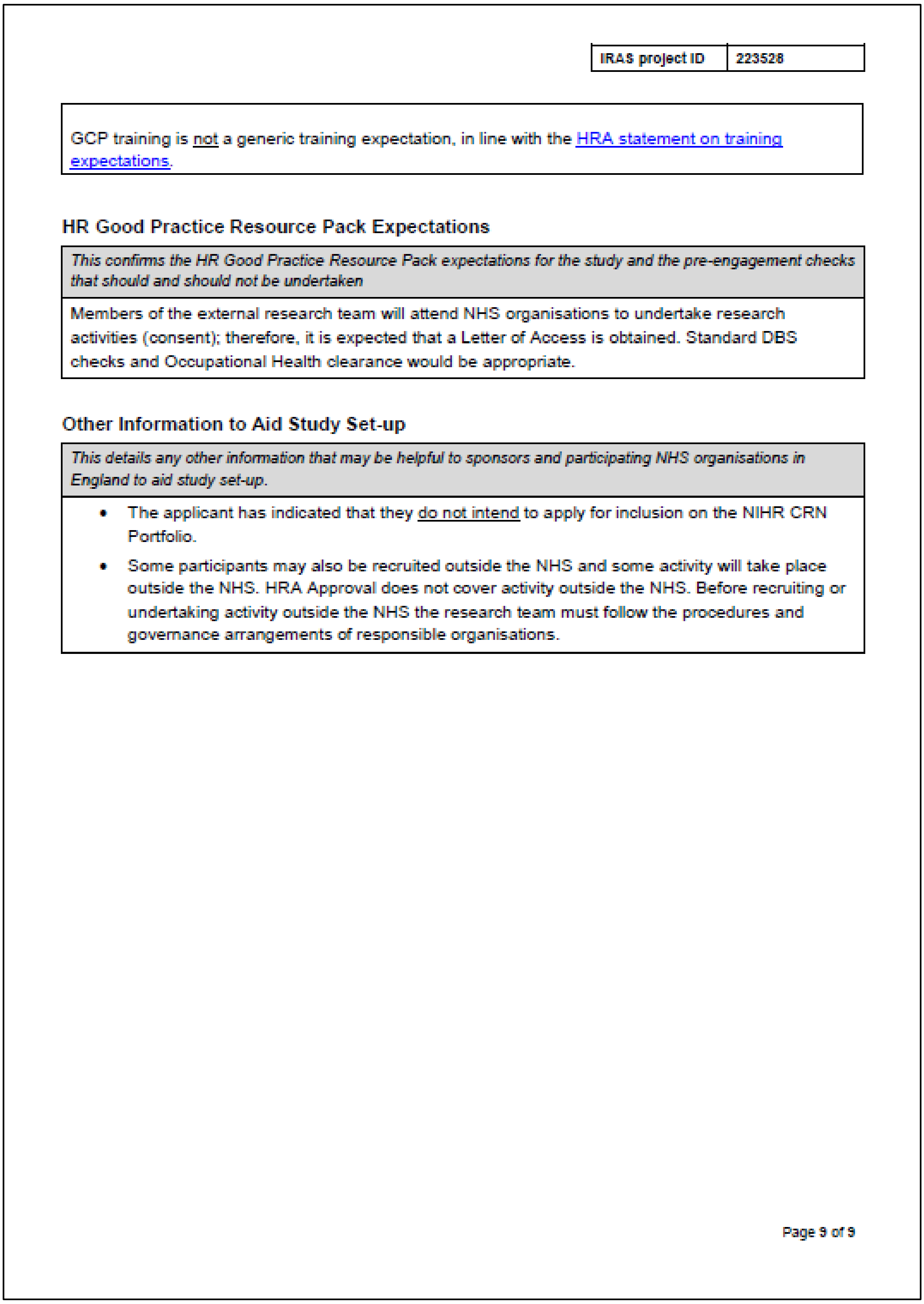
The Assessing, Arranging, and Confirming document on the HRA website provides further information for the sponsor and NHS organisations on assessing, arranging and confirming capacity and capability.

Principal Investigator Suitability

This confirms whether the sponsor position on whether a PI, LC or neither should be in place is correct for each type of participating NHS organisation in England and the minimum expectations for education, training and experience that PIs should meet (where applicable).

Local Collaborators (LCs) are expected for this type of study. The LCs have been identified at the NHS sites and are listed in Part C of the IRAS form.

The Sponsor expects local staff to be trained by the Chief Investigator on the inclusion and exclusion criteria of the study, as detailed in the Statement of Activities.



IRAS project ID	223528

GCP training is not a generic training expectation, in line with the HRA statement on training expectations.

HR Good Practice Resource Pack Expectations

This confirms the HR Good Practice Resource Pack expectations for the study and the pre-engagement checks that should and should not be undertaken
Members of the external research team will attend NHS organisations to undertake research activities (consent); therefore, it is expected that a Letter of Access is obtained. Standard DBS checks and Occupational Health clearance would be appropriate.

Other Information to Aid Study Set-up

This details any other information that may be helpful to sponsors and participating NHS organisations in England to aid study set-up.

- The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio.
- Some participants may also be recruited outside the NHS and some activity will take place outside the NHS. HRA Approval does not cover activity outside the NHS. Before recruiting or undertaking activity outside the NHS the research team must follow the procedures and governance arrangements of responsible organisations.

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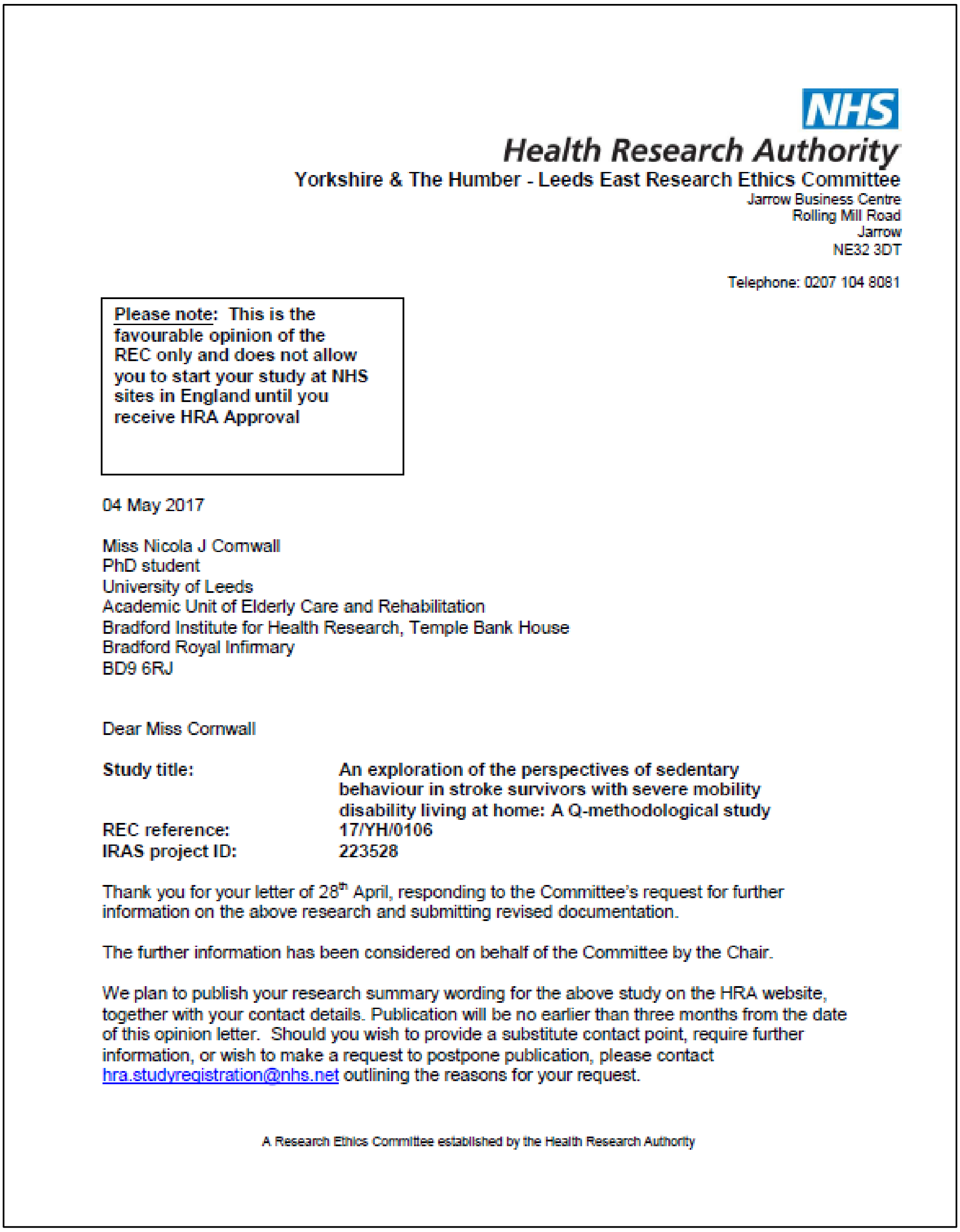
Appendix F Letter of Favourable Opinion Research Ethics Committee – Q-Methodology Study



Health Research Authority
Yorkshire & The Humber - Leeds East Research Ethics Committee
Jarrow Business Centre
Rolling Mill Road
Jarrow
NE32 3DT

Telephone: 0207 104 8081

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

04 May 2017

Miss Nicola J Cornwall
PhD student
University of Leeds
Academic Unit of Elderly Care and Rehabilitation
Bradford Institute for Health Research, Temple Bank House
Bradford Royal Infirmary
BD9 6RJ

Dear Miss Cornwall

Study title:	**An exploration of the perspectives of sedentary behaviour in stroke survivors with severe mobility disability living at home: A Q-methodological study**
REC reference:	**17/YH/0106**
IRAS project ID:	**223528**

Thank you for your letter of 28th April, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact hra.studyregistration@nhs.net outlining the reasons for your request.

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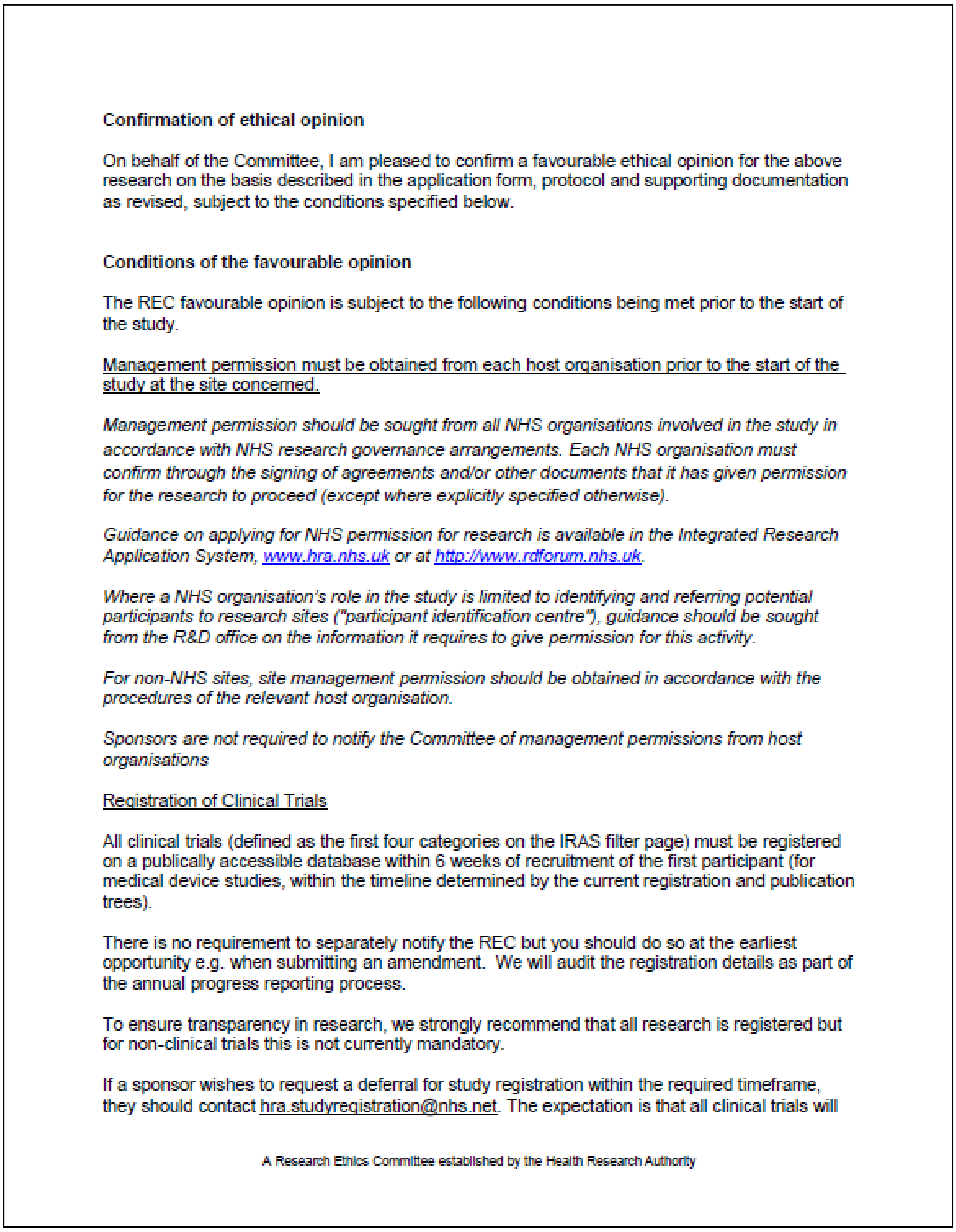


Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

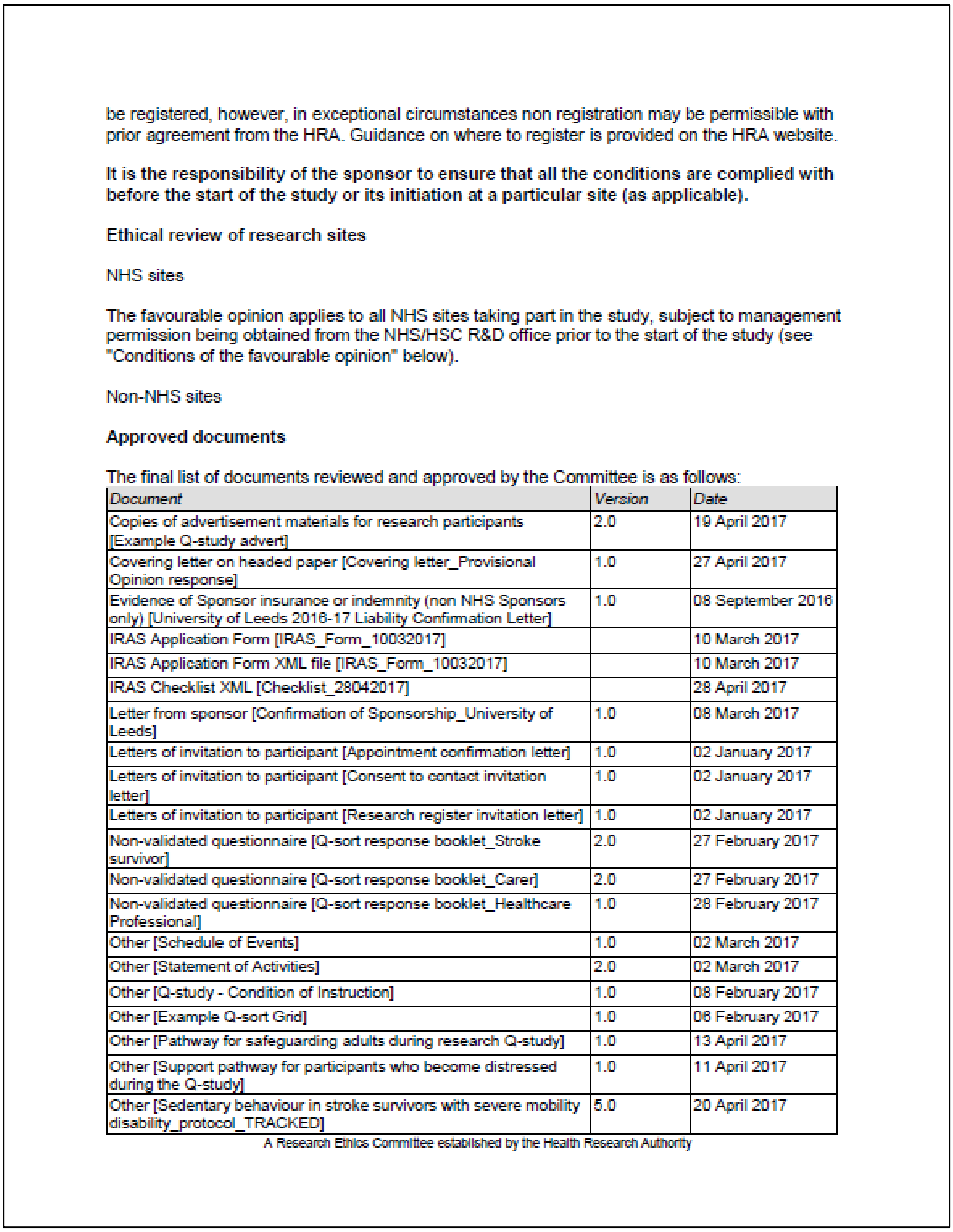
Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will



be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

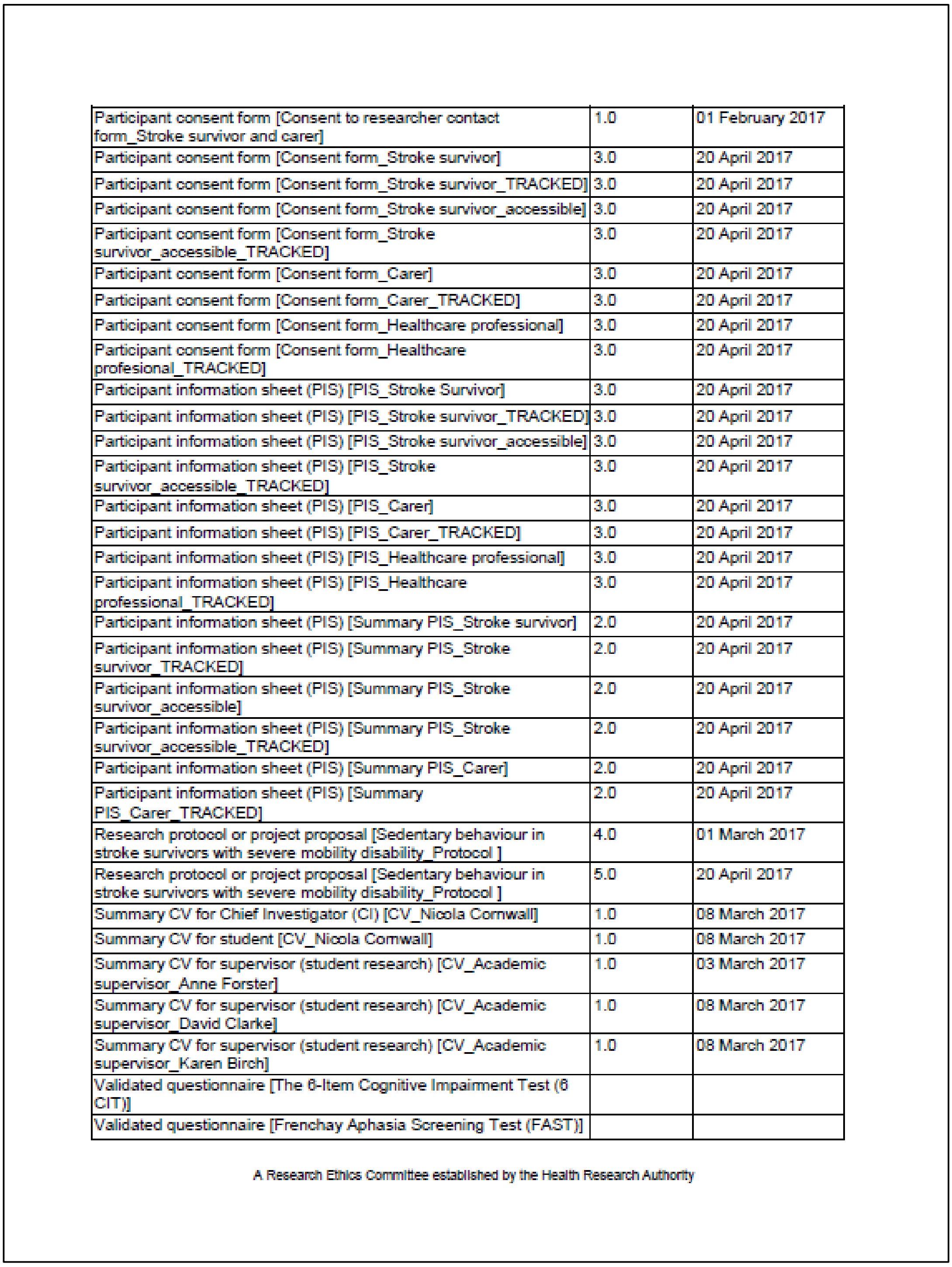
The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Copies of advertisement materials for research participants [Example Q-study advert]	2.0	19 April 2017
Covering letter on headed paper [Covering letter_Provisional Opinion response]	1.0	27 April 2017
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [University of Leeds 2016-17 Liability Confirmation Letter]	1.0	08 September 2016
IRAS Application Form [IRAS_Form_10032017]		10 March 2017
IRAS Application Form XML file [IRAS_Form_10032017]		10 March 2017
IRAS Checklist XML [Checklist_28042017]		28 April 2017
Letter from sponsor [Confirmation of Sponsorship_University of Leeds]	1.0	08 March 2017
Letters of invitation to participant [Appointment confirmation letter]	1.0	02 January 2017
Letters of invitation to participant [Consent to contact invitation letter]	1.0	02 January 2017
Letters of invitation to participant [Research register invitation letter]	1.0	02 January 2017
Non-validated questionnaire [Q-sort response booklet_Stroke survivor]	2.0	27 February 2017
Non-validated questionnaire [Q-sort response booklet_Carer]	2.0	27 February 2017
Non-validated questionnaire [Q-sort response booklet_Healthcare Professional]	1.0	28 February 2017
Other [Schedule of Events]	1.0	02 March 2017
Other [Statement of Activities]	2.0	02 March 2017
Other [Q-study - Condition of Instruction]	1.0	08 February 2017
Other [Example Q-sort Grid]	1.0	06 February 2017
Other [Pathway for safeguarding adults during research Q-study]	1.0	13 April 2017
Other [Support pathway for participants who become distressed during the Q-study]	1.0	11 April 2017
Other [Sedentary behaviour in stroke survivors with severe mobility disability_protocol_TRACKED]	5.0	20 April 2017



Participant consent form [Consent to researcher contact form_Stroke survivor and carer]	1.0	01 February 2017
Participant consent form [Consent form_Stroke survivor]	3.0	20 April 2017
Participant consent form [Consent form_Stroke survivor_TRACKED]	3.0	20 April 2017
Participant consent form [Consent form_Stroke survivor_accessible]	3.0	20 April 2017
Participant consent form [Consent form_Stroke survivor_accessible_TRACKED]	3.0	20 April 2017
Participant consent form [Consent form_Carer]	3.0	20 April 2017
Participant consent form [Consent form_Carer_TRACKED]	3.0	20 April 2017
Participant consent form [Consent form_Healthcare professional]	3.0	20 April 2017
Participant consent form [Consent form_Healthcare profesional_TRACKED]	3.0	20 April 2017
Participant information sheet (PIS) [PIS_Stroke Survivor]	3.0	20 April 2017
Participant information sheet (PIS) [PIS_Stroke survivor_TRACKED]	3.0	20 April 2017
Participant information sheet (PIS) [PIS_Stroke survivor_accessible]	3.0	20 April 2017
Participant information sheet (PIS) [PIS_Stroke survivor_accessible_TRACKED]	3.0	20 April 2017
Participant information sheet (PIS) [PIS_Carer]	3.0	20 April 2017
Participant information sheet (PIS) [PIS_Carer_TRACKED]	3.0	20 April 2017
Participant information sheet (PIS) [PIS_Healthcare professional]	3.0	20 April 2017
Participant information sheet (PIS) [PIS_Healthcare professional_TRACKED]	3.0	20 April 2017
Participant information sheet (PIS) [Summary PIS_Stroke survivor]	2.0	20 April 2017
Participant information sheet (PIS) [Summary PIS_Stroke survivor_TRACKED]	2.0	20 April 2017
Participant information sheet (PIS) [Summary PIS_Stroke survivor_accessible]	2.0	20 April 2017
Participant information sheet (PIS) [Summary PIS_Stroke survivor_accessible_TRACKED]	2.0	20 April 2017
Participant information sheet (PIS) [Summary PIS_Carer]	2.0	20 April 2017
Participant information sheet (PIS) [Summary PIS_Carer_TRACKED]	2.0	20 April 2017
Research protocol or project proposal [Sedentary behaviour in stroke survivors with severe mobility disability_Protocol]	4.0	01 March 2017
Research protocol or project proposal [Sedentary behaviour in stroke survivors with severe mobility disability_Protocol]	5.0	20 April 2017
Summary CV for Chief Investigator (CI) [CV_Nicola Cornwall]	1.0	08 March 2017
Summary CV for student [CV_Nicola Cornwall]	1.0	08 March 2017
Summary CV for supervisor (student research) [CV_Academic supervisor_Anne Forster]	1.0	03 March 2017
Summary CV for supervisor (student research) [CV_Academic supervisor_David Clarke]	1.0	08 March 2017
Summary CV for supervisor (student research) [CV_Academic supervisor_Karen Birch]	1.0	08 March 2017
Validated questionnaire [The 6-Item Cognitive Impairment Test (6 CIT)]		
Validated questionnaire [Frenchay Aphasia Screening Test (FAST)]		

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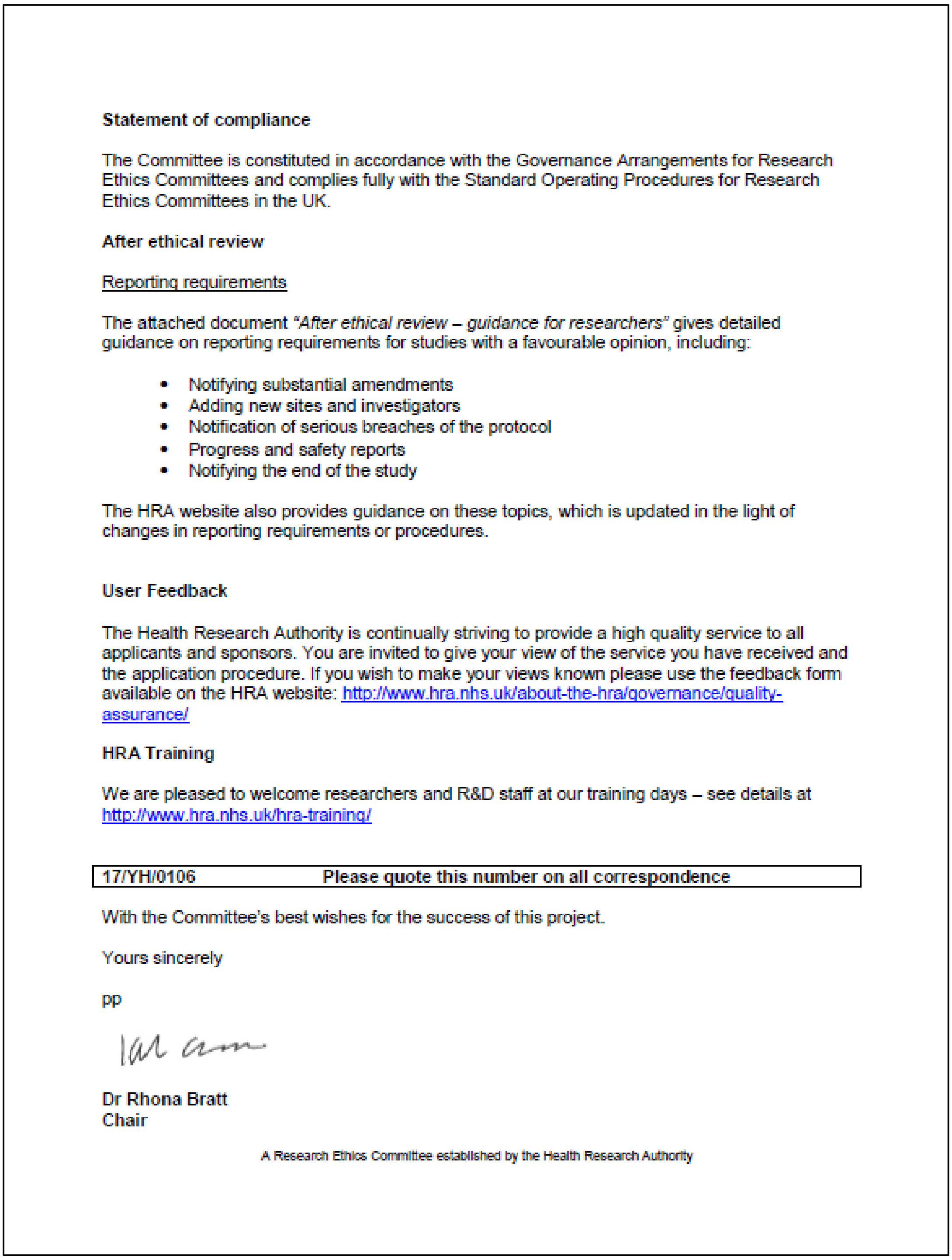

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

17/YH/0106	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project.

Yours sincerely

pp

Dr Rhona Bratt
Chair

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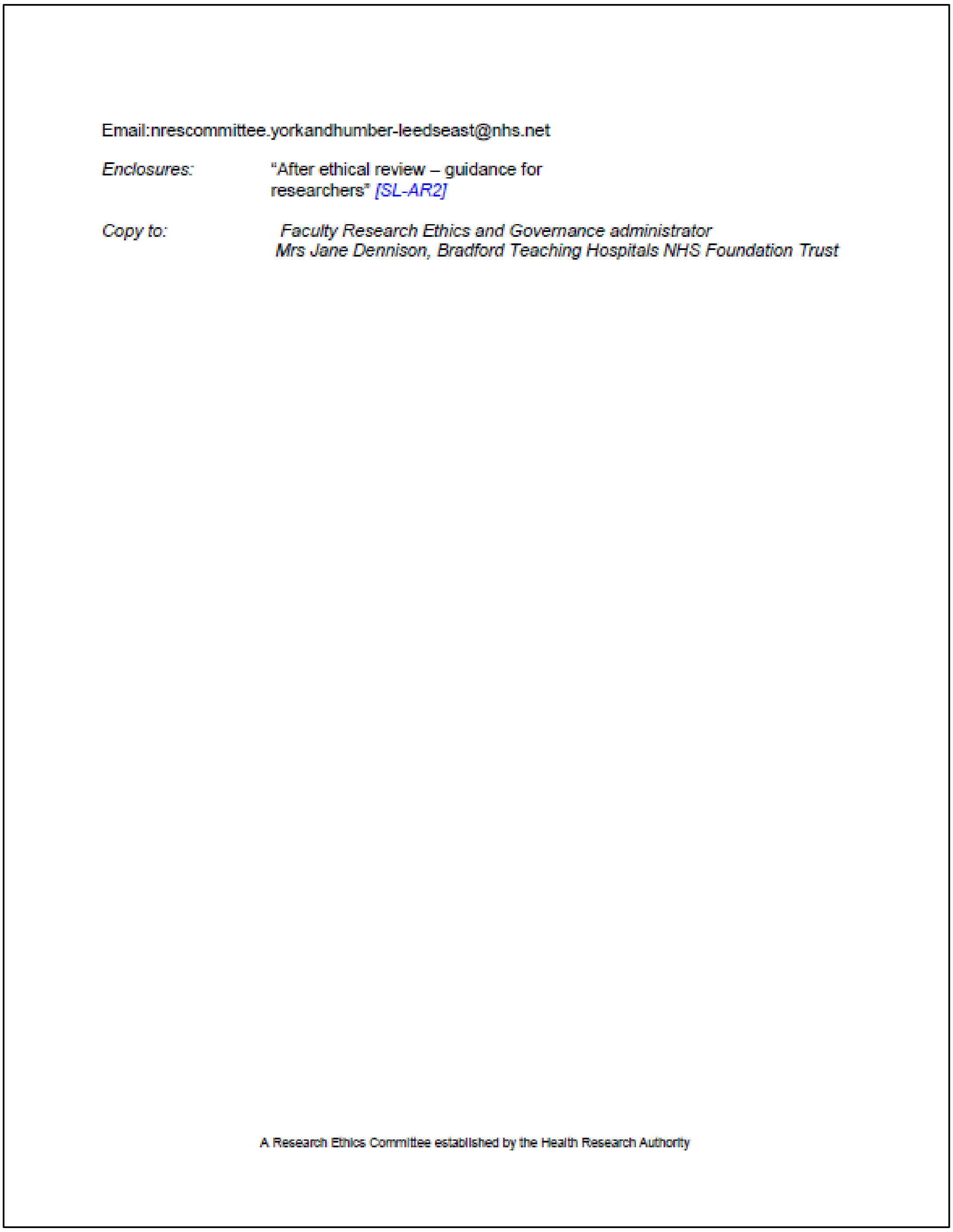

Email:nrescommittee.yorkandhumber-leedseast@nhs.net

Enclosures: “After ethical review – guidance for researchers” *[SL-AR2]*

Copy to: *Faculty Research Ethics and Governance administrator*
Mrs Jane Dennison, Bradford Teaching Hospitals NHS Foundation Trust

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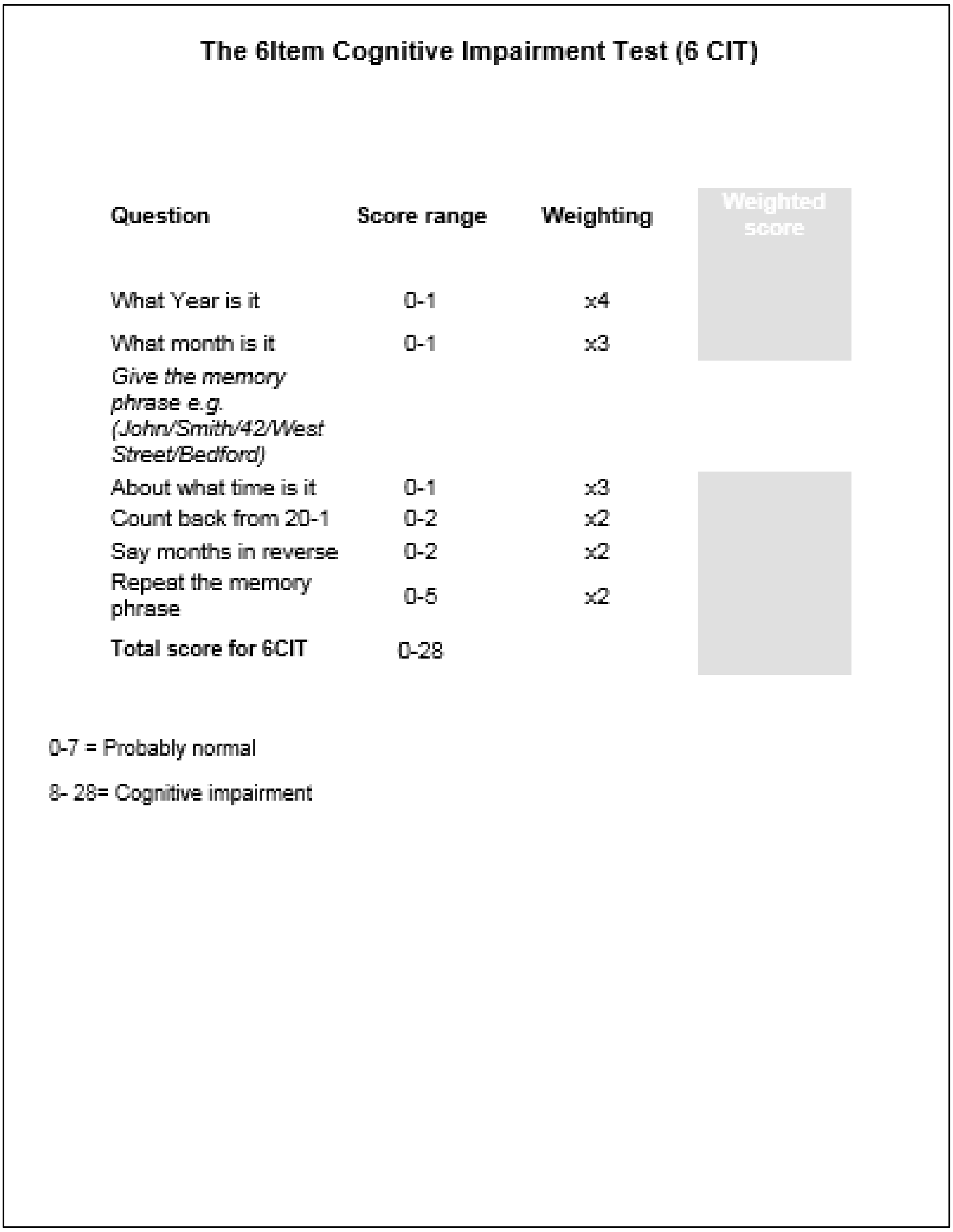
Appendix G 6-Item Cognitive Impairment Test(6-CIT)

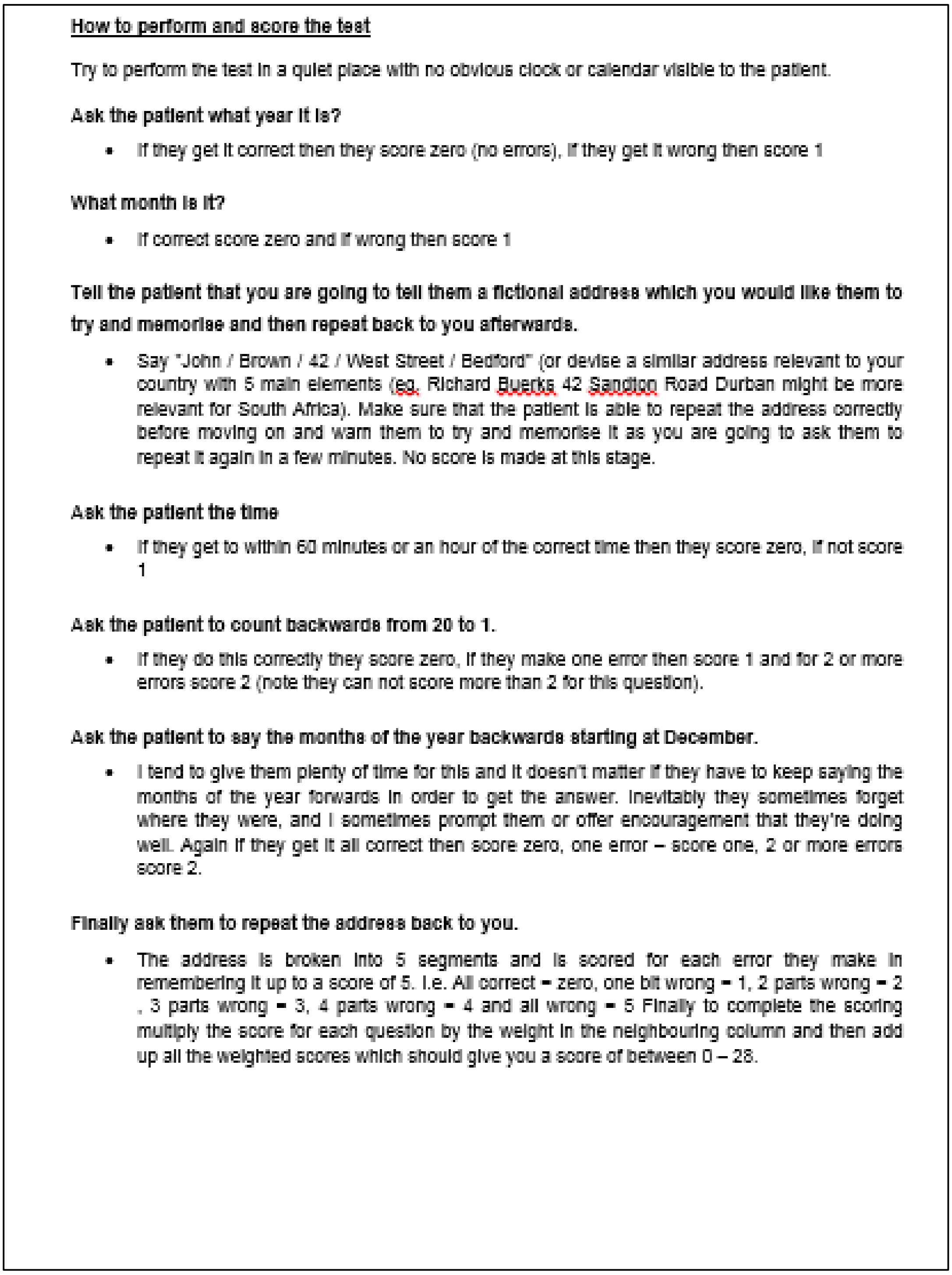


The 6Item Cognitive Impairment Test (6 CIT)

Question	**Score range**	**Weighting**	Weighted score
What Year is it	0-1	x4	
What month is it	0-1	x3	
Give the memory phrase e.g. (John/Smith/42/West Street/Bedford)			
About what time is it	0-1	x3	
Count back from 20-1	0-2	x2	
Say months in reverse	0-2	x2	
Repeat the memory phrase	0-5	x2	
Total score for 6CIT	0-28		

0-7 = Probably normal

8- 28= Cognitive impairment



How to perform and score the test

Try to perform the test in a quiet place with no obvious clock or calendar visible to the patient.

Ask the patient what year it is?

- If they get it correct then they score zero (no errors), if they get it wrong then score 1

What month is it?

- If correct score zero and if wrong then score 1

Tell the patient that you are going to tell them a fictional address which you would like them to try and memorise and then repeat back to you afterwards.

- Say "John / Brown / 42 / West Street / Bedford" (or devise a similar address relevant to your country with 5 main elements (eg. Richard Buerks 42 Sandton Road Durban might be more relevant for South Africa). Make sure that the patient is able to repeat the address correctly before moving on and warn them to try and memorise it as you are going to ask them to repeat it again in a few minutes. No score is made at this stage.

Ask the patient the time

- If they get to within 60 minutes or an hour of the correct time then they score zero, if not score 1

Ask the patient to count backwards from 20 to 1.

- If they do this correctly they score zero, if they make one error then score 1 and for 2 or more errors score 2 (note they can not score more than 2 for this question).

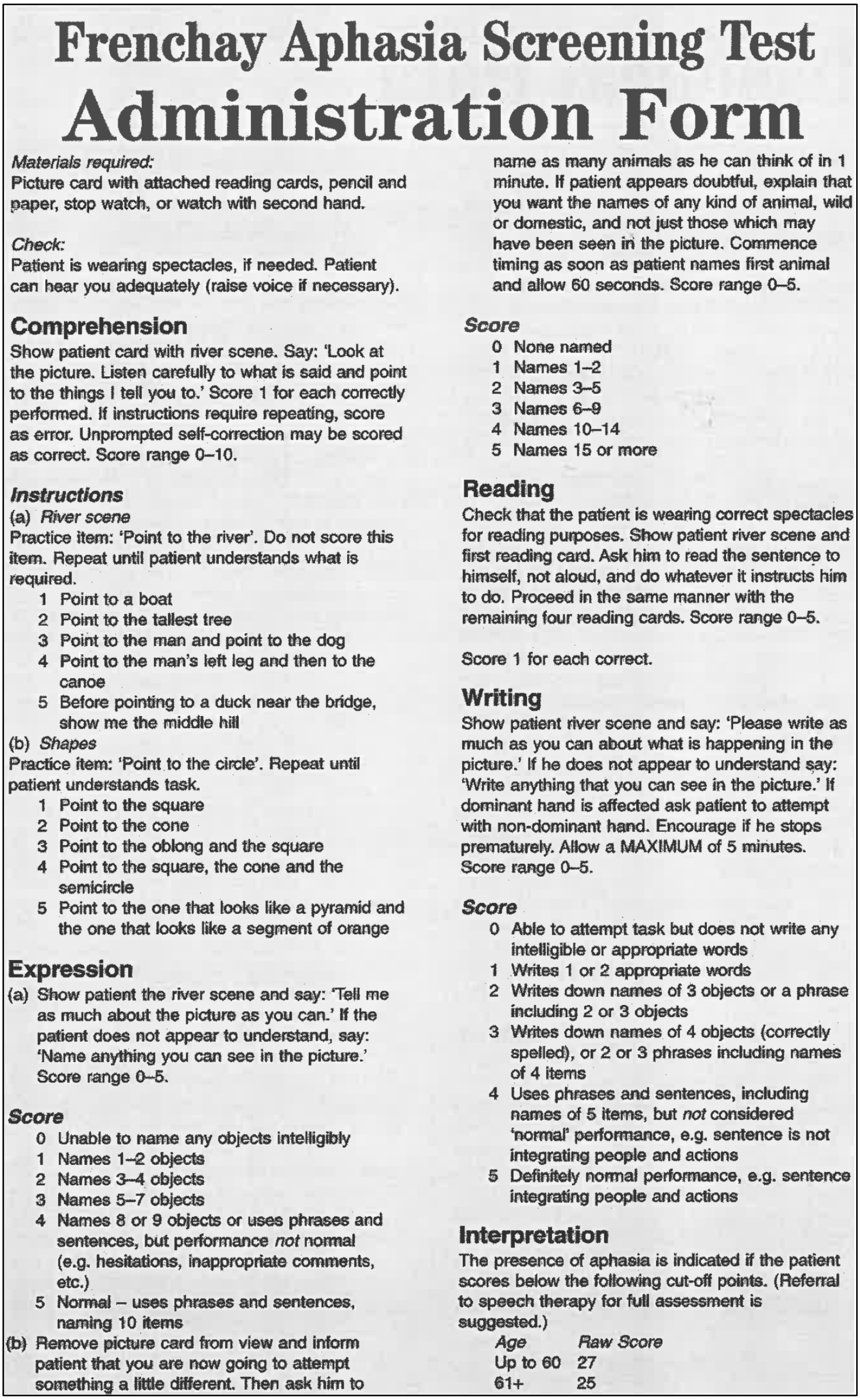
Ask the patient to say the months of the year backwards starting at December.

- I tend to give them plenty of time for this and it doesn't matter if they have to keep saying the months of the year forwards in order to get the answer. Inevitably they sometimes forget where they were, and I sometimes prompt them or offer encouragement that they're doing well. Again if they get it all correct then score zero, one error – score one, 2 or more errors score 2.

Finally ask them to repeat the address back to you.

- The address is broken into 5 segments and is scored for each error they make in remembering it up to a score of 5. I.e. All correct = zero, one bit wrong = 1, 2 parts wrong = 2 , 3 parts wrong = 3, 4 parts wrong = 4 and all wrong = 5 Finally to complete the scoring multiply the score for each question by the weight in the neighbouring column and then add up all the weighted scores which should give you a score of between 0 – 28.

Appendix H Frenchay Aphasia Screening Test (FAST)



Frenchay Aphasia Screening Test
Administration Form

Materials required:
Picture card with attached reading cards, pencil and paper, stop watch, or watch with second hand.

Check:
Patient is wearing spectacles, if needed. Patient can hear you adequately (raise voice if necessary).

Comprehension

Show patient card with river scene. Say: 'Look at the picture. Listen carefully to what is said and point to the things I tell you to.' Score 1 for each correctly performed. If instructions require repeating, score as error. Unprompted self-correction may be scored as correct. Score range 0–10.

Instructions

(a) *River scene*
Practice item: 'Point to the river'. Do not score this item. Repeat until patient understands what is required.

1 Point to a boat
2 Point to the tallest tree
3 Point to the man and point to the dog
4 Point to the man's left leg and then to the canoe
5 Before pointing to a duck near the bridge, show me the middle hill

(b) *Shapes*
Practice item: 'Point to the circle'. Repeat until patient understands task.

1 Point to the square
2 Point to the cone
3 Point to the oblong and the square
4 Point to the square, the cone and the semicircle
5 Point to the one that looks like a pyramid and the one that looks like a segment of orange

Expression

(a) Show patient the river scene and say: 'Tell me as much about the picture as you can.' If the patient does not appear to understand, say: 'Name anything you can see in the picture.' Score range 0–5.

Score

0 Unable to name any objects intelligibly
1 Names 1–2 objects
2 Names 3–4 objects
3 Names 5–7 objects
4 Names 8 or 9 objects or uses phrases and sentences, but performance *not* normal (e.g. hesitations, inappropriate comments, etc.)
5 Normal – uses phrases and sentences, naming 10 items

(b) Remove picture card from view and inform patient that you are now going to attempt something a little different. Then ask him to name as many animals as he can think of in 1 minute. If patient appears doubtful, explain that you want the names of any kind of animal, wild or domestic, and not just those which may have been seen in the picture. Commence timing as soon as patient names first animal and allow 60 seconds. Score range 0–5.

Score

0 None named
1 Names 1–2
2 Names 3–5
3 Names 6–9
4 Names 10–14
5 Names 15 or more

Reading

Check that the patient is wearing correct spectacles for reading purposes. Show patient river scene and first reading card. Ask him to read the sentence to himself, not aloud, and do whatever it instructs him to do. Proceed in the same manner with the remaining four reading cards. Score range 0–5.

Score 1 for each correct.

Writing

Show patient river scene and say: 'Please write as much as you can about what is happening in the picture.' If he does not appear to understand say: 'Write anything that you can see in the picture.' If dominant hand is affected ask patient to attempt with non-dominant hand. Encourage if he stops prematurely. Allow a MAXIMUM of 5 minutes. Score range 0–5.

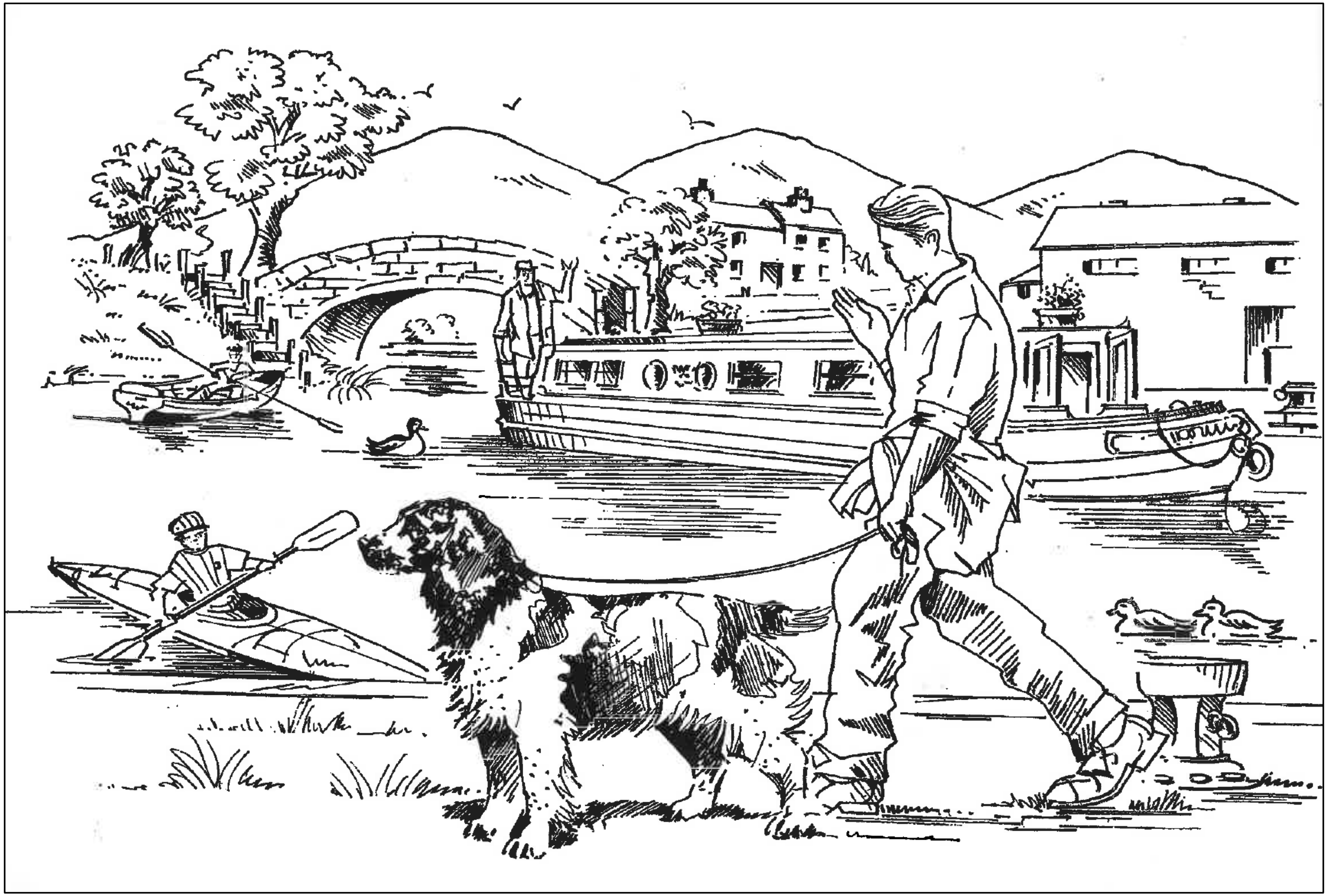
Score

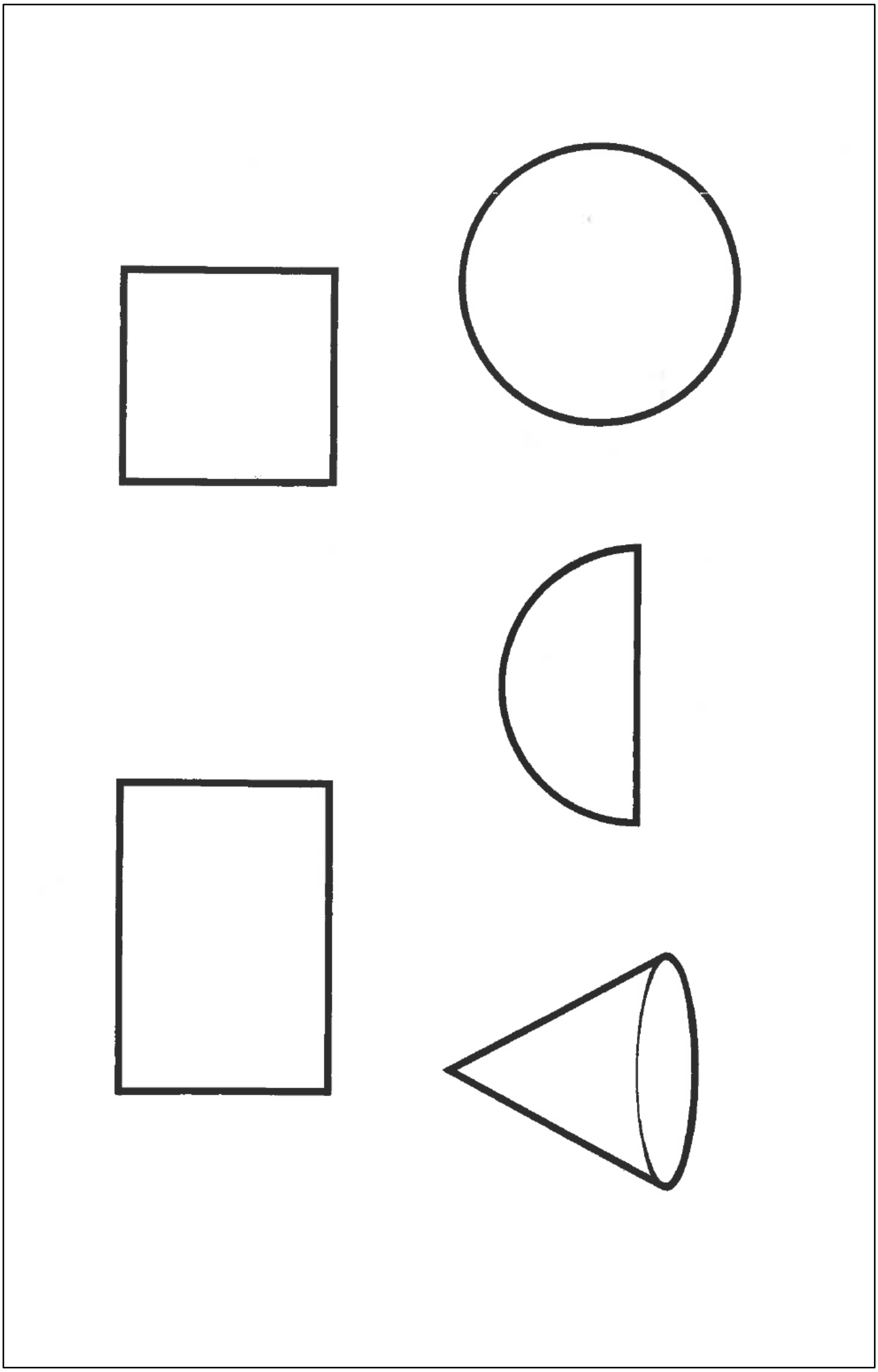
0 Able to attempt task but does not write any intelligible or appropriate words
1 Writes 1 or 2 appropriate words
2 Writes down names of 3 objects or a phrase including 2 or 3 objects
3 Writes down names of 4 objects (correctly spelled), or 2 or 3 phrases including names of 4 items
4 Uses phrases and sentences, including names of 5 items, but *not* considered 'normal' performance, e.g. sentence is not integrating people and actions
5 Definitely normal performance, e.g. sentence integrating people and actions

Interpretation

The presence of aphasia is indicated if the patient scores below the following cut-off points. (Referral to speech therapy for full assessment is suggested.)

Age	*Raw Score*
Up to 60	27
61+	25





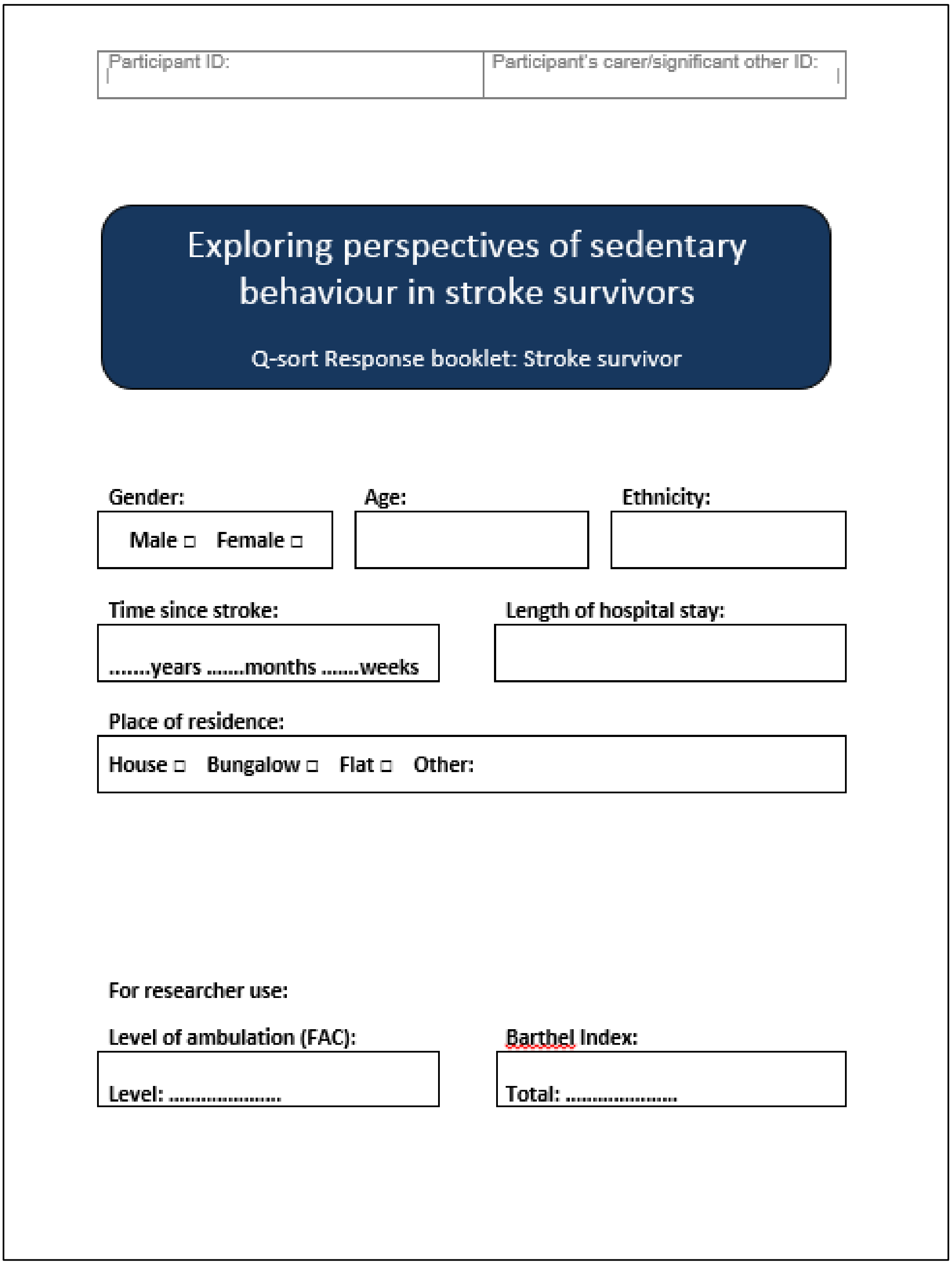
Appendix I List of Initial Q-Set Statements

Initial Shortlisted Q-set statements (214 statements initially reduced to 63):

HEALTH	
1.	The health effects of not moving regularly are different to physical inactivity
2.	Being active is important to reduce my risk of developing other health problems
3.	To be healthy you must be active
4.	Moving regularly is important to reduce my risks of having another stroke
FUNCTION	
5.	Exercise is important after a stroke
6.	Movement is different to exercise
7.	Moving regularly helps to improve and maintain physical functioning after stroke
8.	Movement is important to keep me flexible and strong
9.	Physiotherapy makes/made me move more
10.	Upper body movement (e.g. arm movements) is not physical activity
11.	Physical activity has to involve the use of the lower body (e.g. legs)
PURPOSE	
12.	Doing jobs around the house is not physical activity
13.	I would like to do more around the house but I am limited by my movement
14.	The only time I am active is during exercise
15.	I cannot exercise because of my mobility problems
16.	Working motivates me to keep active and move regularly
17.	The activities I like to do in my free time involve sitting or lying down without moving (e.g. watching TV, reading, using the computer)
18.	I find being able to care for myself (e.g. washing and dressing, preparing and cooking food) difficult because of my physical impairment
19.	To have an active social life you must be able to walk
20.	To be independent you must be able to walk and stand without help
21.	Moving more would allow me to be more independent
22.	Occupational therapists encourage me to move more by helping me to adapt how I do things (e.g. making a cup of tea, going to the toilet)
QUALITY OF LIFE	
23.	I would be happier if I could move more (regularly)
24.	My lack of confidence affects how much I move
25.	My mobility problems have made me dependent on others
26.	I find it difficult to accept that I cannot move like I used to before my stroke
FEAR	
27.	I often worry about the health consequences of not moving enough / being active
28.	The risk of falling stops me from trying to move
29.	I’m unsure on how to safely increase my movement / activity
30.	I’m scared of moving too much in case I have another stroke
FREQUENCY	
31.	I do not move enough
32.	I would move more if I was helped
33.	I would move more if I was with others
34.	I have no choice but to sit or lie-down for long periods
35.	I move when reminded
36.	Breaking tasks and exercises into smaller chunks would make trying to move more easier
37.	It is important to break-up long periods of sitting
38.	There is no point in trying to move as I cannot do as much as I used to

39.	The physical activity guidelines of 30 minutes per day are unrealistic for stroke survivors with mobility problems
BENEFITS	
40.	Breaking up the time I sit an lie down would make me happier
41.	A benefit of moving regularly is the reduction in my pain
42.	Practising my exercises and movements will improve my co-ordination and balance
CHALLENGES / BARRIERS	
43.	My family, friends and carers often stop me from trying to move
44.	I don't like to ask my family and friends to help me get around
45.	Pain stops me moving more
46.	Fatigue limits how much I can move throughout the day
47.	Having to spend the majority of my day sitting or lying down is frustrating
48.	I am embarrassed of my mobility problems
49.	Reducing sedentary time is impossible in stroke survivors with severe mobility problems
50.	I find it difficult to move regularly because of my mobility problems
51.	I do not move as much since physiotherapy and occupational therapy input stopped
ENABLERS	
52.	The support of family, friends and carers is important to help me keep active
53.	Practising exercises and tasks is key to improving mobility and increasing movement
54.	Practical advice and tips would help stroke survivors with mobility problems to try to increase their level of physical activity
55.	I was given information after my stroke about the importance of keeping moving and breaking long periods of sitting or lying
56.	You sometimes have to force yourself to move when you do not have the motivation
57.	Motivation is important when trying to increase people's movement
58.	You have to adapt and develop new skills when you have mobility problems after a stroke
59.	It is impossible to increase the amount of movement if the environment is not accessible, adapted or suitable
60.	Setting goals and recording progress is a good way of trying to increase physical activity
61.	Being encouraged to move more is important to keep active
62.	Movement aids (e.g. wheelchair, walking stick) make it easier to keep active
63.	Safety aids and adaptations (e.g. handrails, ramps) for the home are important to keep moving around the home

Appendix J Q-Response Booklet (Stroke Survivor)



Participant ID:	Participant's carer/significant other ID:

Exploring perspectives of sedentary behaviour in stroke survivors

Q-sort Response booklet: Stroke survivor

Gender:
Male ☐ Female ☐

Age:

Ethnicity:

Time since stroke:
.......years ....months ....weeks

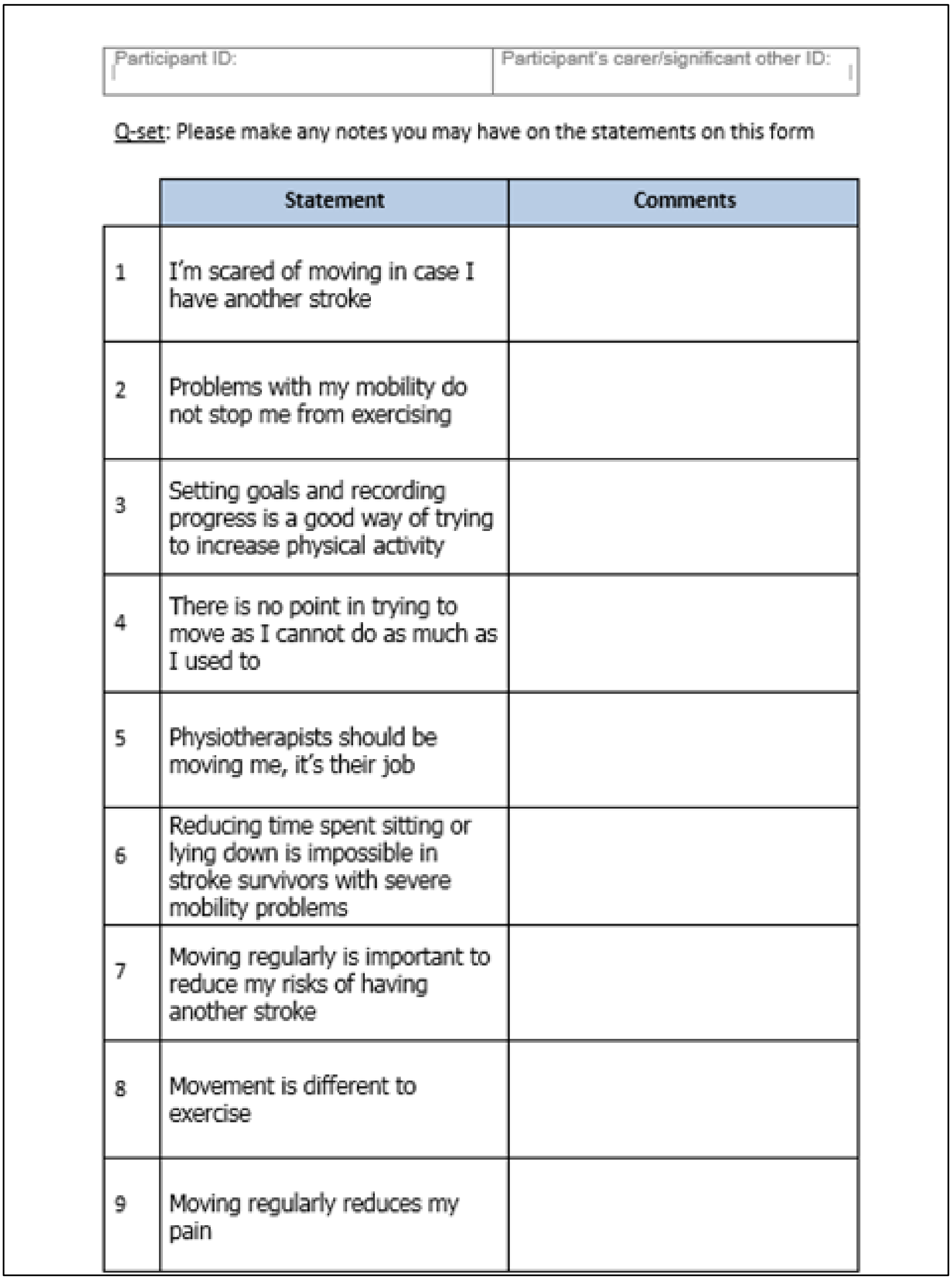
Length of hospital stay:

Place of residence:
House ☐ Bungalow ☐ Flat ☐ Other:

For researcher use:

Level of ambulation (FAC):
Level: ....

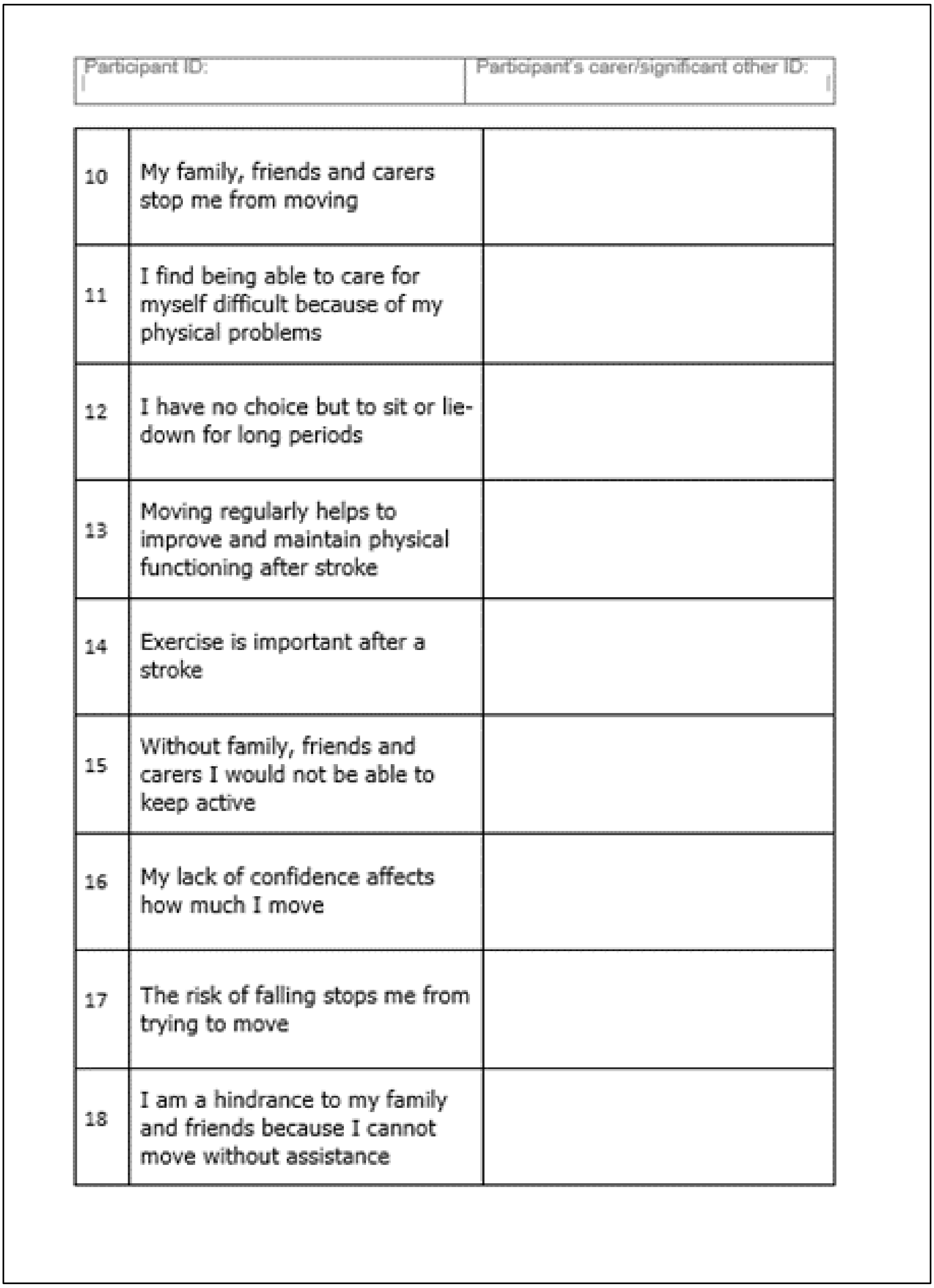
Barthel Index:
Total: ....



Participant ID:	Participant's carer/significant other ID:

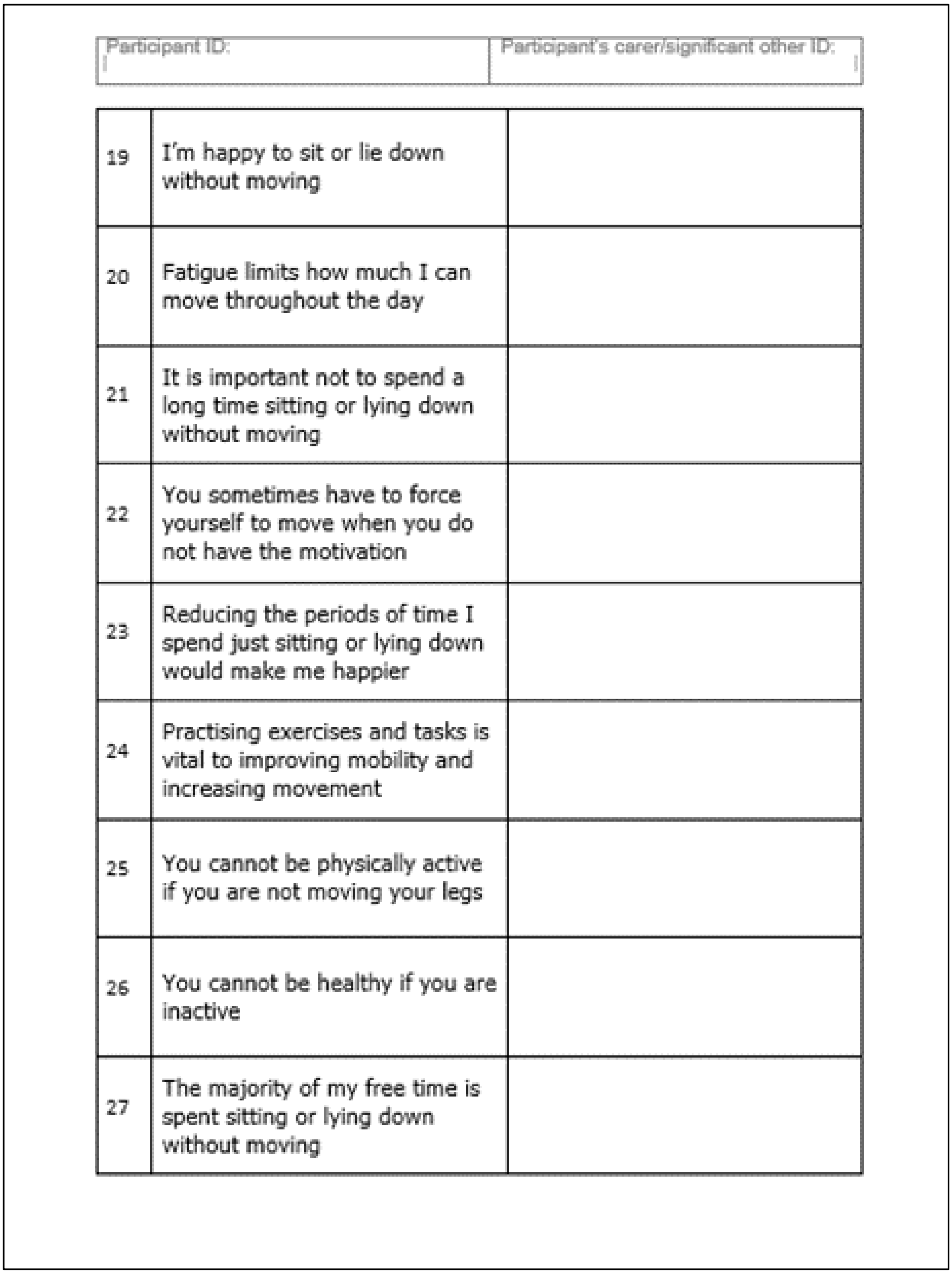
Q-set: Please make any notes you may have on the statements on this form

	Statement	Comments
1	I'm scared of moving in case I have another stroke	
2	Problems with my mobility do not stop me from exercising	
3	Setting goals and recording progress is a good way of trying to increase physical activity	
4	There is no point in trying to move as I cannot do as much as I used to	
5	Physiotherapists should be moving me, it's their job	
6	Reducing time spent sitting or lying down is impossible in stroke survivors with severe mobility problems	
7	Moving regularly is important to reduce my risks of having another stroke	
8	Movement is different to exercise	
9	Moving regularly reduces my pain	



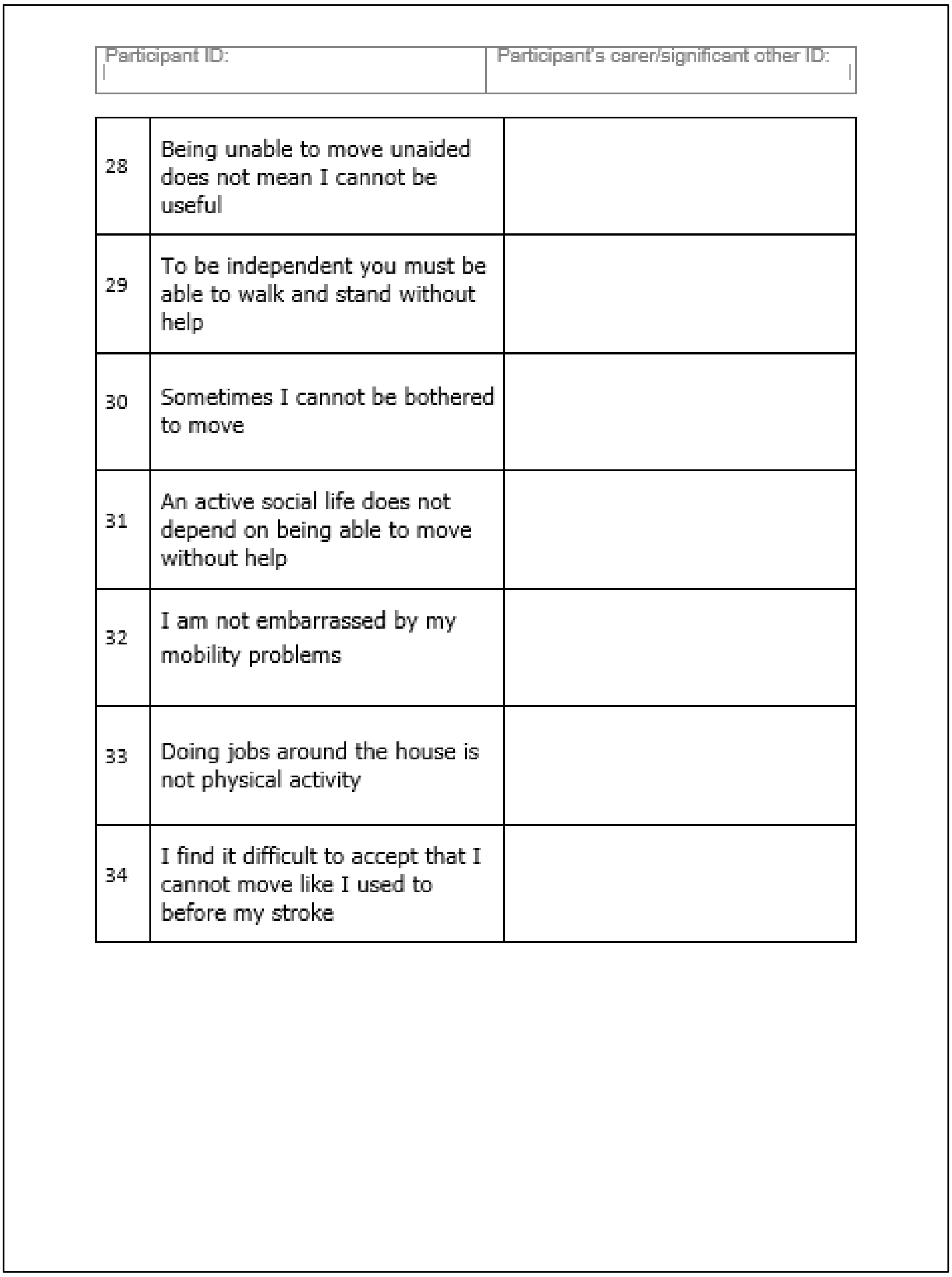
Participant ID:	Participant's carer/significant other ID:

10	My family, friends and carers stop me from moving	
11	I find being able to care for myself difficult because of my physical problems	
12	I have no choice but to sit or lie-down for long periods	
13	Moving regularly helps to improve and maintain physical functioning after stroke	
14	Exercise is important after a stroke	
15	Without family, friends and carers I would not be able to keep active	
16	My lack of confidence affects how much I move	
17	The risk of falling stops me from trying to move	
18	I am a hindrance to my family and friends because I cannot move without assistance	



Participant ID:	Participant's carer/significant other ID:

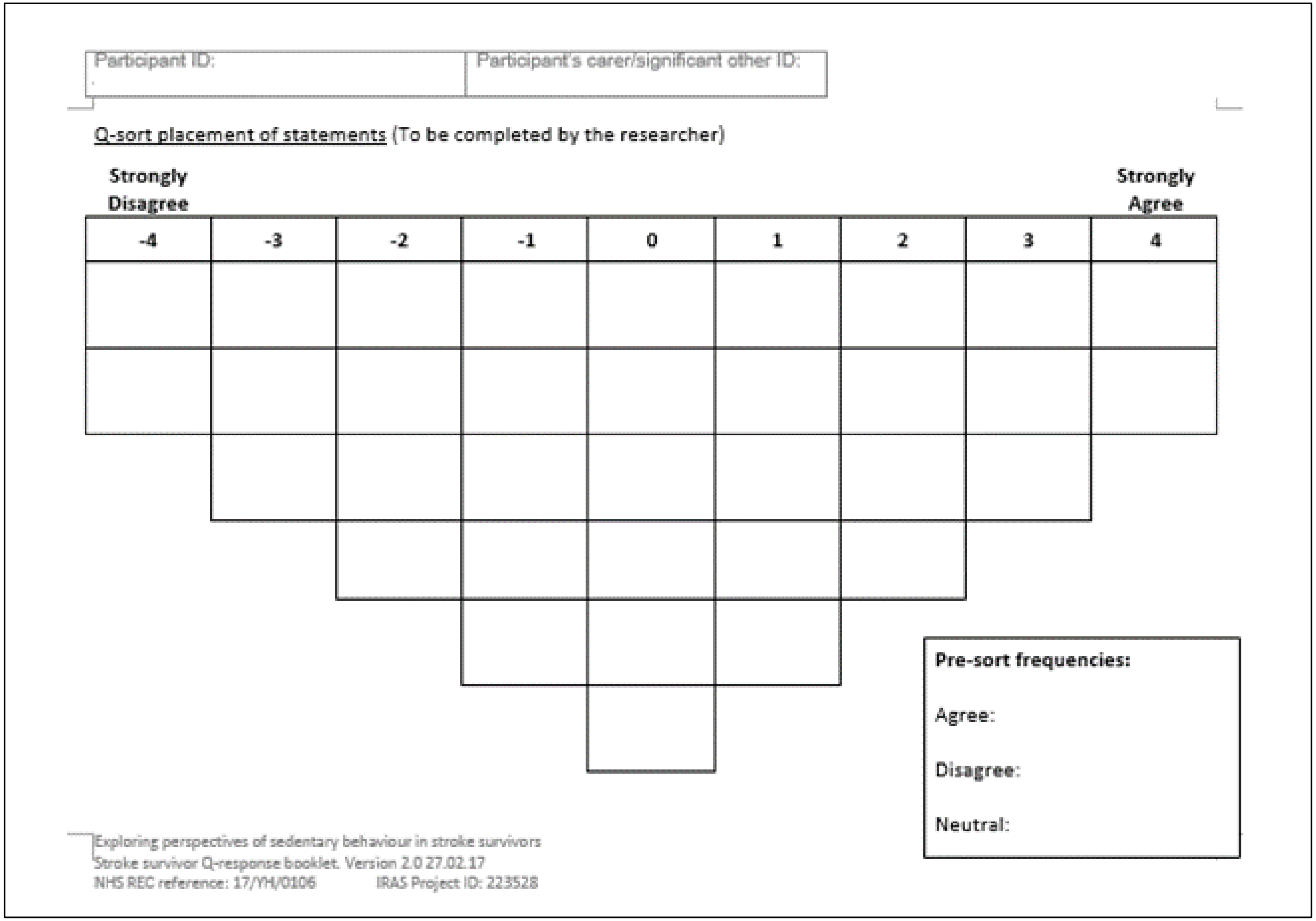
19	I'm happy to sit or lie down without moving	
20	Fatigue limits how much I can move throughout the day	
21	It is important not to spend a long time sitting or lying down without moving	
22	You sometimes have to force yourself to move when you do not have the motivation	
23	Reducing the periods of time I spend just sitting or lying down would make me happier	
24	Practising exercises and tasks is vital to improving mobility and increasing movement	
25	You cannot be physically active if you are not moving your legs	
26	You cannot be healthy if you are inactive	
27	The majority of my free time is spent sitting or lying down without moving	



Participant ID:

Participant's carer/significant other ID:

28	Being unable to move unaided does not mean I cannot be useful	
29	To be independent you must be able to walk and stand without help	
30	Sometimes I cannot be bothered to move	
31	An active social life does not depend on being able to move without help	
32	I am not embarrassed by my mobility problems	
33	Doing jobs around the house is not physical activity	
34	I find it difficult to accept that I cannot move like I used to before my stroke	



Participant ID:

Participant's carer/significant other ID:

Q-sort placement of statements (To be completed by the researcher)

Strongly Disagree								**Strongly Agree**
-4	**-3**	**-2**	**-1**	**0**	**1**	**2**	**3**	**4**

Pre-sort frequencies:

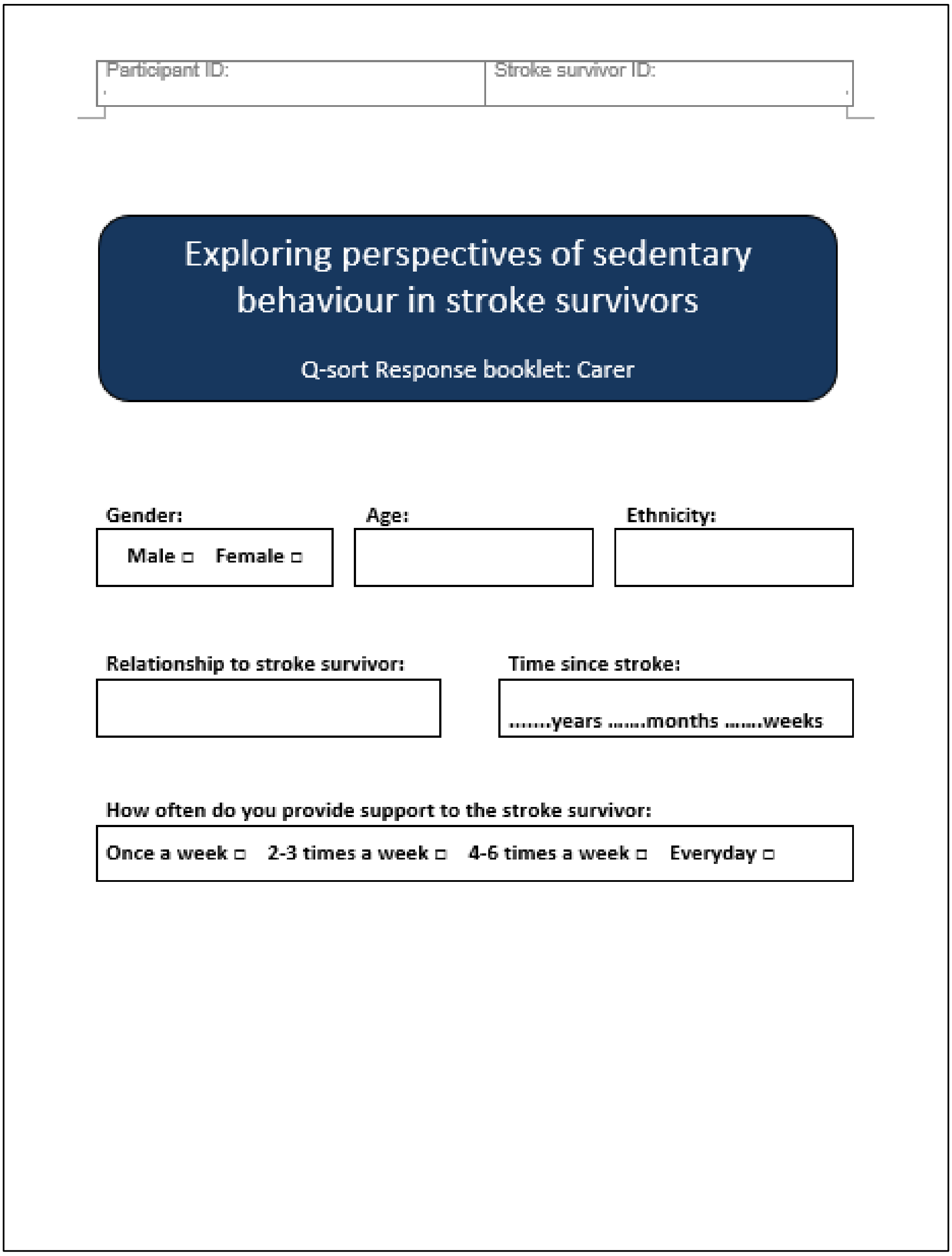
Agree:

Disagree:

Neutral:

Exploring perspectives of sedentary behaviour in stroke survivors
Stroke survivor Q-response booklet. Version 2.0 27.02.17
NHS REC reference: 17/YH/0106 IRAS Project ID: 223528

Appendix K Q-Response Booklet (Carers)



Participant ID:	Stroke survivor ID:

Exploring perspectives of sedentary behaviour in stroke survivors

Q-sort Response booklet: Carer

Gender:
Male ☐ Female ☐

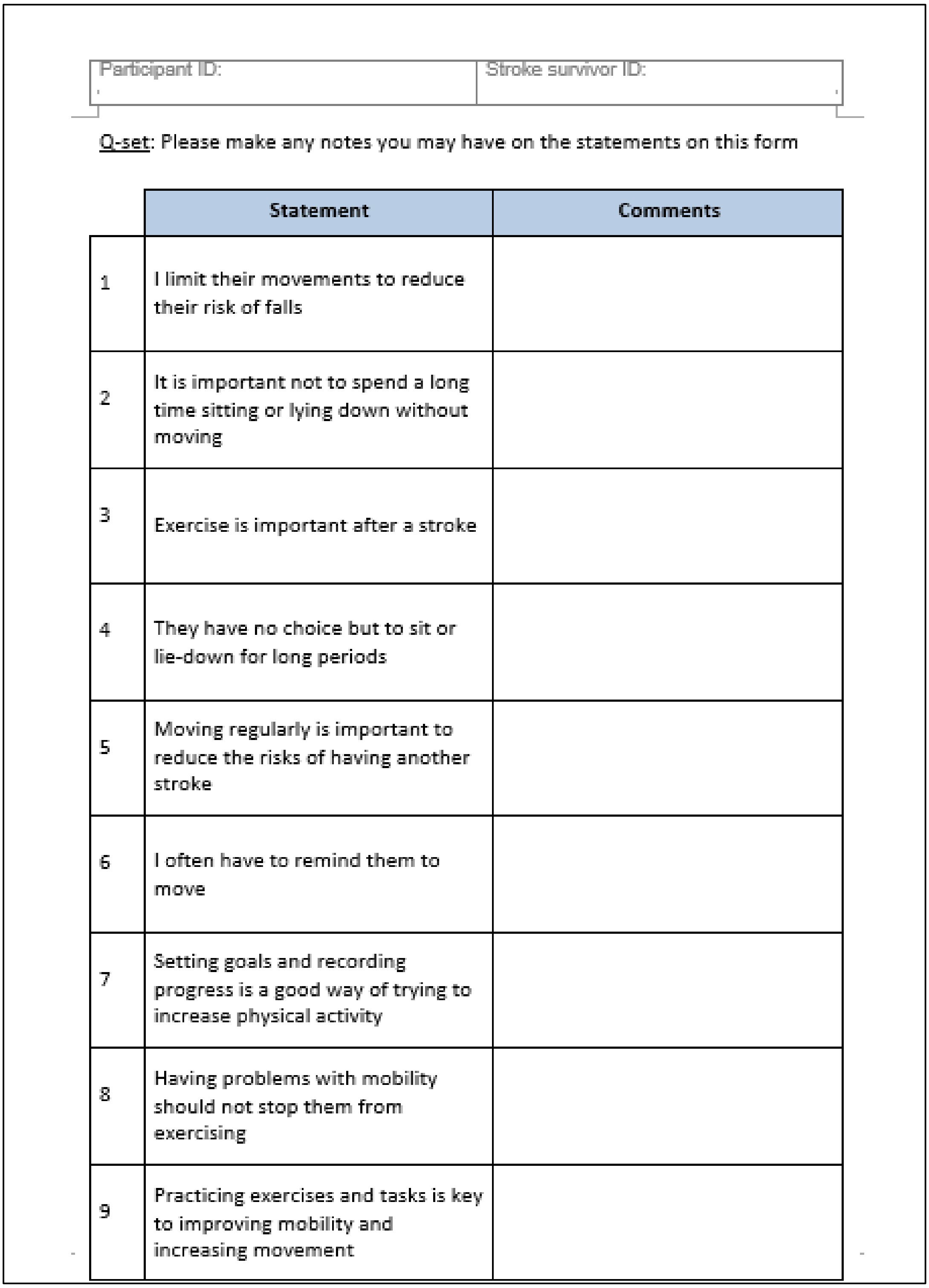
Age:

Ethnicity:

Relationship to stroke survivor:

Time since stroke:
……..years ……..months ……..weeks

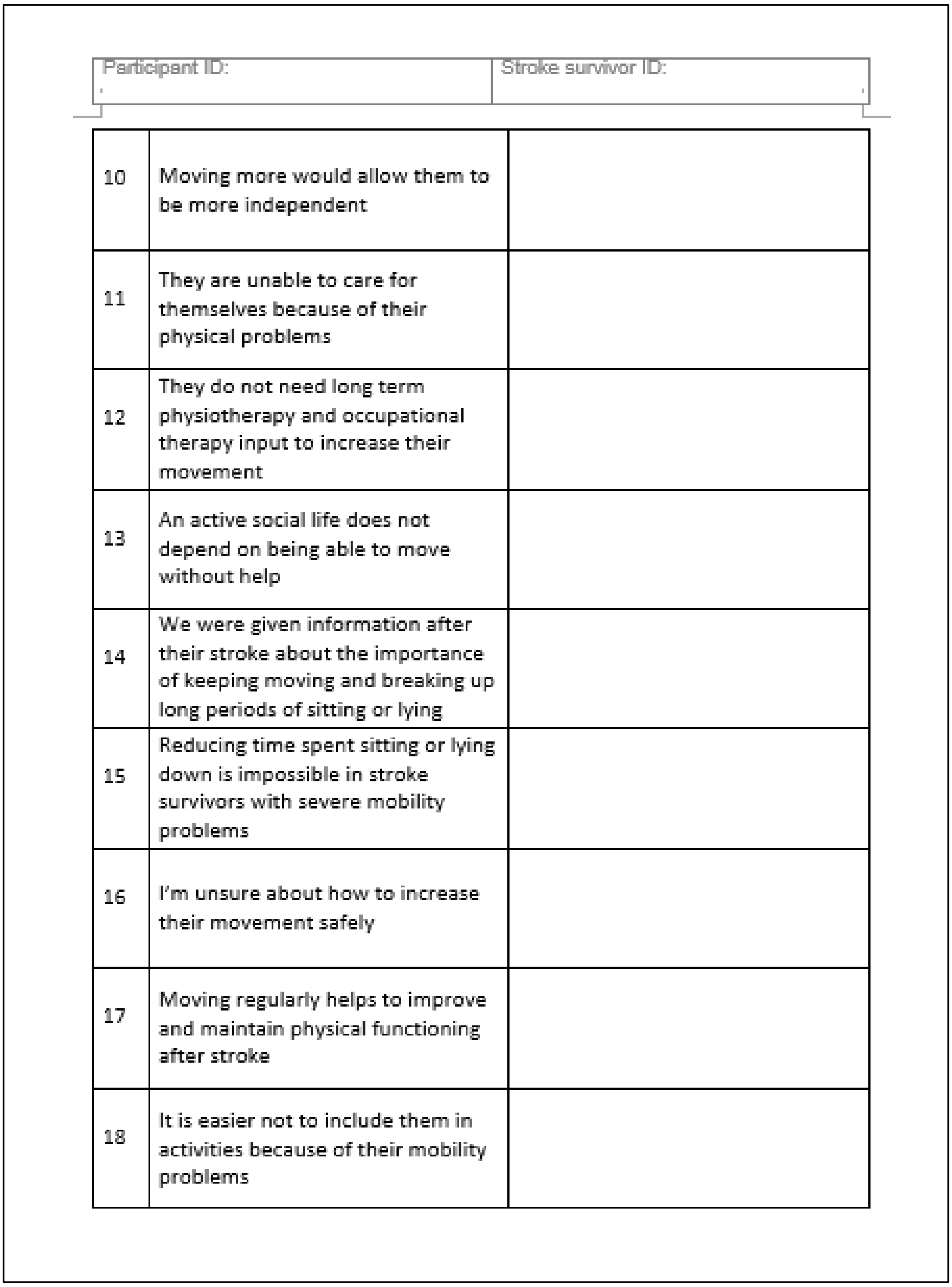
How often do you provide support to the stroke survivor:
Once a week ☐ 2-3 times a week ☐ 4-6 times a week ☐ Everyday ☐



Participant ID:	Stroke survivor ID:

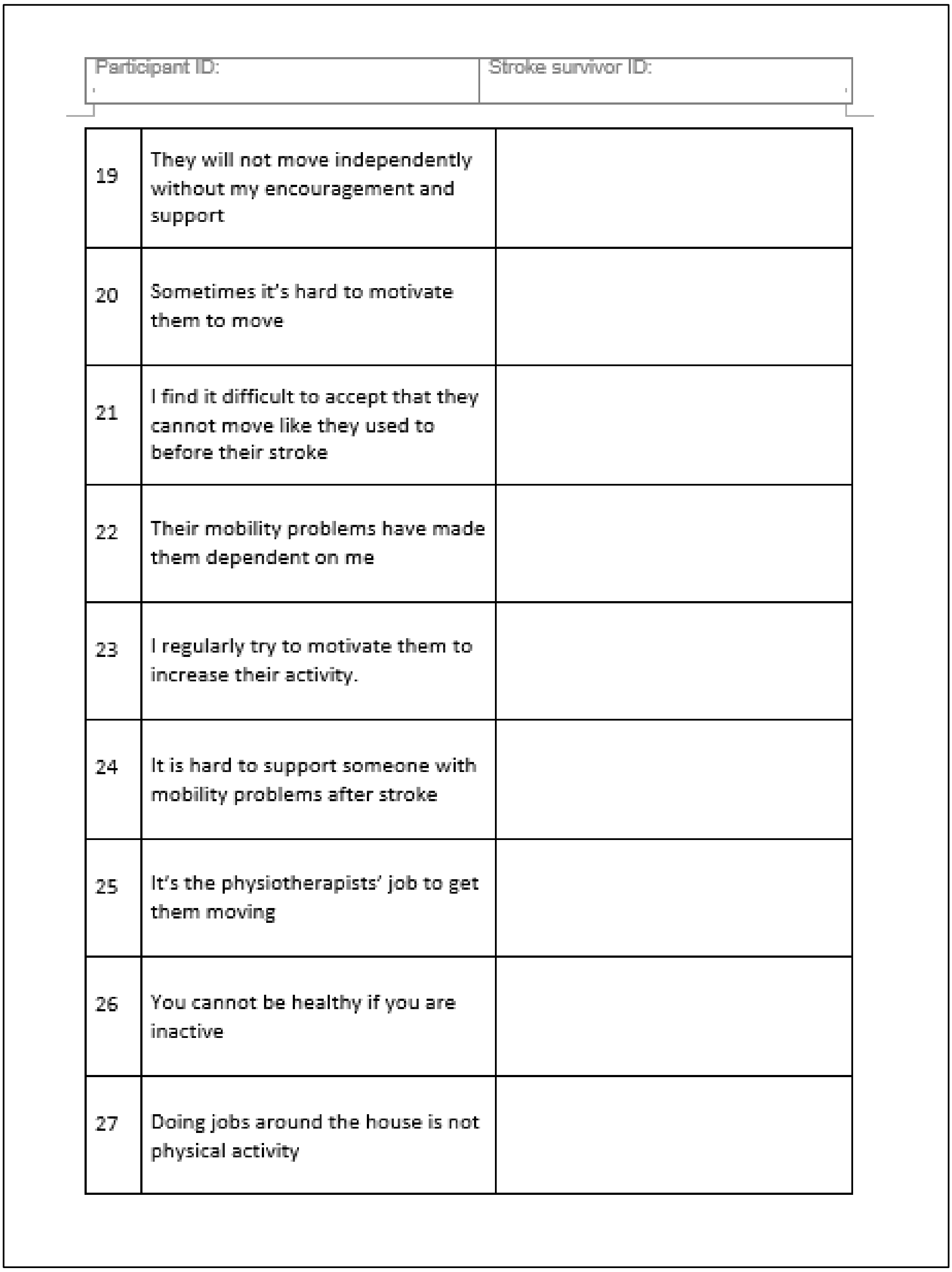
Q-set: Please make any notes you may have on the statements on this form

	Statement	Comments
1	I limit their movements to reduce their risk of falls	
2	It is important not to spend a long time sitting or lying down without moving	
3	Exercise is important after a stroke	
4	They have no choice but to sit or lie-down for long periods	
5	Moving regularly is important to reduce the risks of having another stroke	
6	I often have to remind them to move	
7	Setting goals and recording progress is a good way of trying to increase physical activity	
8	Having problems with mobility should not stop them from exercising	
9	Practicing exercises and tasks is key to improving mobility and increasing movement	



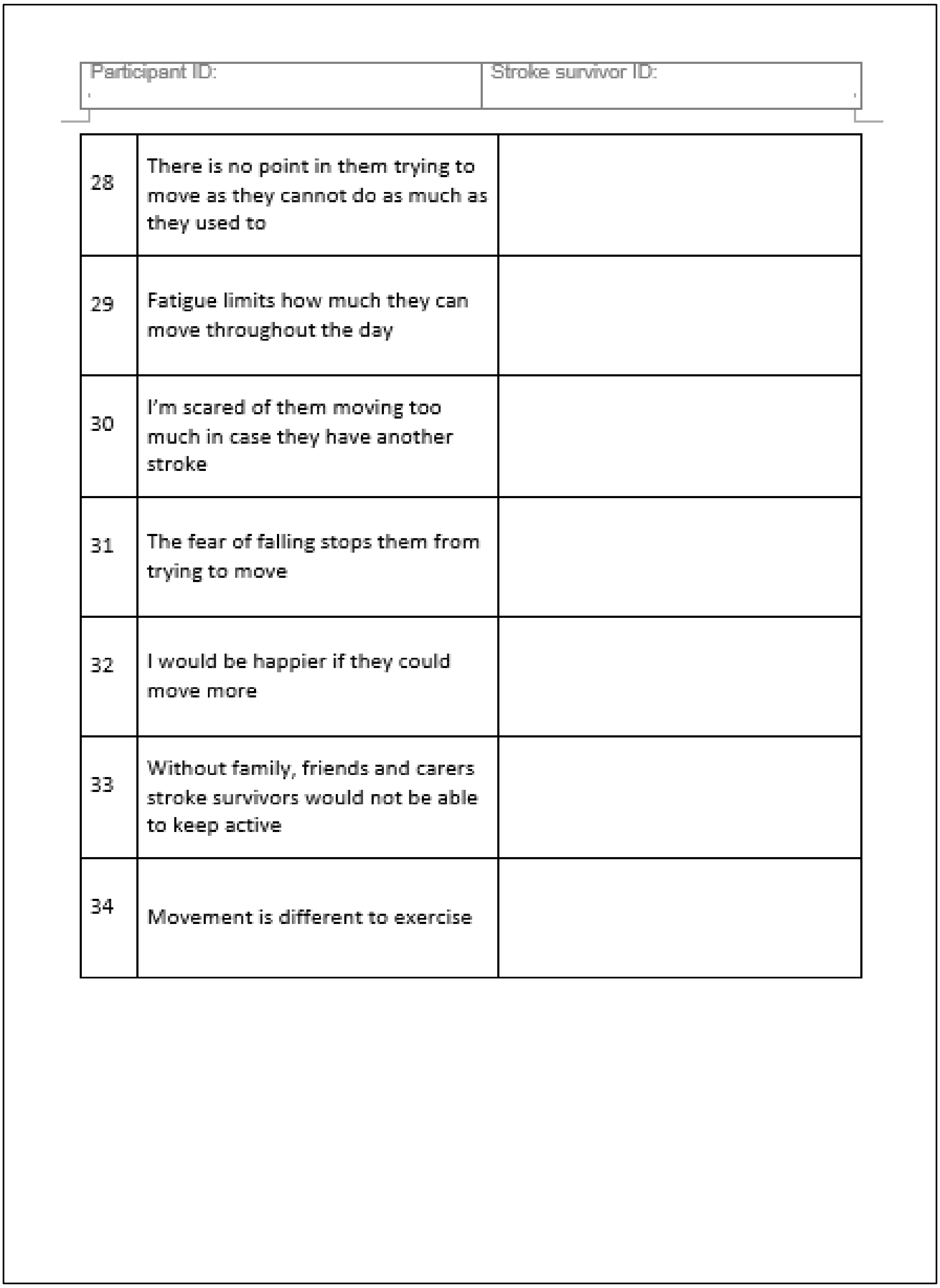
Participant ID:	Stroke survivor ID:

10	Moving more would allow them to be more independent	
11	They are unable to care for themselves because of their physical problems	
12	They do not need long term physiotherapy and occupational therapy input to increase their movement	
13	An active social life does not depend on being able to move without help	
14	We were given information after their stroke about the importance of keeping moving and breaking up long periods of sitting or lying	
15	Reducing time spent sitting or lying down is impossible in stroke survivors with severe mobility problems	
16	I'm unsure about how to increase their movement safely	
17	Moving regularly helps to improve and maintain physical functioning after stroke	
18	It is easier not to include them in activities because of their mobility problems	



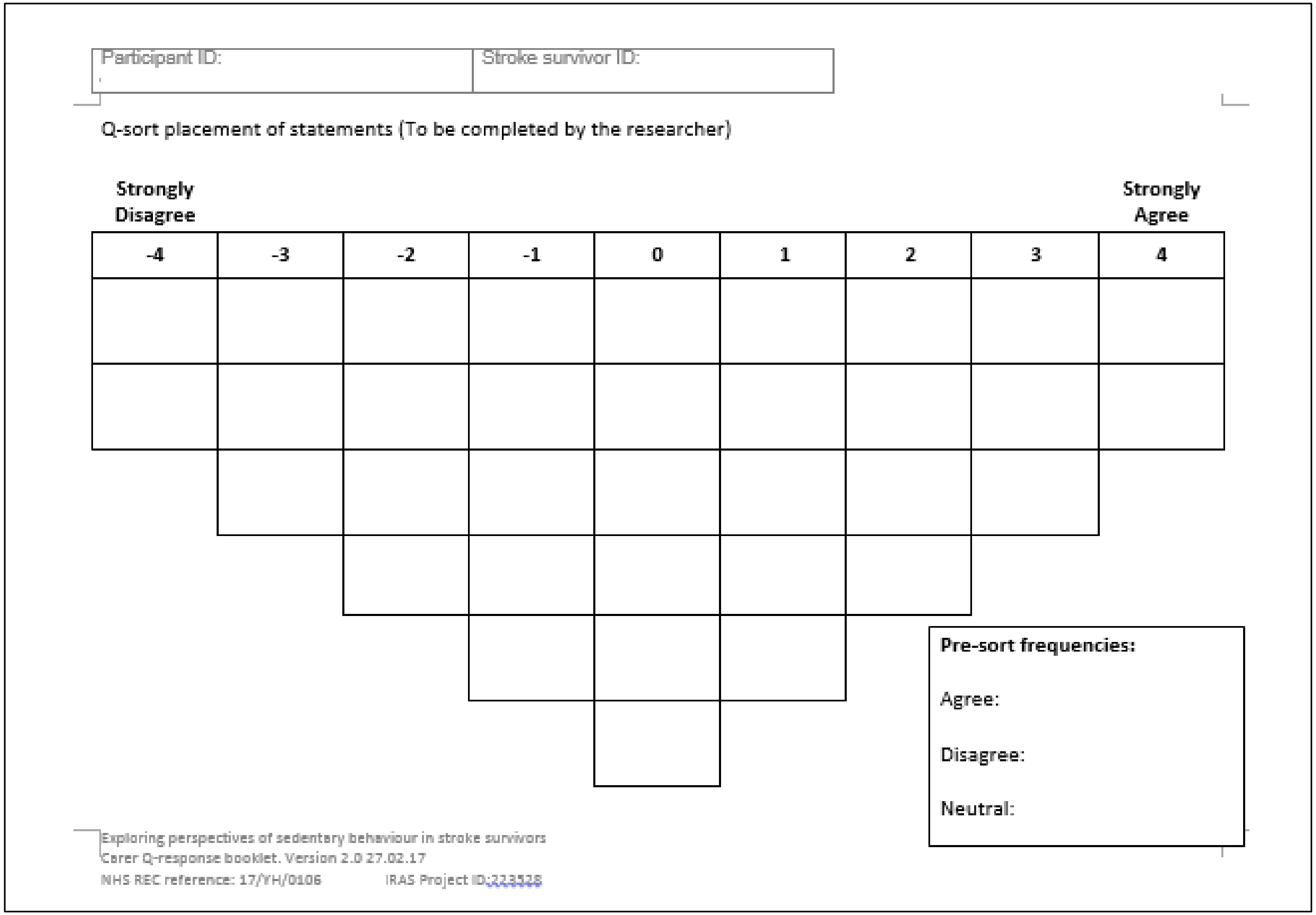
Participant ID:	Stroke survivor ID:

19	They will not move independently without my encouragement and support	
20	Sometimes it's hard to motivate them to move	
21	I find it difficult to accept that they cannot move like they used to before their stroke	
22	Their mobility problems have made them dependent on me	
23	I regularly try to motivate them to increase their activity.	
24	It is hard to support someone with mobility problems after stroke	
25	It's the physiotherapists' job to get them moving	
26	You cannot be healthy if you are inactive	
27	Doing jobs around the house is not physical activity	



Participant ID:	Stroke survivor ID:

28	There is no point in them trying to move as they cannot do as much as they used to	
29	Fatigue limits how much they can move throughout the day	
30	I'm scared of them moving too much in case they have another stroke	
31	The fear of falling stops them from trying to move	
32	I would be happier if they could move more	
33	Without family, friends and carers stroke survivors would not be able to keep active	
34	Movement is different to exercise	



Participant ID:	Stroke survivor ID:

Q-sort placement of statements (To be completed by the researcher)

Strongly Disagree **-4**	**-3**	**-2**	**-1**	**0**	**1**	**2**	**3**	**Strongly Agree** **4**

Pre-sort frequencies:

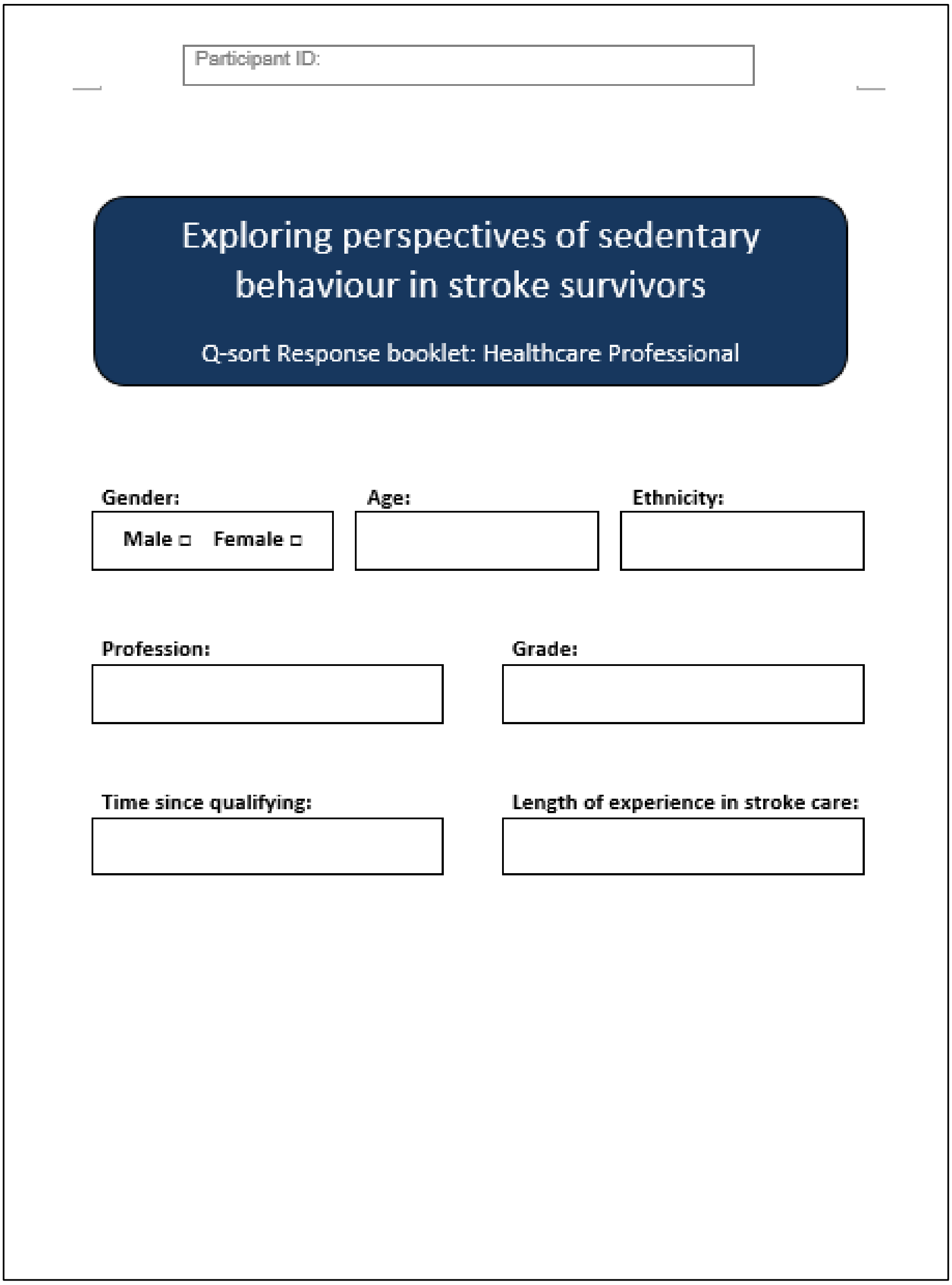
Agree:

Disagree:

Neutral:

Exploring perspectives of sedentary behaviour in stroke survivors
Carer Q-response booklet. Version 2.0 27.02.17
NHS REC reference: 17/YH/0106 IRAS Project ID:223528

Appendix L Q-Response Booklets (Healthcare Professional)



Participant ID:

Exploring perspectives of sedentary behaviour in stroke survivors

Q-sort Response booklet: Healthcare Professional

Gender: Male ☐ Female ☐

Age:

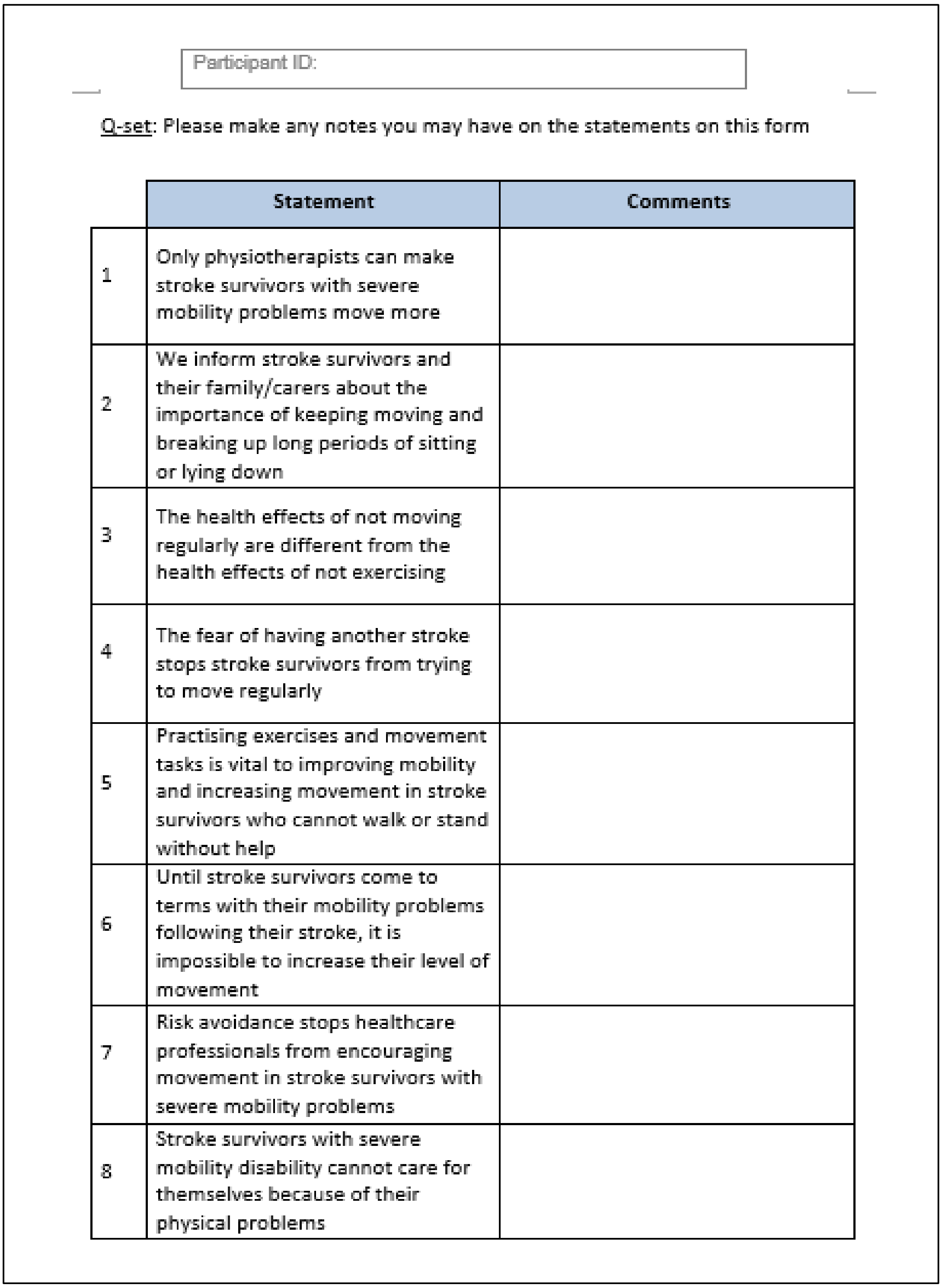
Ethnicity:

Profession:

Grade:

Time since qualifying:

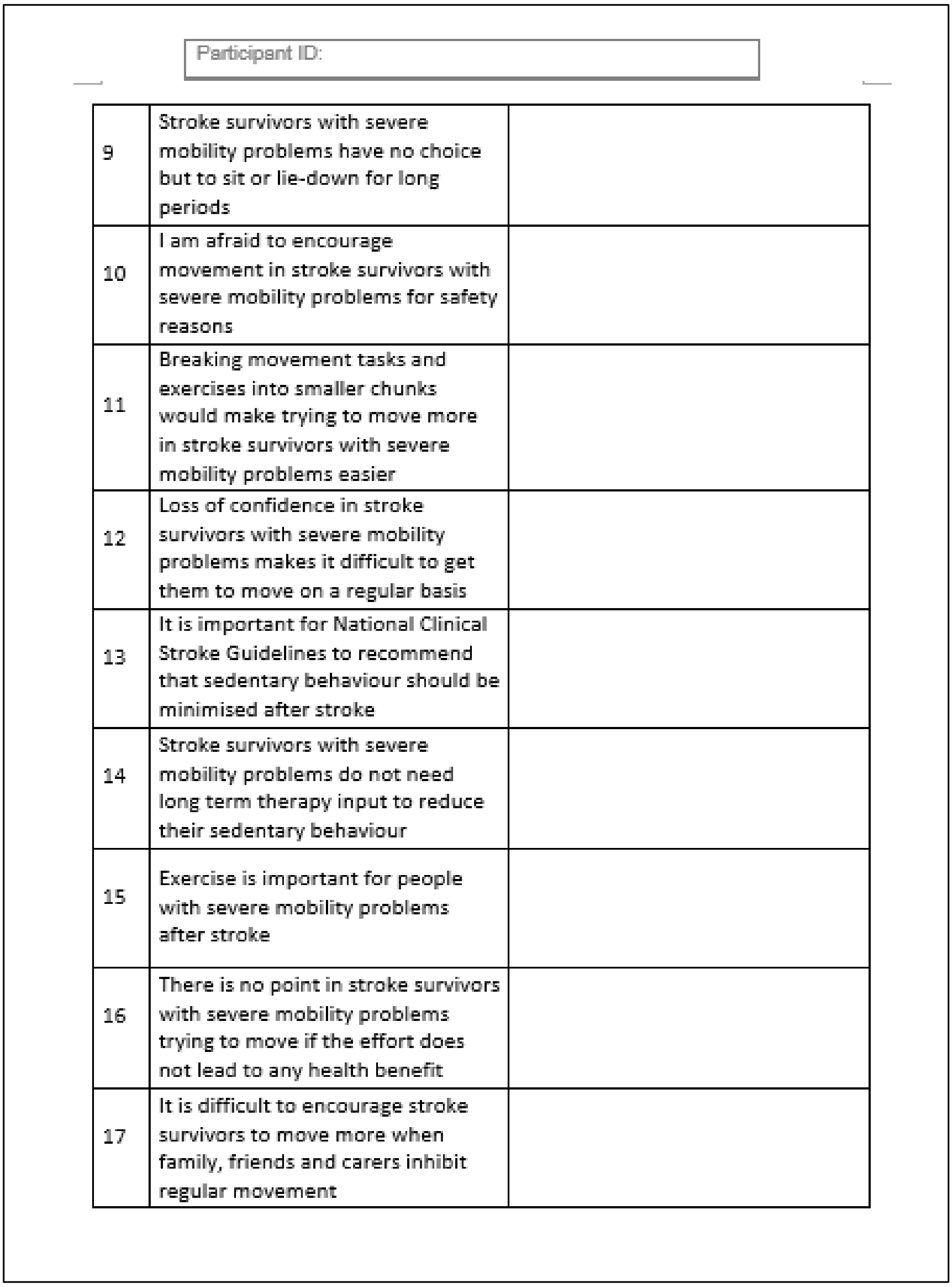
Length of experience in stroke care:



Participant ID:

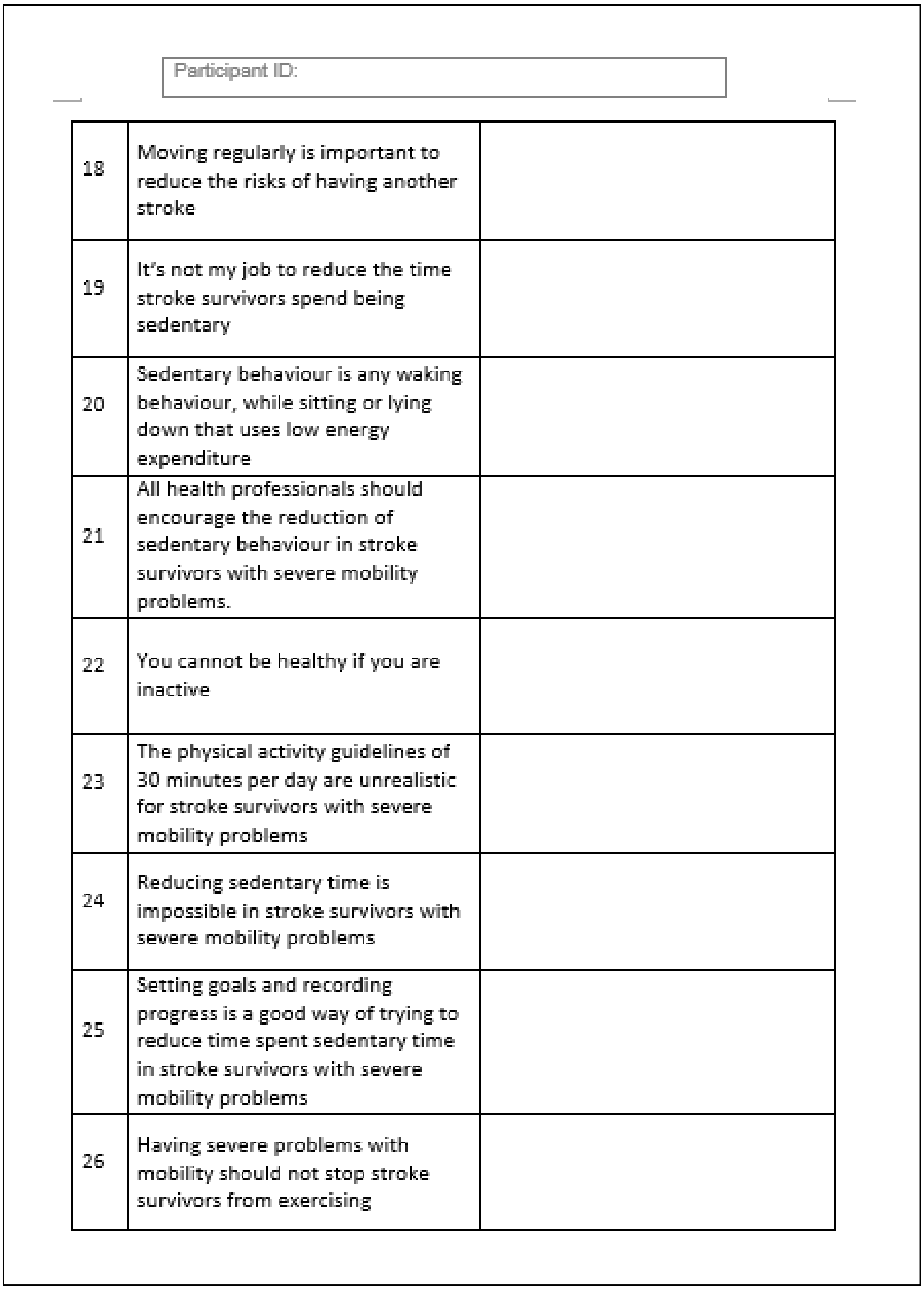
Q-set: Please make any notes you may have on the statements on this form

	Statement	Comments
1	Only physiotherapists can make stroke survivors with severe mobility problems move more	
2	We inform stroke survivors and their family/carers about the importance of keeping moving and breaking up long periods of sitting or lying down	
3	The health effects of not moving regularly are different from the health effects of not exercising	
4	The fear of having another stroke stops stroke survivors from trying to move regularly	
5	Practising exercises and movement tasks is vital to improving mobility and increasing movement in stroke survivors who cannot walk or stand without help	
6	Until stroke survivors come to terms with their mobility problems following their stroke, it is impossible to increase their level of movement	
7	Risk avoidance stops healthcare professionals from encouraging movement in stroke survivors with severe mobility problems	
8	Stroke survivors with severe mobility disability cannot care for themselves because of their physical problems	



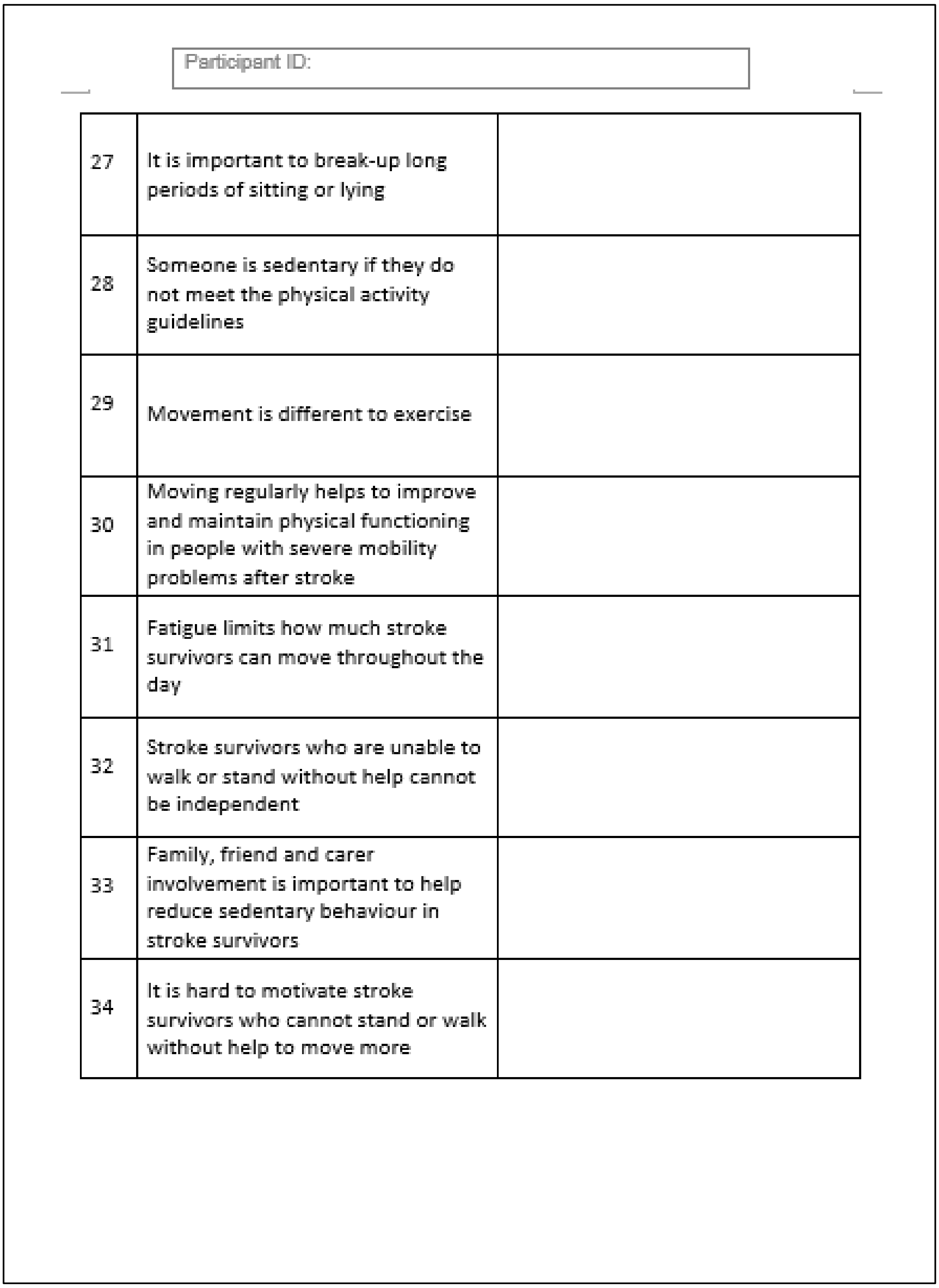
Participant ID:

9	Stroke survivors with severe mobility problems have no choice but to sit or lie-down for long periods	
10	I am afraid to encourage movement in stroke survivors with severe mobility problems for safety reasons	
11	Breaking movement tasks and exercises into smaller chunks would make trying to move more in stroke survivors with severe mobility problems easier	
12	Loss of confidence in stroke survivors with severe mobility problems makes it difficult to get them to move on a regular basis	
13	It is important for National Clinical Stroke Guidelines to recommend that sedentary behaviour should be minimised after stroke	
14	Stroke survivors with severe mobility problems do not need long term therapy input to reduce their sedentary behaviour	
15	Exercise is important for people with severe mobility problems after stroke	
16	There is no point in stroke survivors with severe mobility problems trying to move if the effort does not lead to any health benefit	
17	It is difficult to encourage stroke survivors to move more when family, friends and carers inhibit regular movement	



Participant ID:

18	Moving regularly is important to reduce the risks of having another stroke	
19	It’s not my job to reduce the time stroke survivors spend being sedentary	
20	Sedentary behaviour is any waking behaviour, while sitting or lying down that uses low energy expenditure	
21	All health professionals should encourage the reduction of sedentary behaviour in stroke survivors with severe mobility problems.	
22	You cannot be healthy if you are inactive	
23	The physical activity guidelines of 30 minutes per day are unrealistic for stroke survivors with severe mobility problems	
24	Reducing sedentary time is impossible in stroke survivors with severe mobility problems	
25	Setting goals and recording progress is a good way of trying to reduce time spent sedentary time in stroke survivors with severe mobility problems	
26	Having severe problems with mobility should not stop stroke survivors from exercising	



Participant ID:

27	It is important to break-up long periods of sitting or lying	
28	Someone is sedentary if they do not meet the physical activity guidelines	
29	Movement is different to exercise	
30	Moving regularly helps to improve and maintain physical functioning in people with severe mobility problems after stroke	
31	Fatigue limits how much stroke survivors can move throughout the day	
32	Stroke survivors who are unable to walk or stand without help cannot be independent	
33	Family, friend and carer involvement is important to help reduce sedentary behaviour in stroke survivors	
34	It is hard to motivate stroke survivors who cannot stand or walk without help to move more	

Participant ID:

Q-sort placement of statements (To be completed by the researcher)

Strongly Disagree **-4**	**-3**	**-2**	**-1**	**0**	**1**	**2**	**3**	**Strongly Agree** **4**

Pre-sort frequencies:

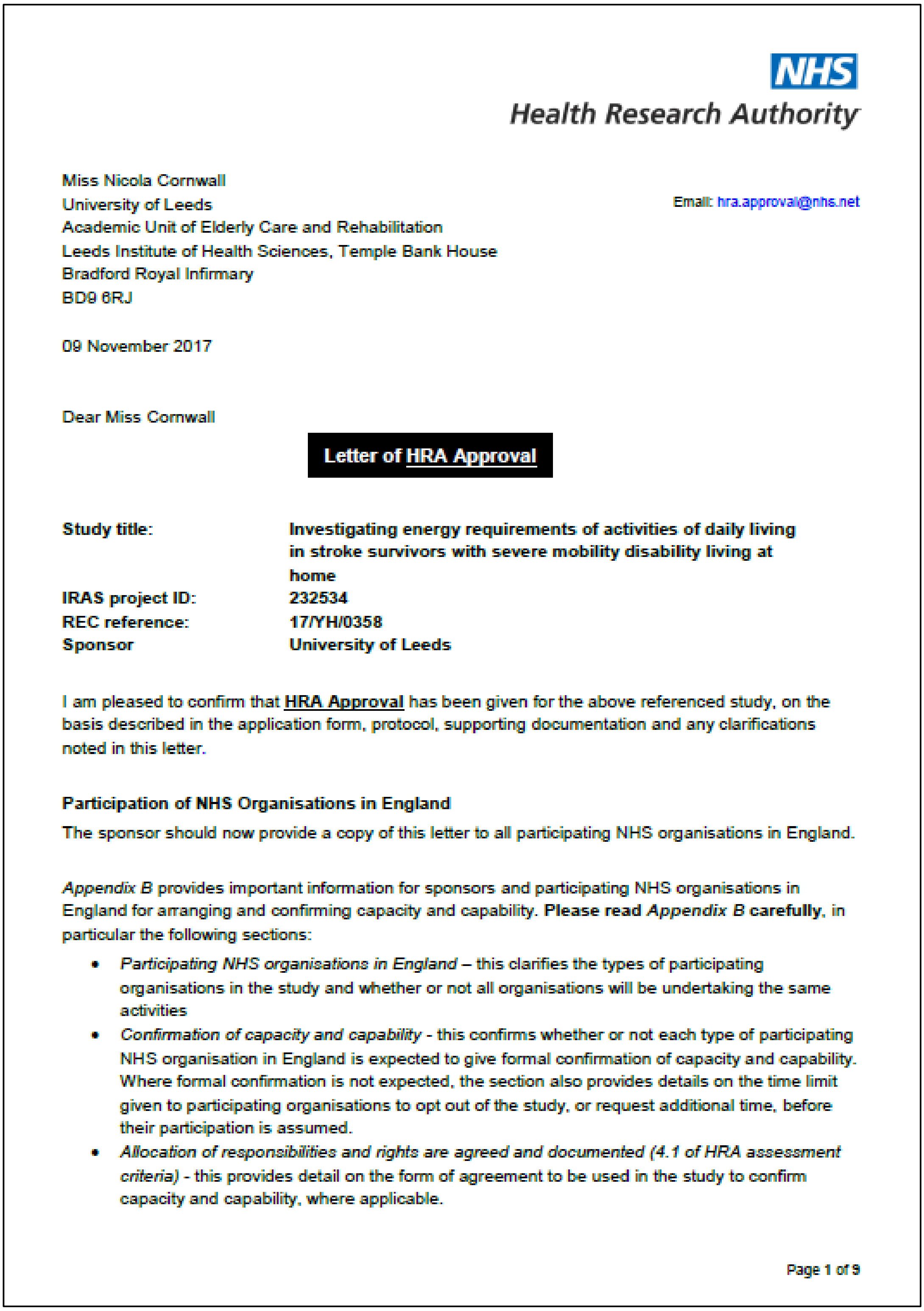
Agree:

Disagree:

Neutral:

Appendix M Letter of HRA Approval – Energy Study

Please note a non-substantial amendment was submitted for review to extend the recruitment period (Amendment date: 23/04/18).



NHS
Health Research Authority

Miss Nicola Cornwall
University of Leeds
Academic Unit of Elderly Care and Rehabilitation
Leeds Institute of Health Sciences, Temple Bank House
Bradford Royal Infirmary
BD9 6RJ

Email: hra.approval@nhs.net

09 November 2017

Dear Miss Cornwall

Letter of HRA Approval

Study title:	**Investigating energy requirements of activities of daily living in stroke survivors with severe mobility disability living at home**
IRAS project ID:	**232534**
REC reference:	**17/YH/0358**
Sponsor	**University of Leeds**

I am pleased to confirm that HRA Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

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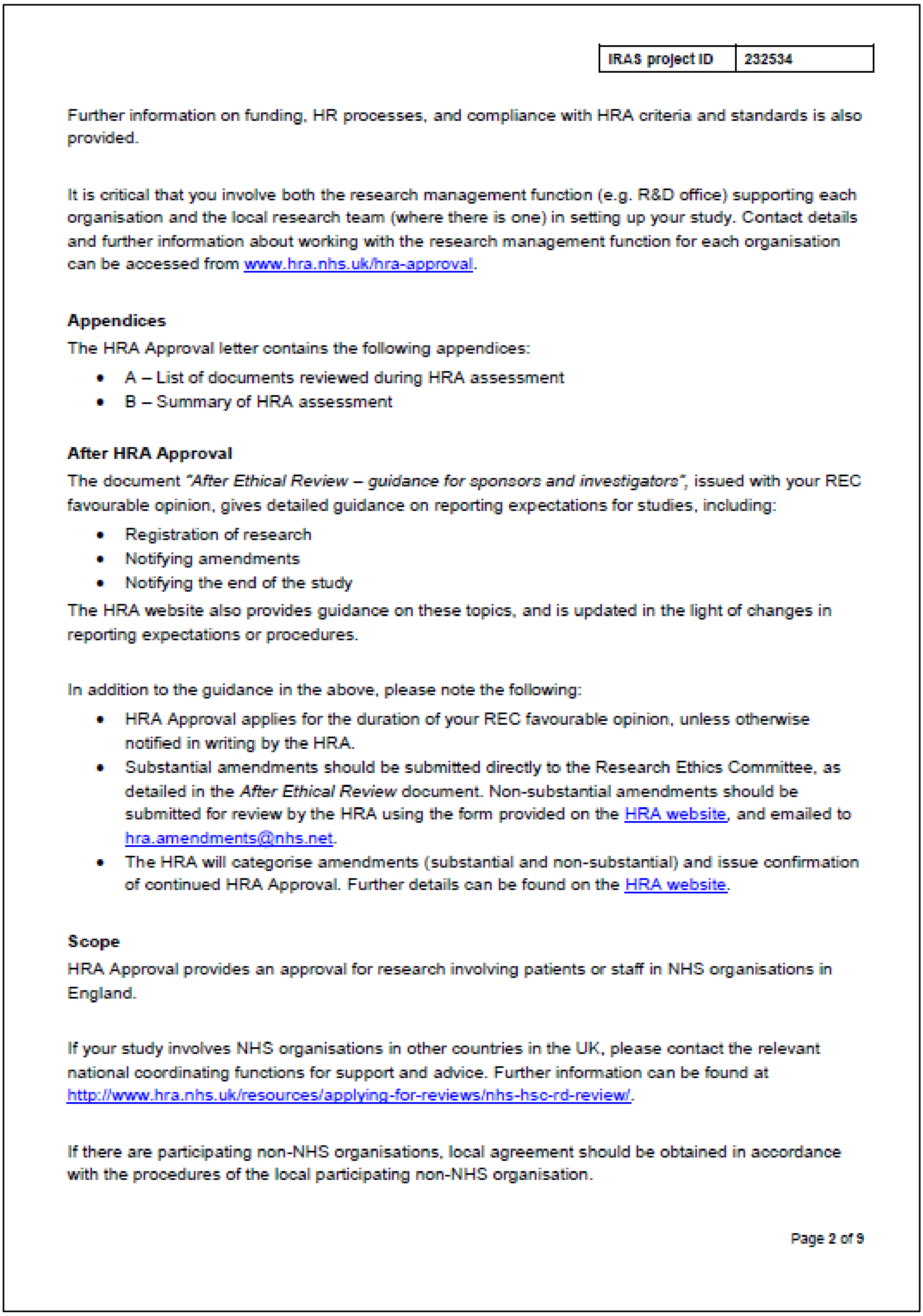


Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from www.hra.nhs.uk/hra-approval.

Appendices

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

After HRA Approval

The document *"After Ethical Review – guidance for sponsors and investigators"*, issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

In addition to the guidance in the above, please note the following:

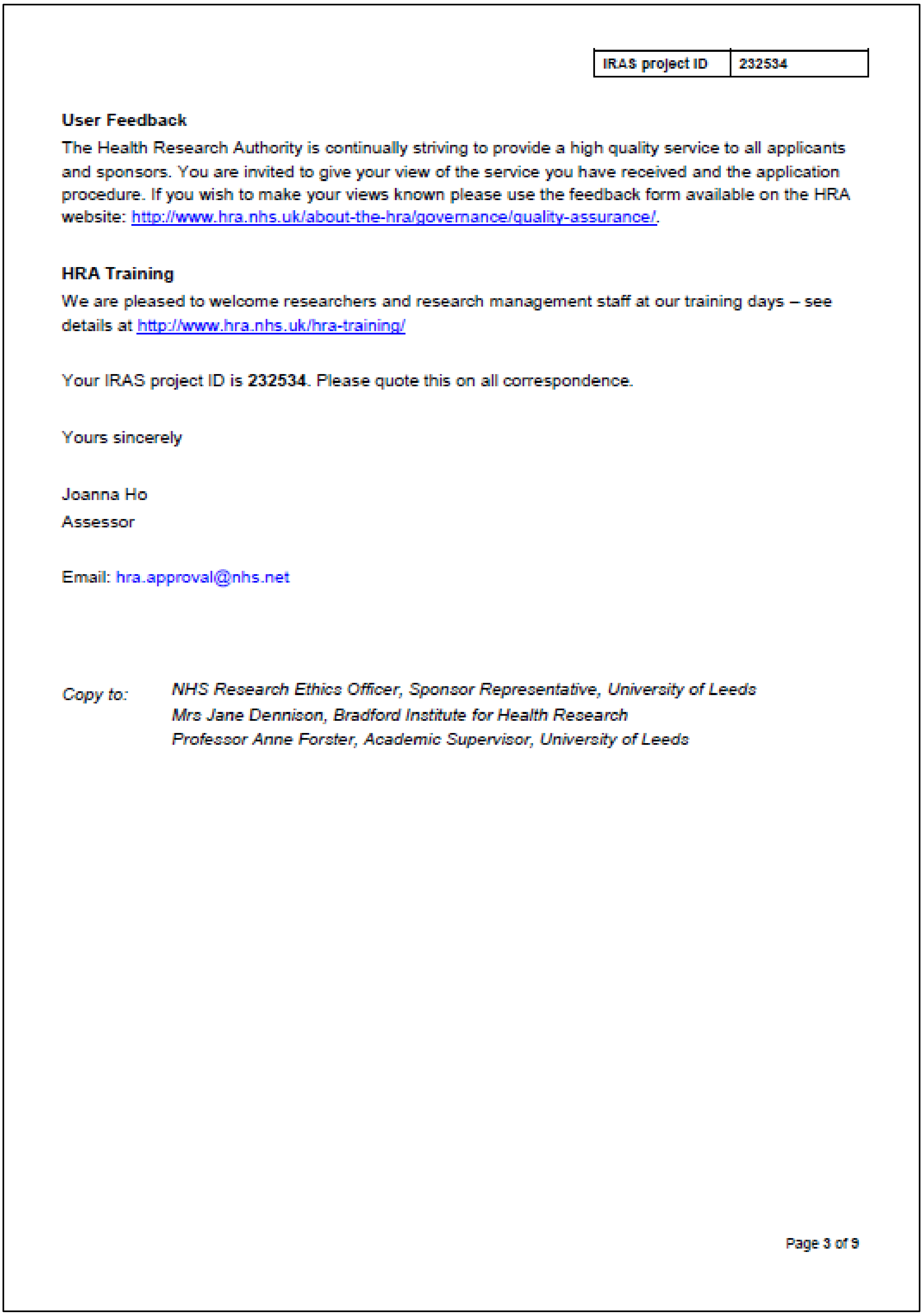
- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the HRA website, and emailed to hra.amendments@nhs.net.
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the HRA website.

Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.



User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/.

HRA Training

We are pleased to welcome researchers and research management staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

Your IRAS project ID is **232534**. Please quote this on all correspondence.

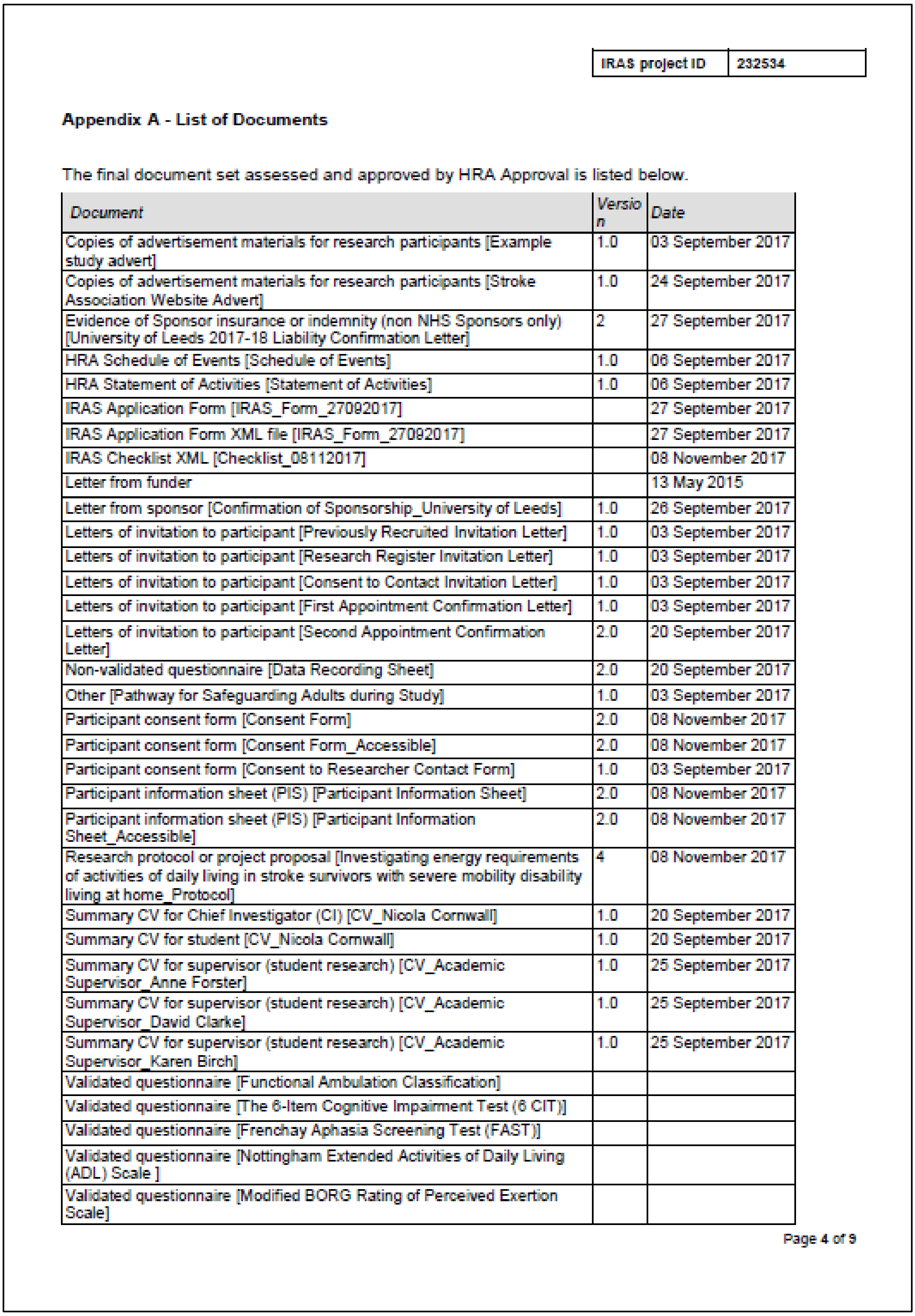
Yours sincerely

Joanna Ho
Assessor

Email: hra.approval@nhs.net

Copy to:

NHS Research Ethics Officer, Sponsor Representative, University of Leeds
Mrs Jane Dennison, Bradford Institute for Health Research
Professor Anne Forster, Academic Supervisor, University of Leeds



IRAS project ID	232534

Appendix A - List of Documents

The final document set assessed and approved by HRA Approval is listed below.

Document	*Version*	*Date*
Copies of advertisement materials for research participants [Example study advert]	1.0	03 September 2017
Copies of advertisement materials for research participants [Stroke Association Website Advert]	1.0	24 September 2017
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [University of Leeds 2017-18 Liability Confirmation Letter]	2	27 September 2017
HRA Schedule of Events [Schedule of Events]	1.0	06 September 2017
HRA Statement of Activities [Statement of Activities]	1.0	06 September 2017
IRAS Application Form [IRAS_Form_27092017]		27 September 2017
IRAS Application Form XML file [IRAS_Form_27092017]		27 September 2017
IRAS Checklist XML [Checklist_08112017]		08 November 2017
Letter from funder		13 May 2015
Letter from sponsor [Confirmation of Sponsorship_University of Leeds]	1.0	26 September 2017
Letters of invitation to participant [Previously Recruited Invitation Letter]	1.0	03 September 2017
Letters of invitation to participant [Research Register Invitation Letter]	1.0	03 September 2017
Letters of invitation to participant [Consent to Contact Invitation Letter]	1.0	03 September 2017
Letters of invitation to participant [First Appointment Confirmation Letter]	1.0	03 September 2017
Letters of invitation to participant [Second Appointment Confirmation Letter]	2.0	20 September 2017
Non-validated questionnaire [Data Recording Sheet]	2.0	20 September 2017
Other [Pathway for Safeguarding Adults during Study]	1.0	03 September 2017
Participant consent form [Consent Form]	2.0	08 November 2017
Participant consent form [Consent Form_Accessible]	2.0	08 November 2017
Participant consent form [Consent to Researcher Contact Form]	1.0	03 September 2017
Participant information sheet (PIS) [Participant Information Sheet]	2.0	08 November 2017
Participant information sheet (PIS) [Participant Information Sheet_Accessible]	2.0	08 November 2017
Research protocol or project proposal [Investigating energy requirements of activities of daily living in stroke survivors with severe mobility disability living at home_Protocol]	4	08 November 2017
Summary CV for Chief Investigator (CI) [CV_Nicola Cornwall]	1.0	20 September 2017
Summary CV for student [CV_Nicola Cornwall]	1.0	20 September 2017
Summary CV for supervisor (student research) [CV_Academic Supervisor_Anne Forster]	1.0	25 September 2017
Summary CV for supervisor (student research) [CV_Academic Supervisor_David Clarke]	1.0	25 September 2017
Summary CV for supervisor (student research) [CV_Academic Supervisor_Karen Birch]	1.0	25 September 2017
Validated questionnaire [Functional Ambulation Classification]		
Validated questionnaire [The 6-Item Cognitive Impairment Test (6 CIT)]		
Validated questionnaire [Frenchay Aphasia Screening Test (FAST)]		
Validated questionnaire [Nottingham Extended Activities of Daily Living (ADL) Scale]		
Validated questionnaire [Modified BORG Rating of Perceived Exertion Scale]		

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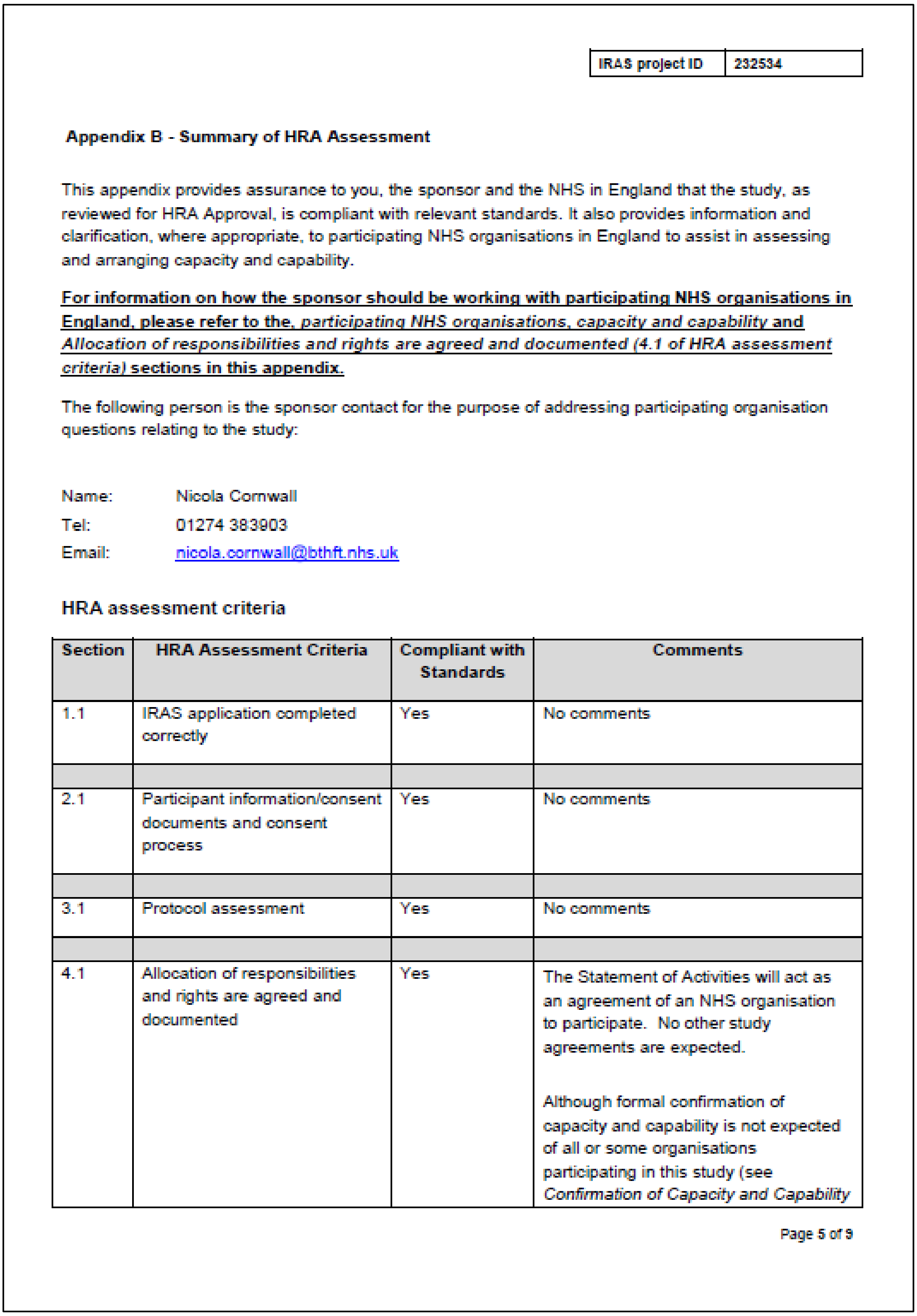


IRAS project ID	232534

Appendix B - Summary of HRA Assessment

This appendix provides assurance to you, the sponsor and the NHS in England that the study, as reviewed for HRA Approval, is compliant with relevant standards. It also provides information and clarification, where appropriate, to participating NHS organisations in England to assist in assessing and arranging capacity and capability.

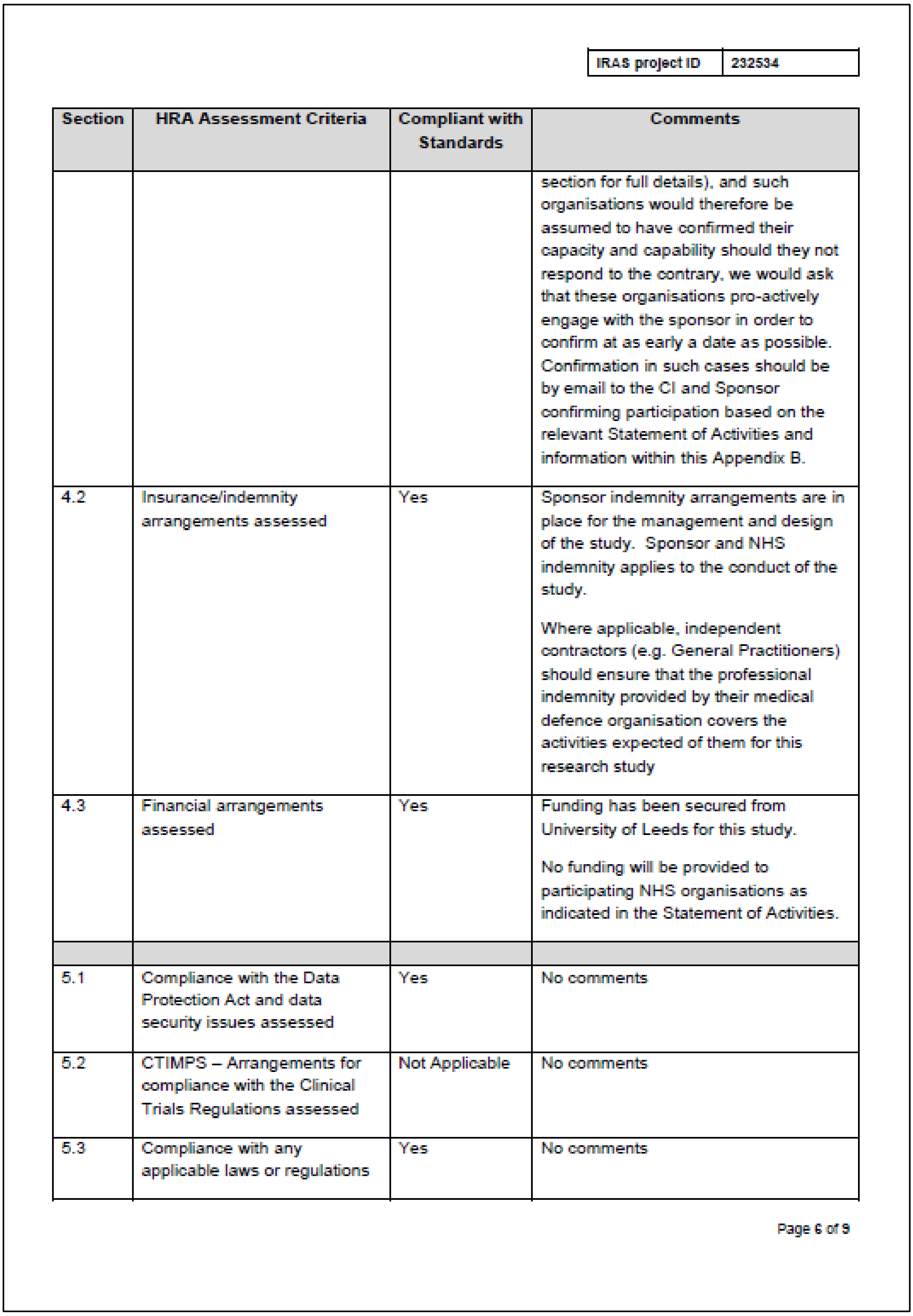
For information on how the sponsor should be working with participating NHS organisations in England, please refer to the, *participating NHS organisations, capacity and capability* and *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* sections in this appendix.

The following person is the sponsor contact for the purpose of addressing participating organisation questions relating to the study:

Name: Nicola Cornwall
Tel: 01274 383903
Email: nicola.cornwall@bthft.nhs.uk

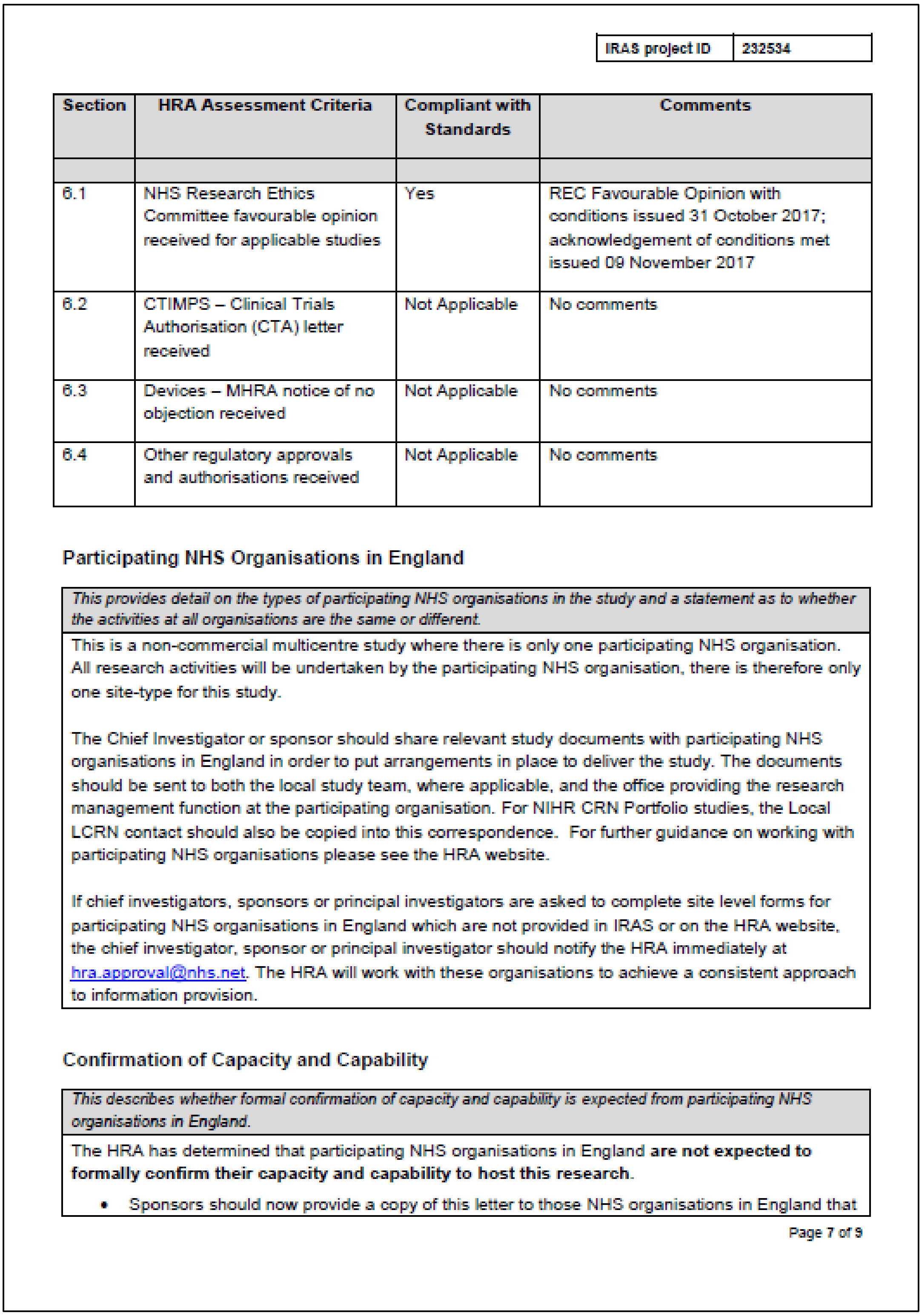
HRA assessment criteria

Section	HRA Assessment Criteria	Compliant with Standards	Comments
1.1	IRAS application completed correctly	Yes	No comments
2.1	Participant information/consent documents and consent process	Yes	No comments
3.1	Protocol assessment	Yes	No comments
4.1	Allocation of responsibilities and rights are agreed and documented	Yes	The Statement of Activities will act as an agreement of an NHS organisation to participate. No other study agreements are expected. Although formal confirmation of capacity and capability is not expected of all or some organisations participating in this study (see *Confirmation of Capacity and Capability*



IRAS project ID	232534

Section	HRA Assessment Criteria	Compliant with Standards	Comments
			section for full details), and such organisations would therefore be assumed to have confirmed their capacity and capability should they not respond to the contrary, we would ask that these organisations pro-actively engage with the sponsor in order to confirm at as early a date as possible. Confirmation in such cases should be by email to the CI and Sponsor confirming participation based on the relevant Statement of Activities and information within this Appendix B.
4.2	Insurance/indemnity arrangements assessed	Yes	Sponsor indemnity arrangements are in place for the management and design of the study. Sponsor and NHS indemnity applies to the conduct of the study. Where applicable, independent contractors (e.g. General Practitioners) should ensure that the professional indemnity provided by their medical defence organisation covers the activities expected of them for this research study
4.3	Financial arrangements assessed	Yes	Funding has been secured from University of Leeds for this study. No funding will be provided to participating NHS organisations as indicated in the Statement of Activities.
5.1	Compliance with the Data Protection Act and data security issues assessed	Yes	No comments
5.2	CTIMPS – Arrangements for compliance with the Clinical Trials Regulations assessed	Not Applicable	No comments
5.3	Compliance with any applicable laws or regulations	Yes	No comments



Section	HRA Assessment Criteria	Compliant with Standards	Comments
6.1	NHS Research Ethics Committee favourable opinion received for applicable studies	Yes	REC Favourable Opinion with conditions issued 31 October 2017; acknowledgement of conditions met issued 09 November 2017
6.2	CTIMPS – Clinical Trials Authorisation (CTA) letter received	Not Applicable	No comments
6.3	Devices – MHRA notice of no objection received	Not Applicable	No comments
6.4	Other regulatory approvals and authorisations received	Not Applicable	No comments

Participating NHS Organisations in England

This provides detail on the types of participating NHS organisations in the study and a statement as to whether the activities at all organisations are the same or different.

This is a non-commercial multicentre study where there is only one participating NHS organisation. All research activities will be undertaken by the participating NHS organisation, there is therefore only one site-type for this study.

The Chief Investigator or sponsor should share relevant study documents with participating NHS organisations in England in order to put arrangements in place to deliver the study. The documents should be sent to both the local study team, where applicable, and the office providing the research management function at the participating organisation. For NIHR CRN Portfolio studies, the Local LCRN contact should also be copied into this correspondence. For further guidance on working with participating NHS organisations please see the HRA website.

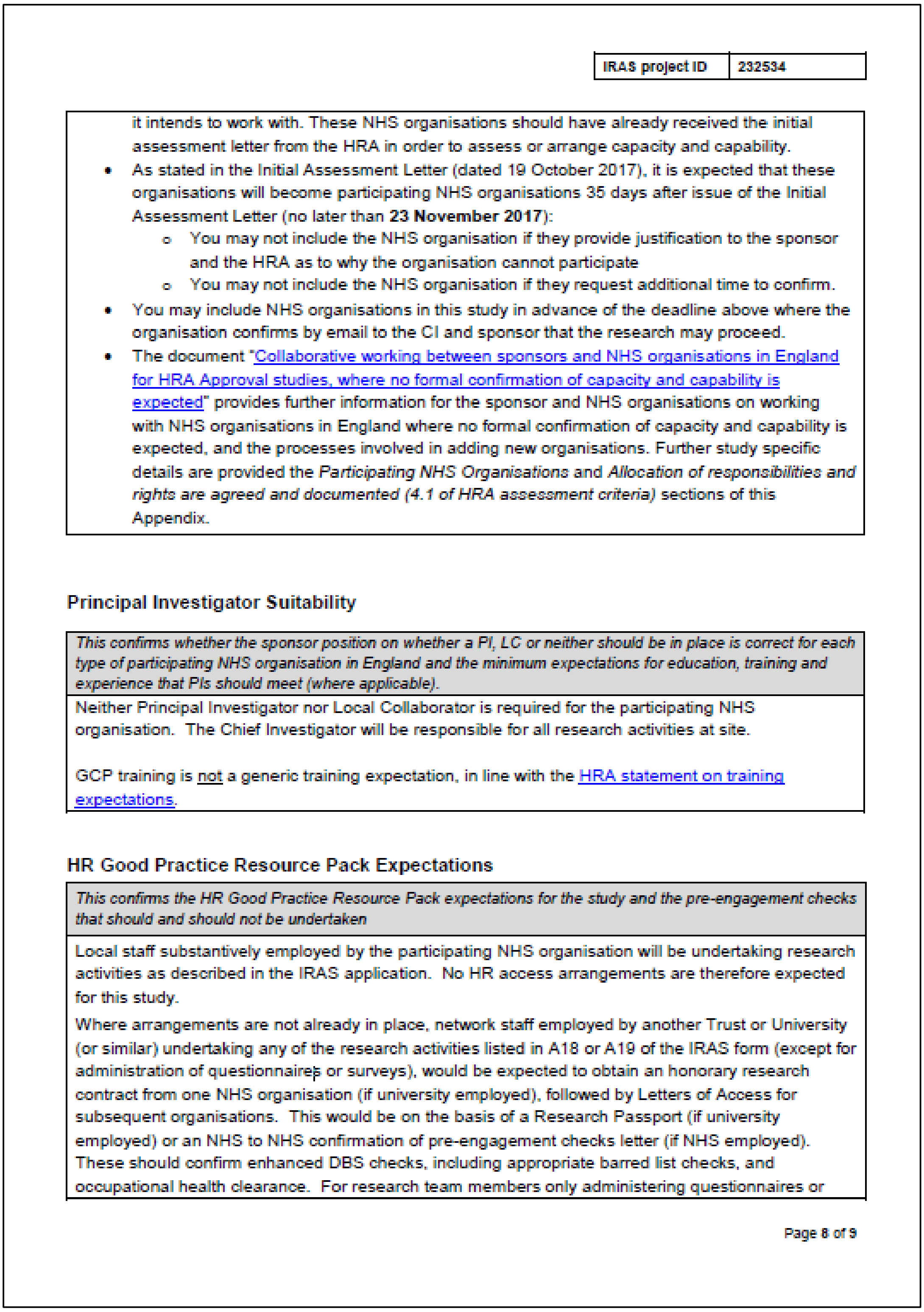
If chief investigators, sponsors or principal investigators are asked to complete site level forms for participating NHS organisations in England which are not provided in IRAS or on the HRA website, the chief investigator, sponsor or principal investigator should notify the HRA immediately at hra.approval@nhs.net. The HRA will work with these organisations to achieve a consistent approach to information provision.

Confirmation of Capacity and Capability

This describes whether formal confirmation of capacity and capability is expected from participating NHS organisations in England.

The HRA has determined that participating NHS organisations in England **are not expected to formally confirm their capacity and capability to host this research.**

- Sponsors should now provide a copy of this letter to those NHS organisations in England that



it intends to work with. These NHS organisations should have already received the initial assessment letter from the HRA in order to assess or arrange capacity and capability.

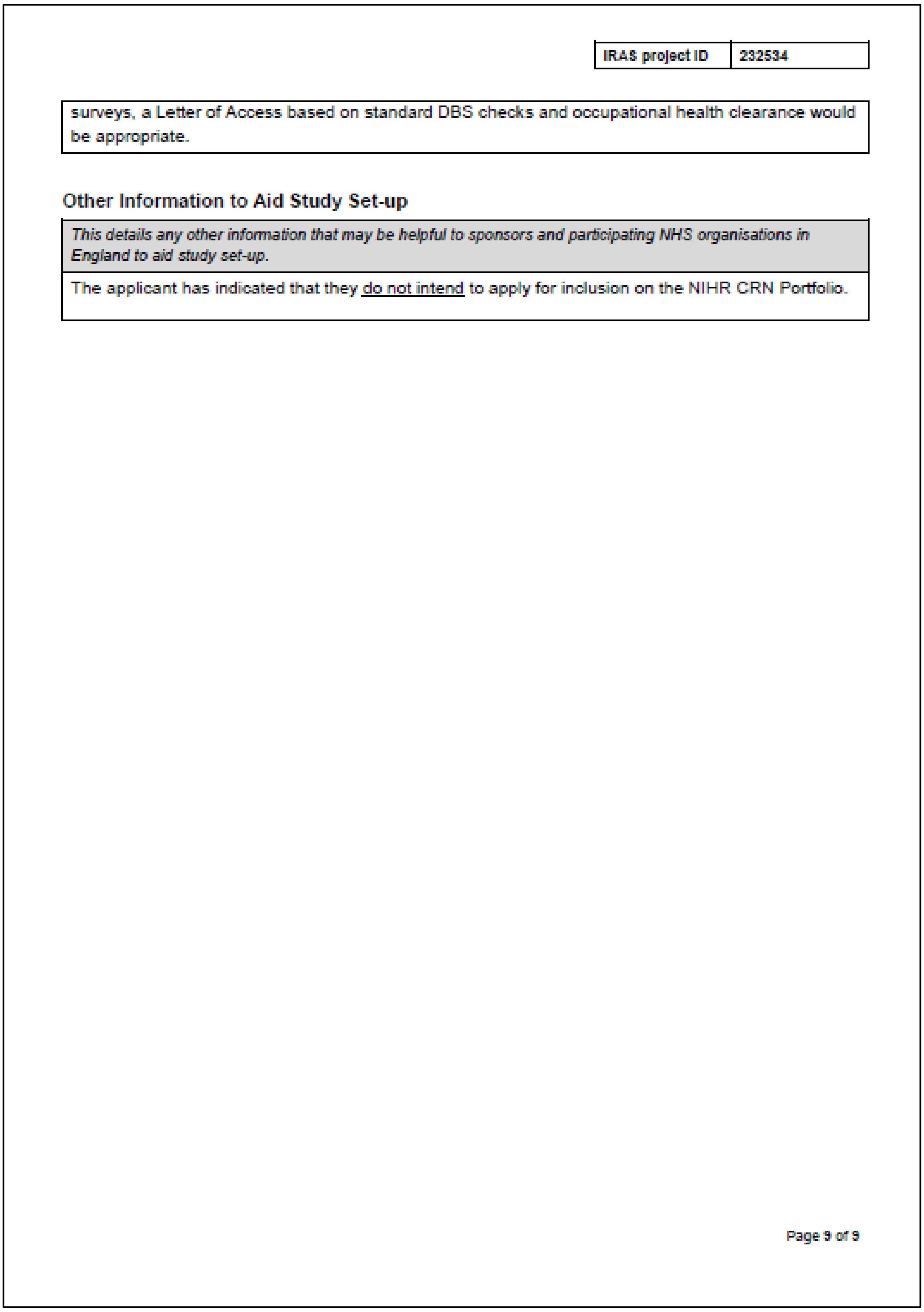
- As stated in the Initial Assessment Letter (dated 19 October 2017), it is expected that these organisations will become participating NHS organisations 35 days after issue of the Initial Assessment Letter (no later than **23 November 2017**):
  - You may not include the NHS organisation if they provide justification to the sponsor and the HRA as to why the organisation cannot participate
  - You may not include the NHS organisation if they request additional time to confirm.
- You may include NHS organisations in this study in advance of the deadline above where the organisation confirms by email to the CI and sponsor that the research may proceed.
- The document "Collaborative working between sponsors and NHS organisations in England for HRA Approval studies, where no formal confirmation of capacity and capability is expected" provides further information for the sponsor and NHS organisations on working with NHS organisations in England where no formal confirmation of capacity and capability is expected, and the processes involved in adding new organisations. Further study specific details are provided the *Participating NHS Organisations* and *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* sections of this Appendix.

Principal Investigator Suitability

This confirms whether the sponsor position on whether a PI, LC or neither should be in place is correct for each type of participating NHS organisation in England and the minimum expectations for education, training and experience that PIs should meet (where applicable).
Neither Principal Investigator nor Local Collaborator is required for the participating NHS organisation. The Chief Investigator will be responsible for all research activities at site. GCP training is not a generic training expectation, in line with the HRA statement on training expectations.

HR Good Practice Resource Pack Expectations

This confirms the HR Good Practice Resource Pack expectations for the study and the pre-engagement checks that should and should not be undertaken
Local staff substantively employed by the participating NHS organisation will be undertaking research activities as described in the IRAS application. No HR access arrangements are therefore expected for this study. Where arrangements are not already in place, network staff employed by another Trust or University (or similar) undertaking any of the research activities listed in A18 or A19 of the IRAS form (except for administration of questionnaires or surveys), would be expected to obtain an honorary research contract from one NHS organisation (if university employed), followed by Letters of Access for subsequent organisations. This would be on the basis of a Research Passport (if university employed) or an NHS to NHS confirmation of pre-engagement checks letter (if NHS employed). These should confirm enhanced DBS checks, including appropriate barred list checks, and occupational health clearance. For research team members only administering questionnaires or



IRAS project ID	232534

surveys, a Letter of Access based on standard DBS checks and occupational health clearance would be appropriate.

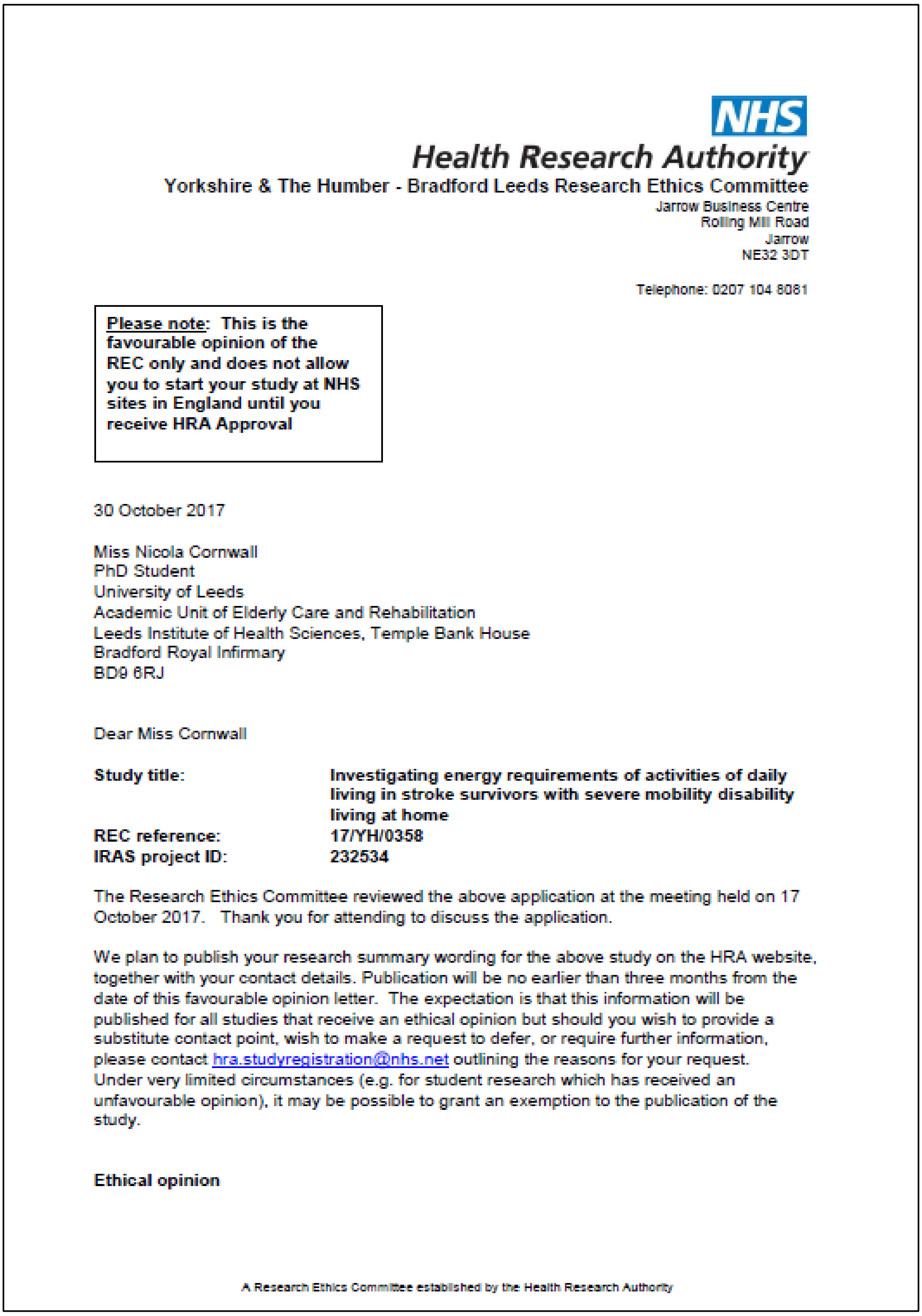
Other Information to Aid Study Set-up

This details any other information that may be helpful to sponsors and participating NHS organisations in England to aid study set-up.

The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio.

Page 9 of 9

Appendix N Letter of Favourable Opinion with Condition – Energy Study



NHS
Health Research Authority
Yorkshire & The Humber - Bradford Leeds Research Ethics Committee
Jarrow Business Centre
Rolling Mill Road
Jarrow
NE32 3DT

Telephone: 0207 104 8081

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

30 October 2017

Miss Nicola Cornwall
PhD Student
University of Leeds
Academic Unit of Elderly Care and Rehabilitation
Leeds Institute of Health Sciences, Temple Bank House
Bradford Royal Infirmary
BD9 6RJ

Dear Miss Cornwall

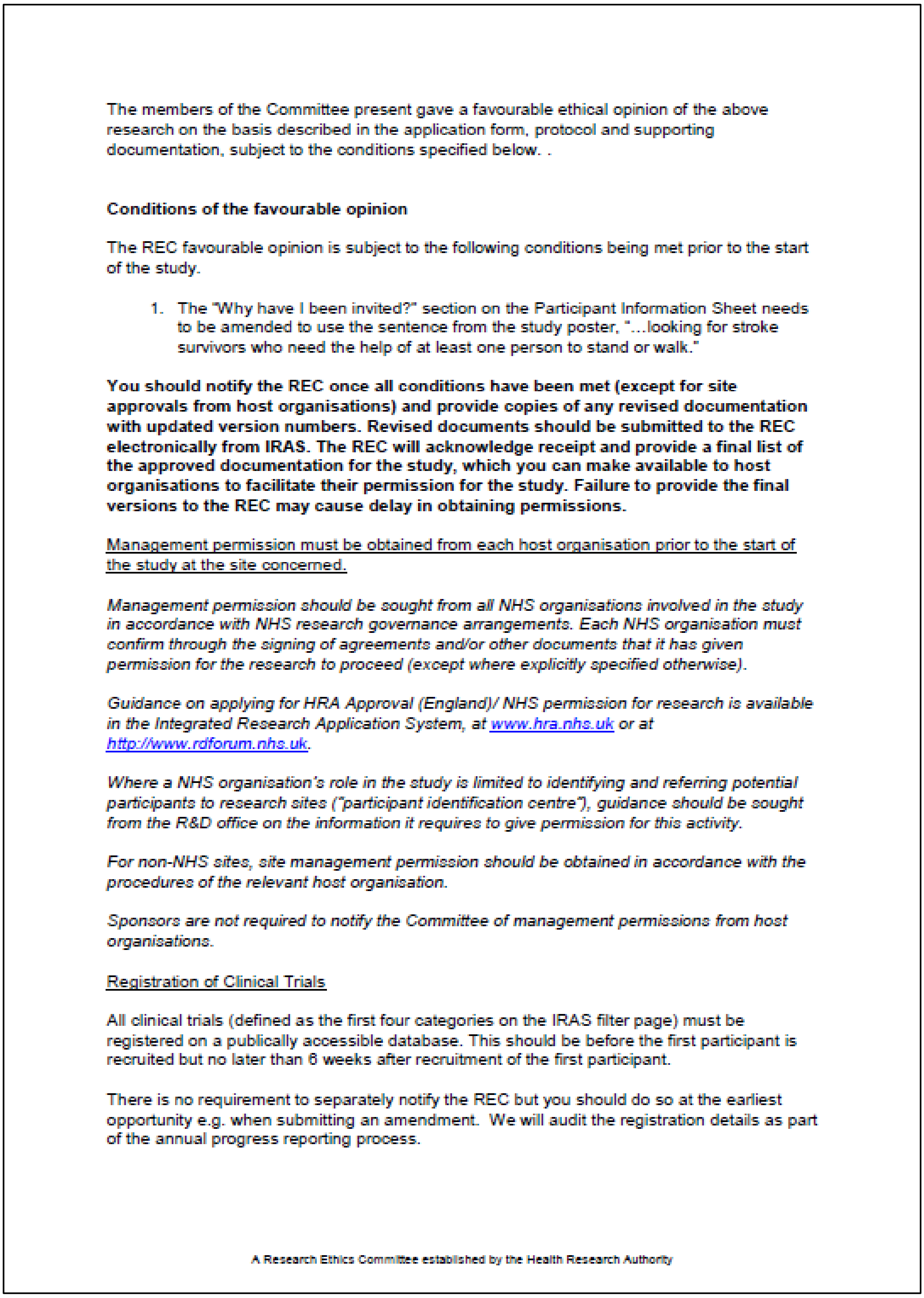
Study title:	**Investigating energy requirements of activities of daily living in stroke survivors with severe mobility disability living at home**
REC reference:	**17/YH/0358**
IRAS project ID:	**232534**

The Research Ethics Committee reviewed the above application at the meeting held on 17 October 2017. Thank you for attending to discuss the application.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact hra.studyregistration@nhs.net outlining the reasons for your request. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Ethical opinion

A Research Ethics Committee established by the Health Research Authority



The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below. .

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

1. The "Why have I been invited?" section on the Participant Information Sheet needs to be amended to use the sentence from the study poster, "…looking for stroke survivors who need the help of at least one person to stand or walk."

You should notify the REC once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Revised documents should be submitted to the REC electronically from IRAS. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which you can make available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA Approval (England)/ NHS permission for research is available in the Integrated Research Application System, at www.hra.nhs.uk or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

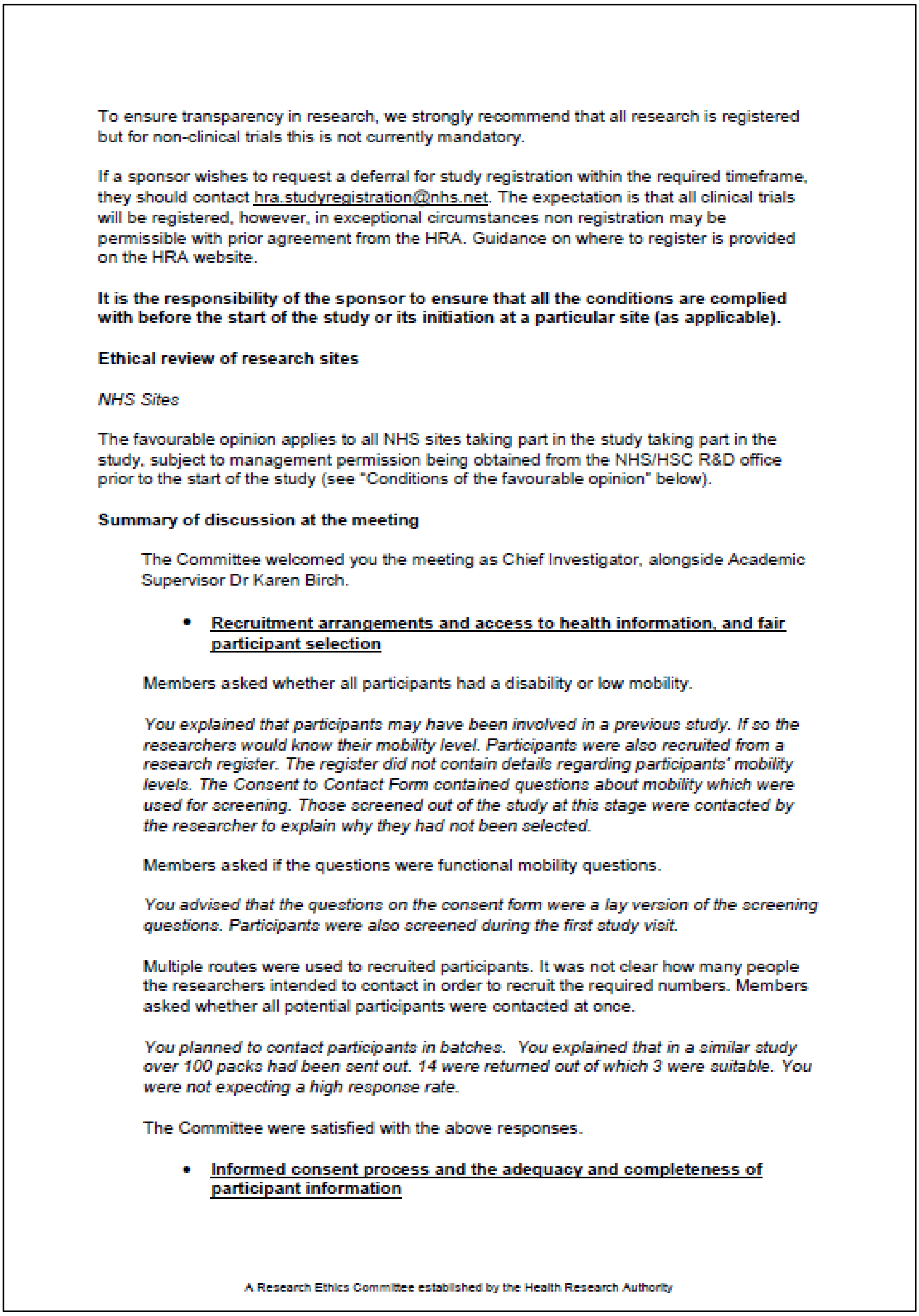
For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.



To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS Sites

The favourable opinion applies to all NHS sites taking part in the study taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Summary of discussion at the meeting

The Committee welcomed you the meeting as Chief Investigator, alongside Academic Supervisor Dr Karen Birch.

- **Recruitment arrangements and access to health information, and fair participant selection**

Members asked whether all participants had a disability or low mobility.

You explained that participants may have been involved in a previous study. If so the researchers would know their mobility level. Participants were also recruited from a research register. The register did not contain details regarding participants' mobility levels. The Consent to Contact Form contained questions about mobility which were used for screening. Those screened out of the study at this stage were contacted by the researcher to explain why they had not been selected.

Members asked if the questions were functional mobility questions.

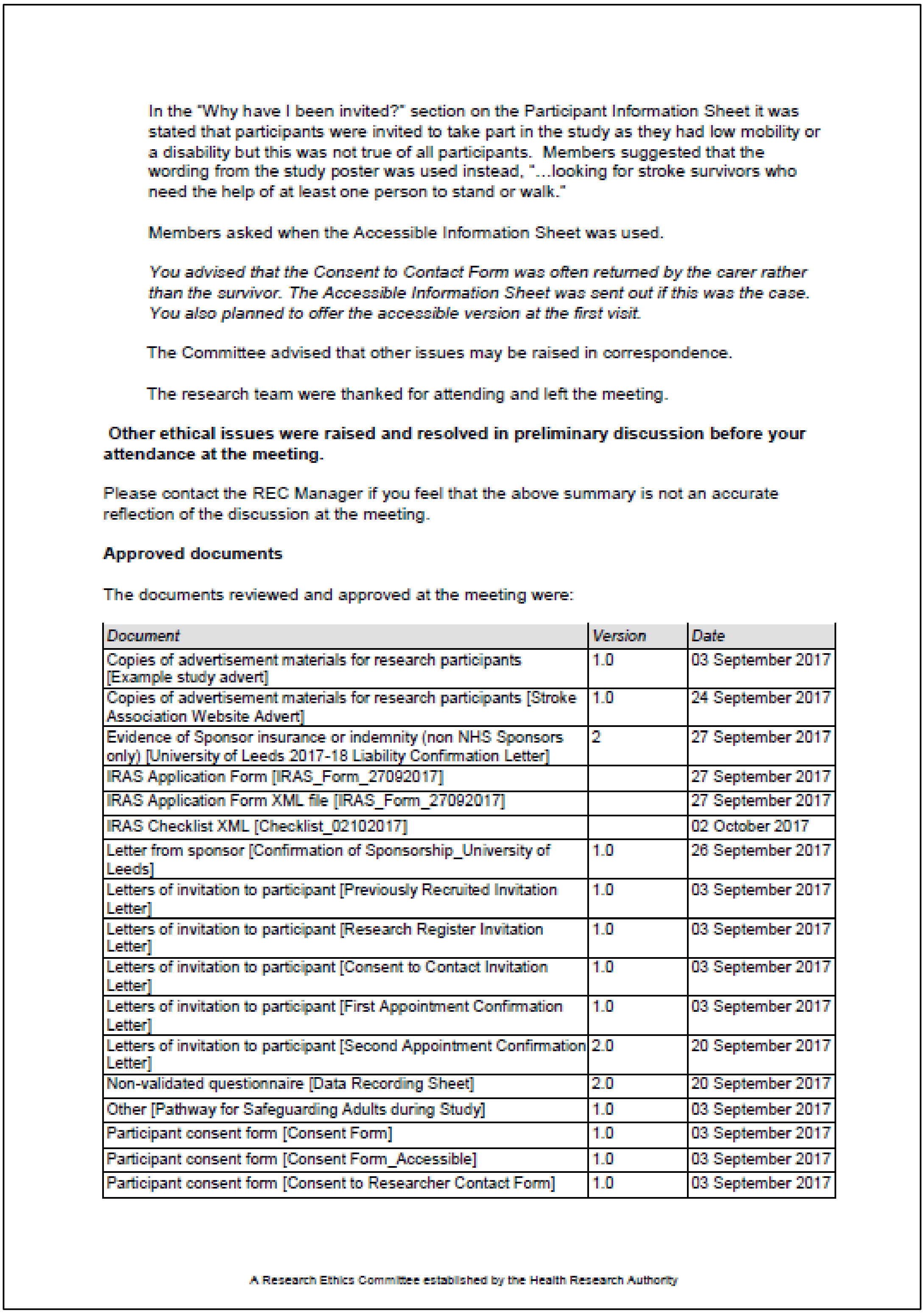
You advised that the questions on the consent form were a lay version of the screening questions. Participants were also screened during the first study visit.

Multiple routes were used to recruited participants. It was not clear how many people the researchers intended to contact in order to recruit the required numbers. Members asked whether all potential participants were contacted at once.

You planned to contact participants in batches. You explained that in a similar study over 100 packs had been sent out. 14 were returned out of which 3 were suitable. You were not expecting a high response rate.

The Committee were satisfied with the above responses.

- **Informed consent process and the adequacy and completeness of participant information**



In the "Why have I been invited?" section on the Participant Information Sheet it was stated that participants were invited to take part in the study as they had low mobility or a disability but this was not true of all participants. Members suggested that the wording from the study poster was used instead, "…looking for stroke survivors who need the help of at least one person to stand or walk."

Members asked when the Accessible Information Sheet was used.

You advised that the Consent to Contact Form was often returned by the carer rather than the survivor. The Accessible Information Sheet was sent out if this was the case. You also planned to offer the accessible version at the first visit.

The Committee advised that other issues may be raised in correspondence.

The research team were thanked for attending and left the meeting.

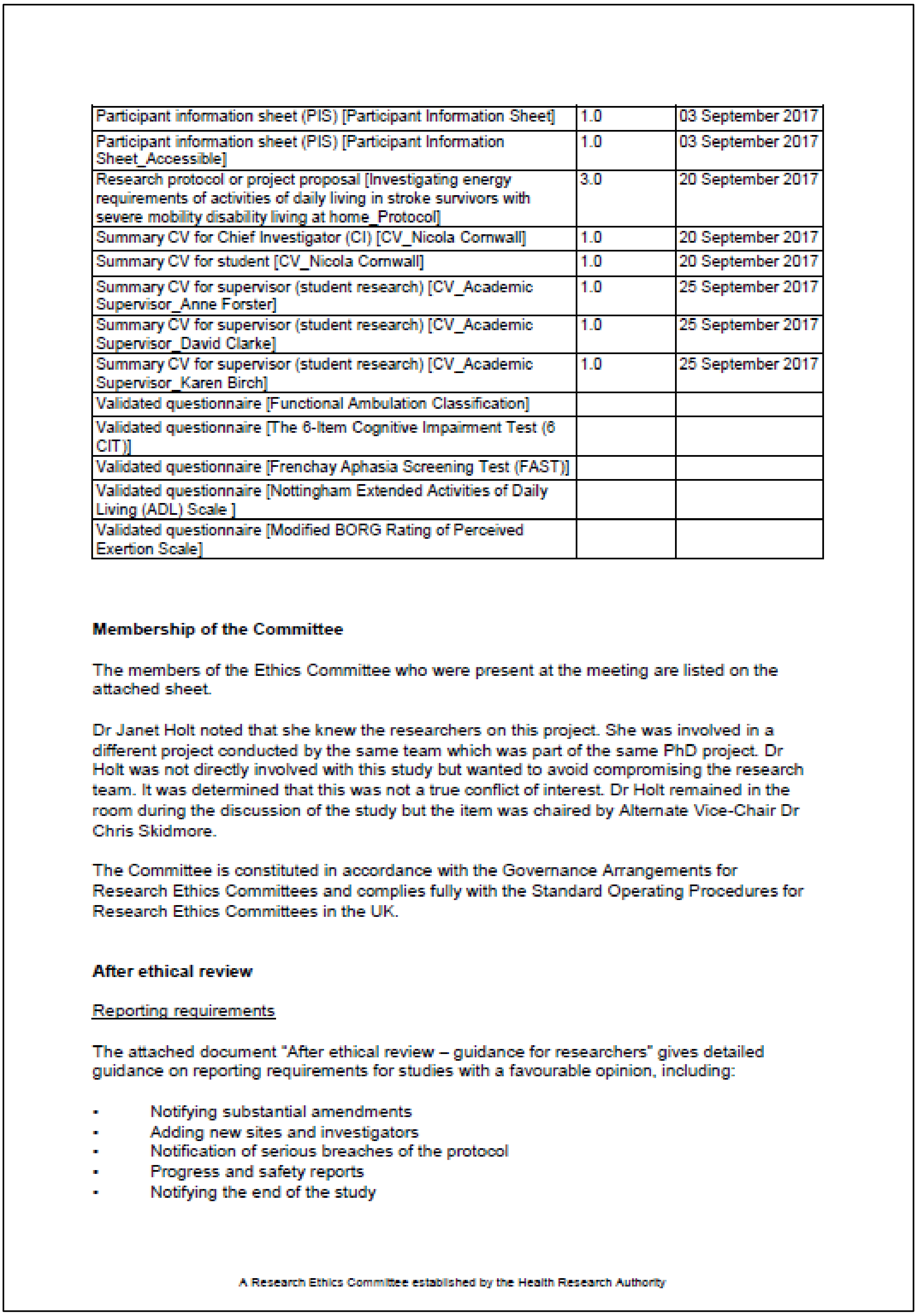
Other ethical issues were raised and resolved in preliminary discussion before your attendance at the meeting.

Please contact the REC Manager if you feel that the above summary is not an accurate reflection of the discussion at the meeting.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Copies of advertisement materials for research participants [Example study advert]	1.0	03 September 2017
Copies of advertisement materials for research participants [Stroke Association Website Advert]	1.0	24 September 2017
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [University of Leeds 2017-18 Liability Confirmation Letter]	2	27 September 2017
IRAS Application Form [IRAS_Form_27092017]		27 September 2017
IRAS Application Form XML file [IRAS_Form_27092017]		27 September 2017
IRAS Checklist XML [Checklist_02102017]		02 October 2017
Letter from sponsor [Confirmation of Sponsorship_University of Leeds]	1.0	26 September 2017
Letters of invitation to participant [Previously Recruited Invitation Letter]	1.0	03 September 2017
Letters of invitation to participant [Research Register Invitation Letter]	1.0	03 September 2017
Letters of invitation to participant [Consent to Contact Invitation Letter]	1.0	03 September 2017
Letters of invitation to participant [First Appointment Confirmation Letter]	1.0	03 September 2017
Letters of invitation to participant [Second Appointment Confirmation Letter]	2.0	20 September 2017
Non-validated questionnaire [Data Recording Sheet]	2.0	20 September 2017
Other [Pathway for Safeguarding Adults during Study]	1.0	03 September 2017
Participant consent form [Consent Form]	1.0	03 September 2017
Participant consent form [Consent Form_Accessible]	1.0	03 September 2017
Participant consent form [Consent to Researcher Contact Form]	1.0	03 September 2017



Participant information sheet (PIS) [Participant Information Sheet]	1.0	03 September 2017
Participant information sheet (PIS) [Participant Information Sheet_Accessible]	1.0	03 September 2017
Research protocol or project proposal [Investigating energy requirements of activities of daily living in stroke survivors with severe mobility disability living at home_Protocol]	3.0	20 September 2017
Summary CV for Chief Investigator (CI) [CV_Nicola Cornwall]	1.0	20 September 2017
Summary CV for student [CV_Nicola Cornwall]	1.0	20 September 2017
Summary CV for supervisor (student research) [CV_Academic Supervisor_Anne Forster]	1.0	25 September 2017
Summary CV for supervisor (student research) [CV_Academic Supervisor_David Clarke]	1.0	25 September 2017
Summary CV for supervisor (student research) [CV_Academic Supervisor_Karen Birch]	1.0	25 September 2017
Validated questionnaire [Functional Ambulation Classification]		
Validated questionnaire [The 6-Item Cognitive Impairment Test (6 CIT)]		
Validated questionnaire [Frenchay Aphasia Screening Test (FAST)]		
Validated questionnaire [Nottingham Extended Activities of Daily Living (ADL) Scale]		
Validated questionnaire [Modified BORG Rating of Perceived Exertion Scale]		

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Dr Janet Holt noted that she knew the researchers on this project. She was involved in a different project conducted by the same team which was part of the same PhD project. Dr Holt was not directly involved with this study but wanted to avoid compromising the research team. It was determined that this was not a true conflict of interest. Dr Holt remained in the room during the discussion of the study but the item was chaired by Alternate Vice-Chair Dr Chris Skidmore.

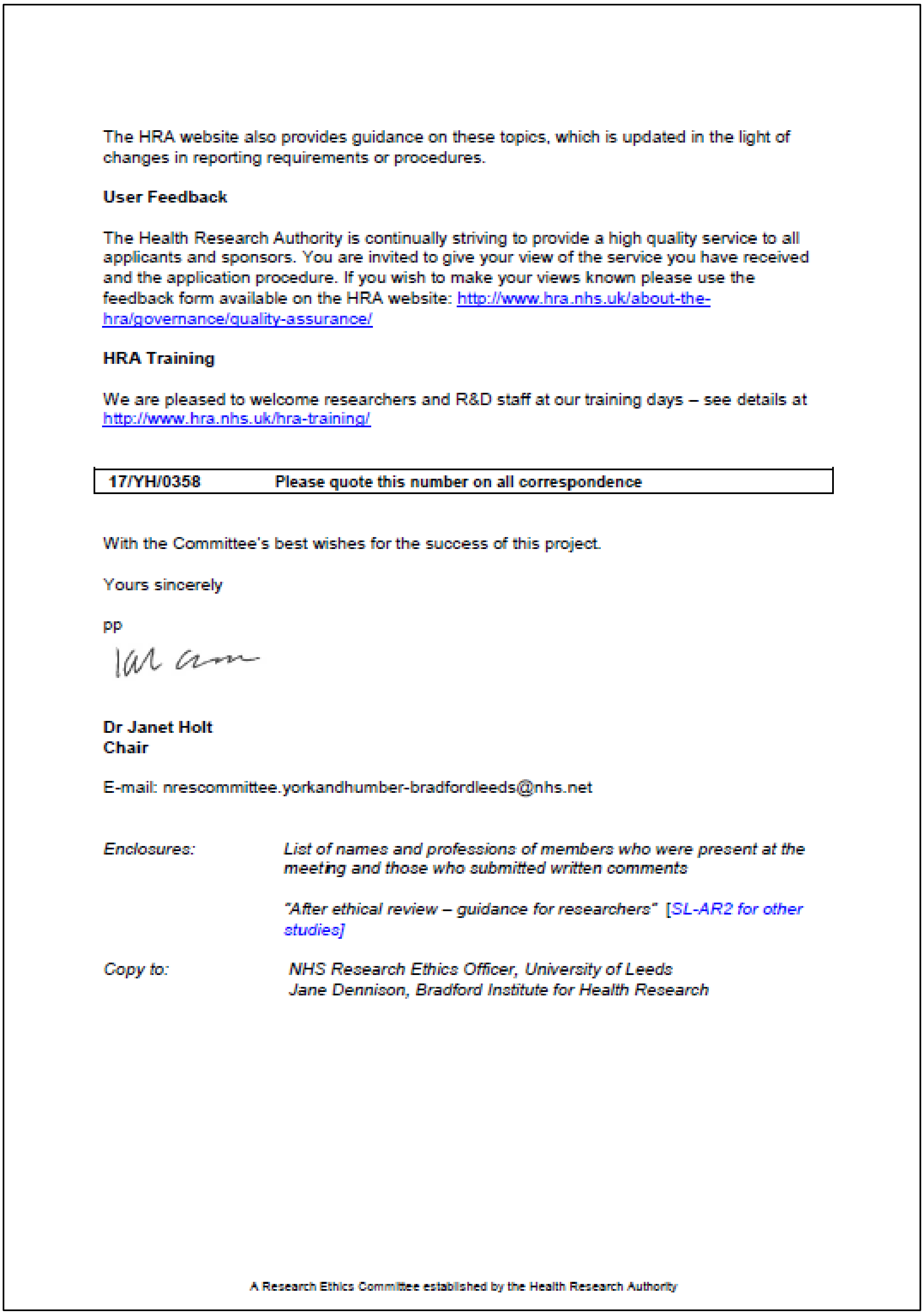
The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study



The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

17/YH/0358	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project.

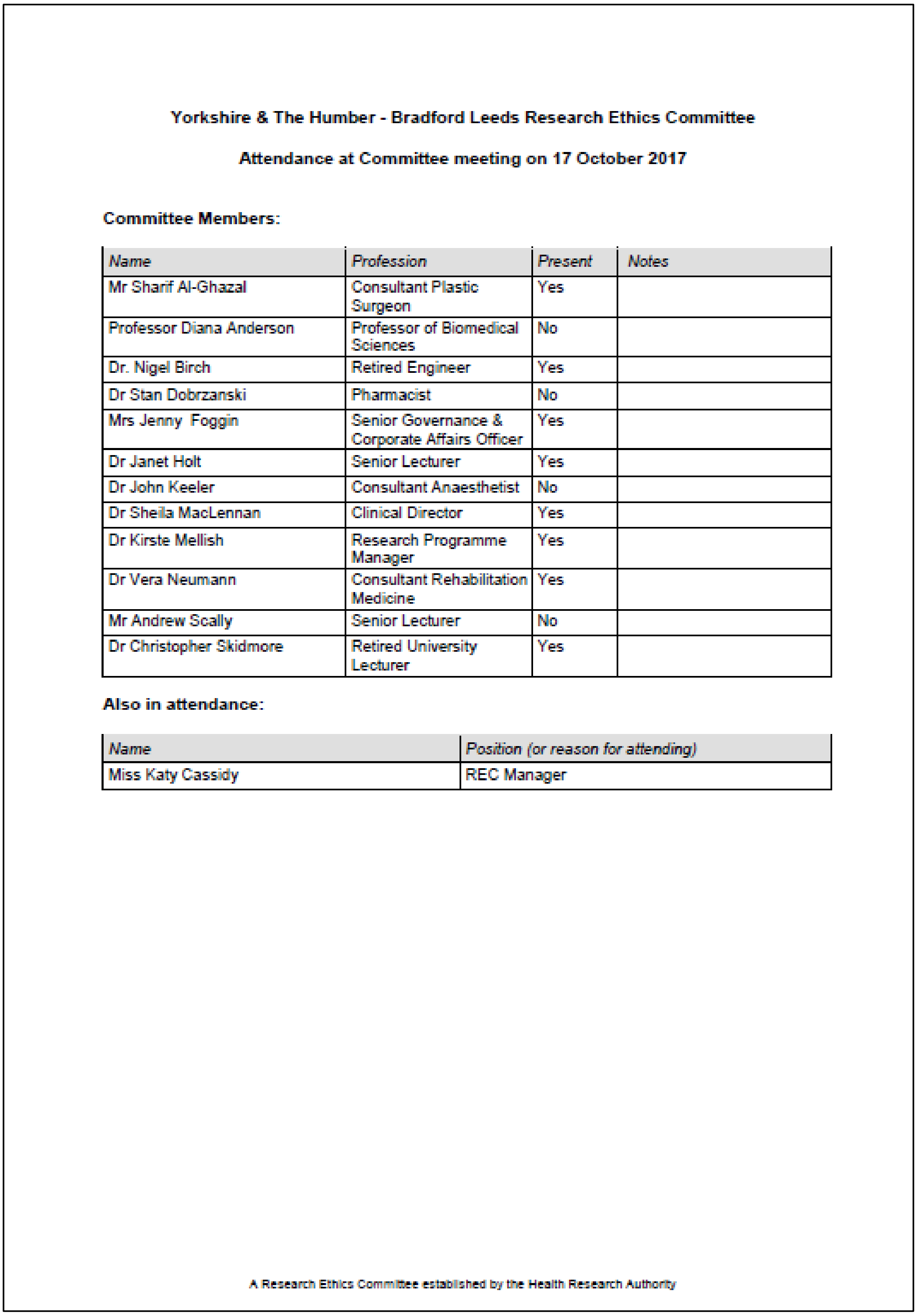
Yours sincerely

pp

Dr Janet Holt
Chair

E-mail: nrescommittee.yorkandhumber-bradfordleeds@nhs.net

Enclosures:	*List of names and professions of members who were present at the meeting and those who submitted written comments* *"After ethical review – guidance for researchers"* *[SL-AR2 for other studies]*
Copy to:	*NHS Research Ethics Officer, University of Leeds* *Jane Dennison, Bradford Institute for Health Research*



Yorkshire & The Humber - Bradford Leeds Research Ethics Committee

Attendance at Committee meeting on 17 October 2017

Committee Members:

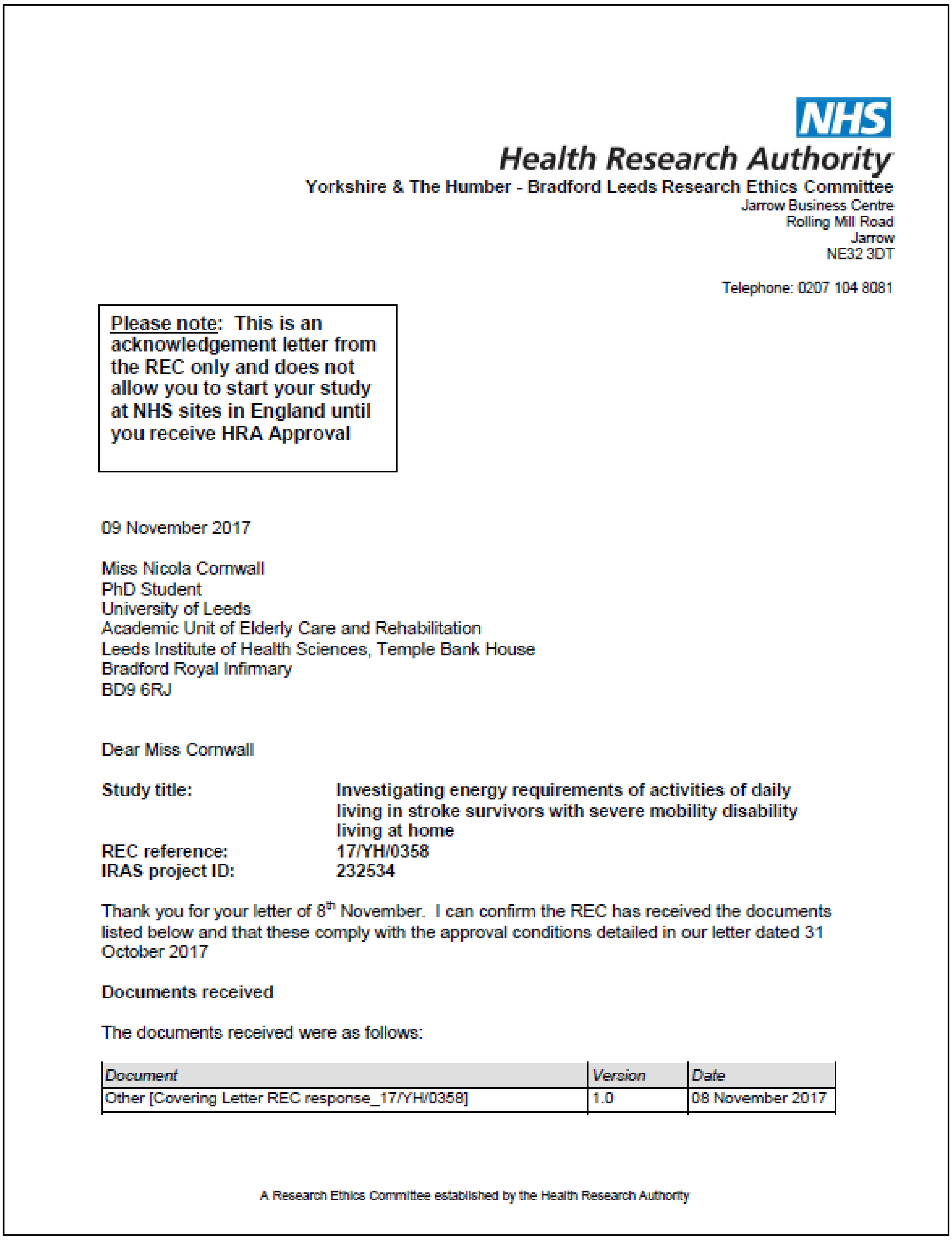
Name	*Profession*	*Present*	*Notes*
Mr Sharif Al-Ghazal	Consultant Plastic Surgeon	Yes	
Professor Diana Anderson	Professor of Biomedical Sciences	No	
Dr. Nigel Birch	Retired Engineer	Yes	
Dr Stan Dobrzanski	Pharmacist	No	
Mrs Jenny Foggin	Senior Governance & Corporate Affairs Officer	Yes	
Dr Janet Holt	Senior Lecturer	Yes	
Dr John Keeler	Consultant Anaesthetist	No	
Dr Sheila MacLennan	Clinical Director	Yes	
Dr Kirste Mellish	Research Programme Manager	Yes	
Dr Vera Neumann	Consultant Rehabilitation Medicine	Yes	
Mr Andrew Scally	Senior Lecturer	No	
Dr Christopher Skidmore	Retired University Lecturer	Yes	

Also in attendance:

Name	*Position (or reason for attending)*
Miss Katy Cassidy	REC Manager

A Research Ethics Committee established by the Health Research Authority

Appendix O Acknowledgment Letter of Approval Conditions met from Research Ethics Committee – Energy Study



NHS
Health Research Authority
Yorkshire & The Humber - Bradford Leeds Research Ethics Committee
Jarrow Business Centre
Rolling Mill Road
Jarrow
NE32 3DT

Telephone: 0207 104 8081

Please note: This is an acknowledgement letter from the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

09 November 2017

Miss Nicola Cornwall
PhD Student
University of Leeds
Academic Unit of Elderly Care and Rehabilitation
Leeds Institute of Health Sciences, Temple Bank House
Bradford Royal Infirmary
BD9 6RJ

Dear Miss Cornwall

Study title: **Investigating energy requirements of activities of daily living in stroke survivors with severe mobility disability living at home**
REC reference: **17/YH/0358**
IRAS project ID: **232534**

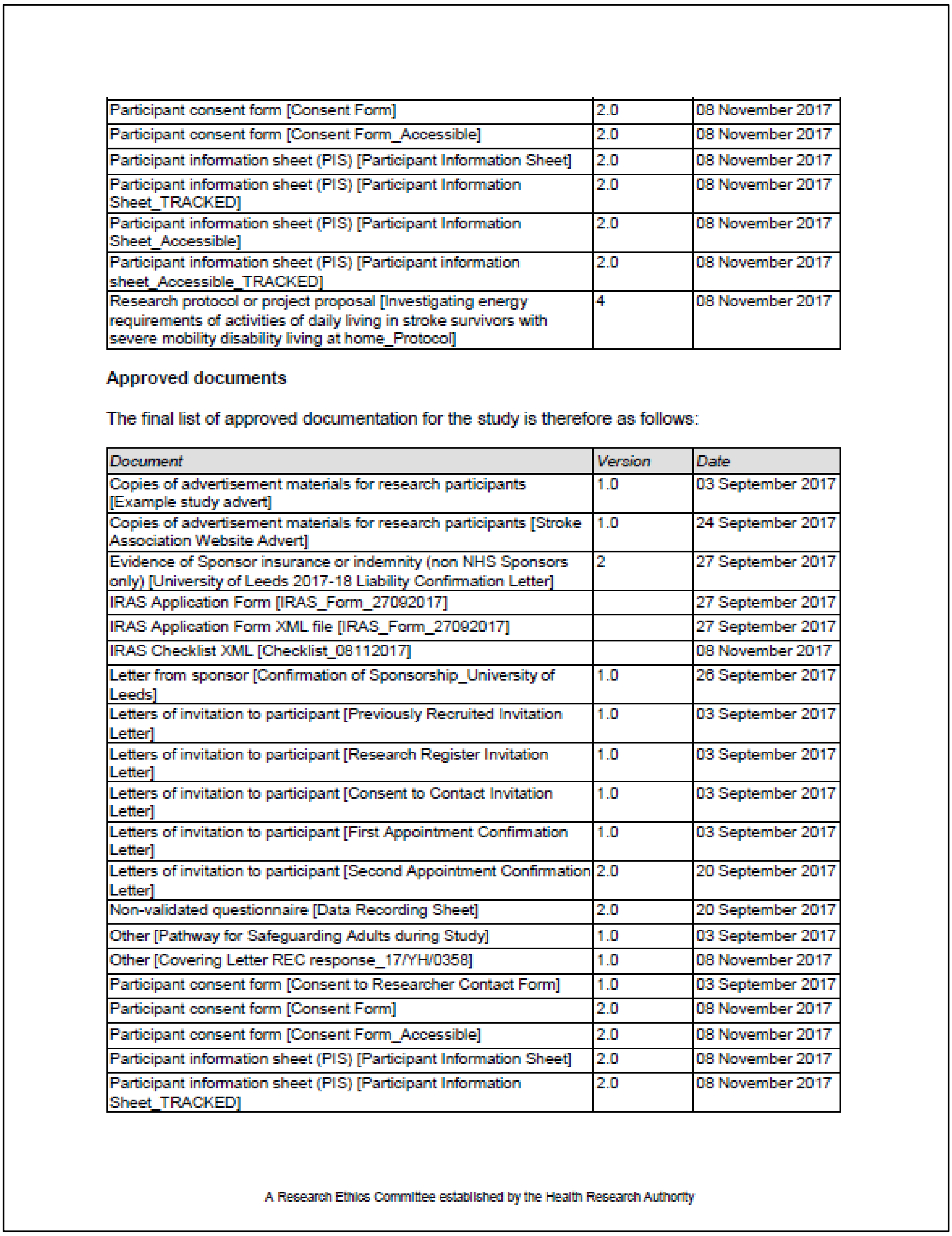
Thank you for your letter of 8th November. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 31 October 2017

Documents received

The documents received were as follows:

Document	*Version*	*Date*
Other [Covering Letter REC response_17/YH/0358]	1.0	08 November 2017

A Research Ethics Committee established by the Health Research Authority



Participant consent form [Consent Form]	2.0	08 November 2017
Participant consent form [Consent Form_Accessible]	2.0	08 November 2017
Participant information sheet (PIS) [Participant Information Sheet]	2.0	08 November 2017
Participant information sheet (PIS) [Participant Information Sheet_TRACKED]	2.0	08 November 2017
Participant information sheet (PIS) [Participant Information Sheet_Accessible]	2.0	08 November 2017
Participant information sheet (PIS) [Participant information sheet_Accessible_TRACKED]	2.0	08 November 2017
Research protocol or project proposal [Investigating energy requirements of activities of daily living in stroke survivors with severe mobility disability living at home_Protocol]	4	08 November 2017

Approved documents

The final list of approved documentation for the study is therefore as follows:

Document	*Version*	*Date*
Copies of advertisement materials for research participants [Example study advert]	1.0	03 September 2017
Copies of advertisement materials for research participants [Stroke Association Website Advert]	1.0	24 September 2017
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [University of Leeds 2017-18 Liability Confirmation Letter]	2	27 September 2017
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Non-validated questionnaire [Data Recording Sheet]	2.0	20 September 2017
Other [Pathway for Safeguarding Adults during Study]	1.0	03 September 2017
Other [Covering Letter REC response_17/YH/0358]	1.0	08 November 2017
Participant consent form [Consent to Researcher Contact Form]	1.0	03 September 2017
Participant consent form [Consent Form]	2.0	08 November 2017
Participant consent form [Consent Form_Accessible]	2.0	08 November 2017
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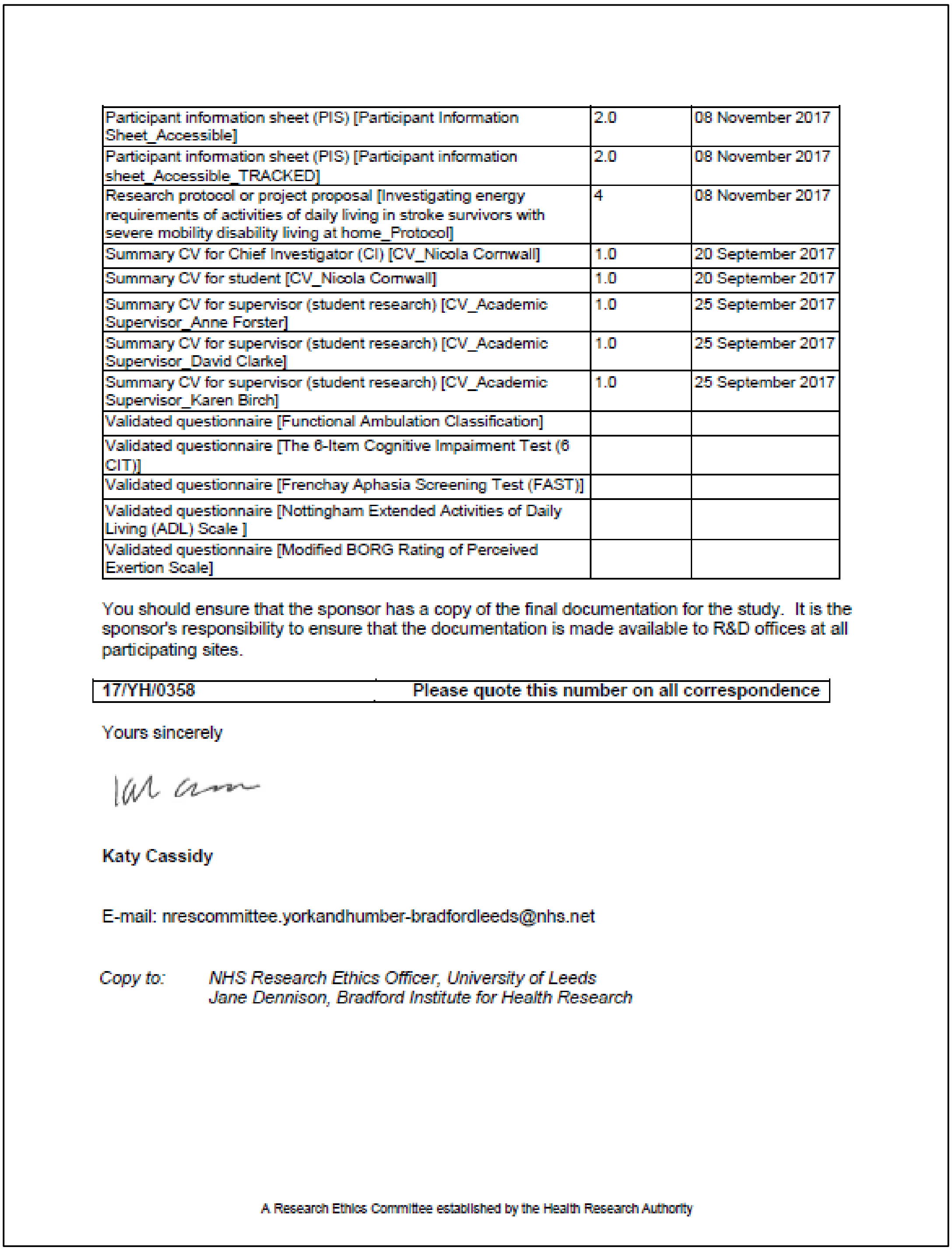
Participant information sheet (PIS) [Participant Information Sheet_TRACKED]	2.0	08 November 2017



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Validated questionnaire [Frenchay Aphasia Screening Test (FAST)]		
Validated questionnaire [Nottingham Extended Activities of Daily Living (ADL) Scale]		
Validated questionnaire [Modified BORG Rating of Perceived Exertion Scale]		

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

17/YH/0358	**Please quote this number on all correspondence**

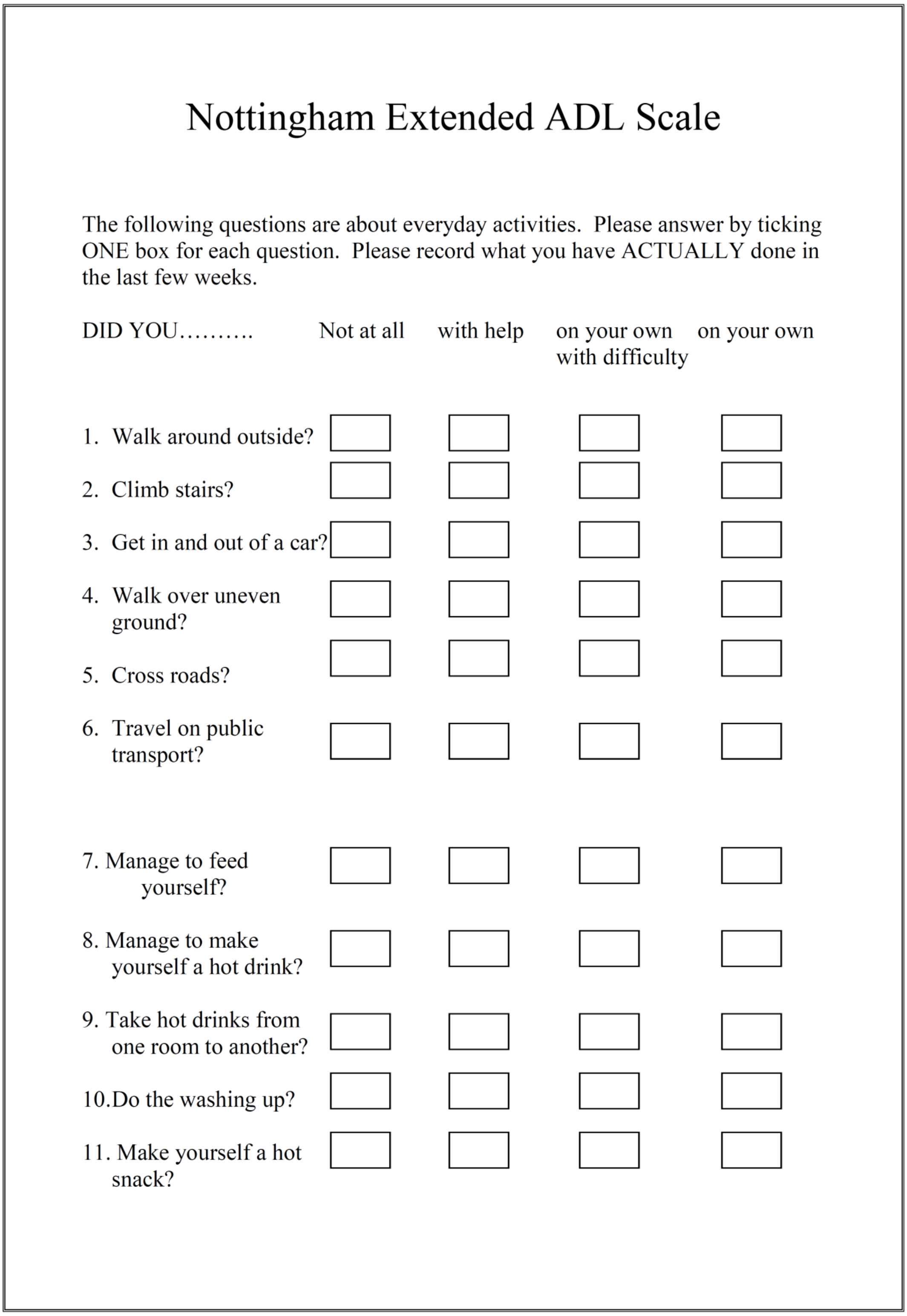
Yours sincerely

Katy Cassidy

E-mail: nrescommittee.yorkandhumber-bradfordleeds@nhs.net

Copy to: *NHS Research Ethics Officer, University of Leeds*
Jane Dennison, Bradford Institute for Health Research

Appendix Q Nottingham Extended Activities of Daily Living Scale (NEADL)



Nottingham Extended ADL Scale

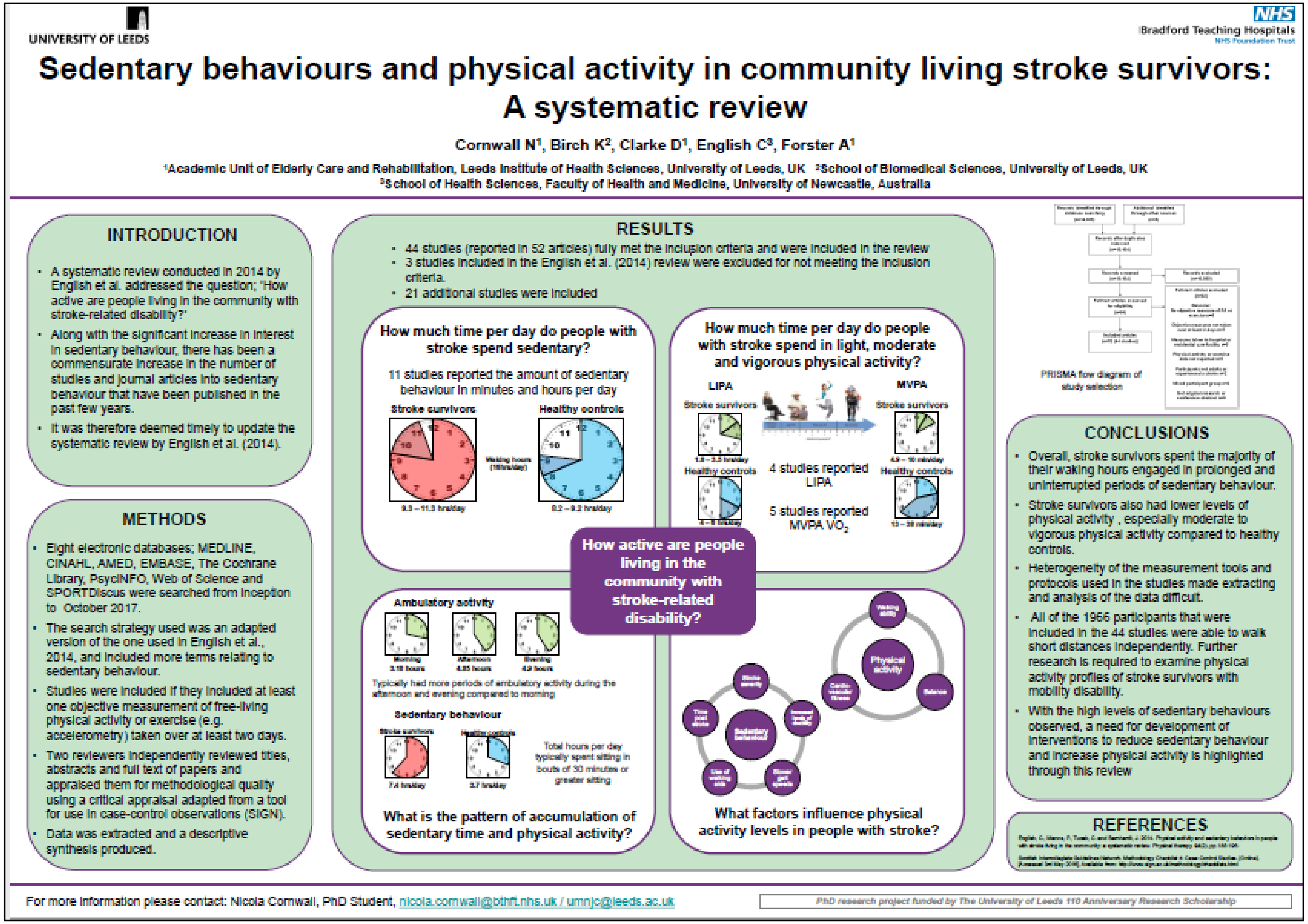
The following questions are about everyday activities. Please answer by ticking ONE box for each question. Please record what you have ACTUALLY done in the last few weeks.

DID YOU……….	Not at all	with help	on your own with difficulty	on your own
1. Walk around outside?	☐	☐	☐	☐
2. Climb stairs?	☐	☐	☐	☐
3. Get in and out of a car?	☐	☐	☐	☐
4. Walk over uneven ground?	☐	☐	☐	☐
5. Cross roads?	☐	☐	☐	☐
6. Travel on public transport?	☐	☐	☐	☐
7. Manage to feed yourself?	☐	☐	☐	☐
8. Manage to make yourself a hot drink?	☐	☐	☐	☐
9. Take hot drinks from one room to another?	☐	☐	☐	☐
10.Do the washing up?	☐	☐	☐	☐
11. Make yourself a hot snack?	☐	☐	☐	☐

	No	With help	On your own with difficulty	On your own
12.Manage your own money when out?	☐	☐	☐	☐
13. Wash small items of clothing?	☐	☐	☐	☐
14.Do your own housework?	☐	☐	☐	☐
15.Do your own shopping?	☐	☐	☐	☐
16. Do a full clothes wash?	☐	☐	☐	☐
17.Read newspapers or books?	☐	☐	☐	☐
18.Use the telephone?	☐	☐	☐	☐
19. Write letters?	☐	☐	☐	☐
20.Go out socially?	☐	☐	☐	☐
21. Manage your own garden?	☐	☐	☐	☐
22. Drive a car?	☐	☐	☐	☐

Appendix R Update of English et al. (2014) Systematic Review (Chapter Three)

Poster Presented at UK Stroke Forum 2018



UNIVERSITY OF LEEDS

NHS Bradford Teaching Hospitals NHS Foundation Trust

Sedentary behaviours and physical activity in community living stroke survivors: A systematic review

Cornwall N[1], Birch K[2], Clarke D[1], English C[3], Forster A[1]

[1]Academic Unit of Elderly Care and Rehabilitation, Leeds Institute of Health Sciences, University of Leeds, UK [2]School of Biomedical Sciences, University of Leeds, UK
[3]School of Health Sciences, Faculty of Health and Medicine, University of Newcastle, Australia

INTRODUCTION

- A systematic review conducted in 2014 by English et al. addressed the question; 'How active are people living in the community with stroke-related disability?'
- Along with the significant increase in interest in sedentary behaviour, there has been a commensurate increase in the number of studies and journal articles into sedentary behaviour that have been published in the past few years.
- It was therefore deemed timely to update the systematic review by English et al. (2014).

METHODS

- Eight electronic databases; MEDLINE, CINAHL, AMED, EMBASE, The Cochrane Library, PsycINFO, Web of Science and SPORTDiscus were searched from inception to October 2017.
- The search strategy used was an adapted version of the one used in English et al., 2014, and included more terms relating to sedentary behaviour.
- Studies were included if they included at least one objective measurement of free-living physical activity or exercise (e.g. accelerometry) taken over at least two days.
- Two reviewers independently reviewed titles, abstracts and full text of papers and appraised them for methodological quality using a critical appraisal adapted from a tool for use in case-control observations (SIGN).
- Data was extracted and a descriptive synthesis produced.

RESULTS

- 44 studies (reported in 52 articles) fully met the inclusion criteria and were included in the review
- 3 studies included in the English et al. (2014) review were excluded for not meeting the inclusion criteria.
- 21 additional studies were included

How much time per day do people with stroke spend sedentary?

11 studies reported the amount of sedentary behaviour in minutes and hours per day

Stroke survivors: 9.3 – 11.3 hrs/day

Waking hours (16hrs/day)

Healthy controls: 8.2 – 9.2 hrs/day

How much time per day do people with stroke spend in light, moderate and vigorous physical activity?

LIPA

Stroke survivors: 1.8 – 3.3 hrs/day

Healthy controls: 4 – 6 hrs/day

4 studies reported LIPA

5 studies reported MVPA VO_2

MVPA

Stroke survivors: 4.9 – 10 min/day

Healthy controls: 13 – 38 min/day

How active are people living in the community with stroke-related disability?

Ambulatory activity

Morning 3.18 hours

Afternoon 4.85 hours

Evening 4.9 hours

Typically had more periods of ambulatory activity during the afternoon and evening compared to morning

Sedentary behaviour

Stroke survivors: 7.4 hrs/day

Healthy controls: 3.7 hrs/day

Total hours per day typically spent sitting in bouts of 30 minutes or greater sitting

What is the pattern of accumulation of sedentary time and physical activity?

What factors influence physical activity levels in people with stroke?

PRISMA flow diagram of study selection

CONCLUSIONS

- Overall, stroke survivors spent the majority of their waking hours engaged in prolonged and uninterrupted periods of sedentary behaviour.
- Stroke survivors also had lower levels of physical activity , especially moderate to vigorous physical activity compared to healthy controls.
- Heterogeneity of the measurement tools and protocols used in the studies made extracting and analysis of the data difficult.
- All of the 1966 participants that were included in the 44 studies were able to walk short distances independently. Further research is required to examine physical activity profiles of stroke survivors with mobility disability.
- With the high levels of sedentary behaviours observed, a need for development of interventions to reduce sedentary behaviour and increase physical activity is highlighted through this review

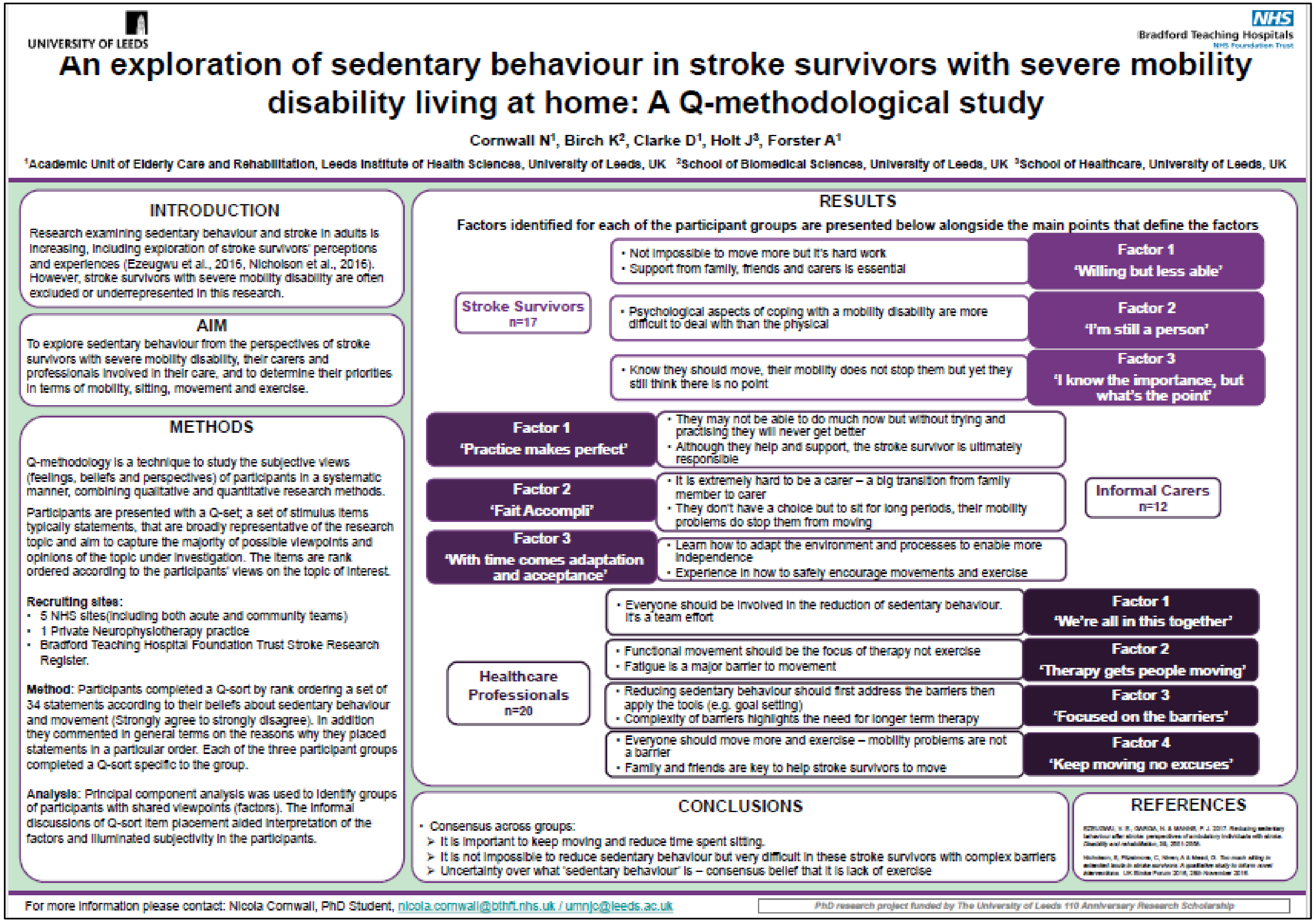
REFERENCES

For more information please contact: Nicola Cornwall, PhD Student, nicola.cornwall@bthft.nhs.uk / umnjc@leeds.ac.uk

PhD research project funded by The University of Leeds 110 Anniversary Research Scholarship

Appendix S Q-Methodology Findings Poster Presented at UK Stroke Forum 2018

Please note this poster was selected as the winner of the 'Poster Tour 16 – Sedentary Behaviour and Rehabilitation'



UNIVERSITY OF LEEDS

NHS Bradford Teaching Hospitals NHS Foundation Trust

An exploration of sedentary behaviour in stroke survivors with severe mobility disability living at home: A Q-methodological study

Cornwall N[1], Birch K[2], Clarke D[1], Holt J[3], Forster A[1]

[1]Academic Unit of Elderly Care and Rehabilitation, Leeds Institute of Health Sciences, University of Leeds, UK [2]School of Biomedical Sciences, University of Leeds, UK [3]School of Healthcare, University of Leeds, UK

INTRODUCTION

Research examining sedentary behaviour and stroke in adults is increasing, including exploration of stroke survivors' perceptions and experiences (Ezeugwu et al., 2016, Nicholson et al., 2016). However, stroke survivors with severe mobility disability are often excluded or underrepresented in this research.

AIM

To explore sedentary behaviour from the perspectives of stroke survivors with severe mobility disability, their carers and professionals involved in their care, and to determine their priorities in terms of mobility, sitting, movement and exercise.

METHODS

Q-methodology is a technique to study the subjective views (feelings, beliefs and perspectives) of participants in a systematic manner, combining qualitative and quantitative research methods.

Participants are presented with a Q-set; a set of stimulus items typically statements, that are broadly representative of the research topic and aim to capture the majority of possible viewpoints and opinions of the topic under investigation. The items are rank ordered according to the participants' views on the topic of interest.

Recruiting sites:

- 5 NHS sites(including both acute and community teams)
- 1 Private Neurophysiotherapy practice
- Bradford Teaching Hospital Foundation Trust Stroke Research Register.

Method: Participants completed a Q-sort by rank ordering a set of 34 statements according to their beliefs about sedentary behaviour and movement (Strongly agree to strongly disagree). In addition they commented in general terms on the reasons why they placed statements in a particular order. Each of the three participant groups completed a Q-sort specific to the group.

Analysis: Principal component analysis was used to identify groups of participants with shared viewpoints (factors). The informal discussions of Q-sort item placement aided interpretation of the factors and illuminated subjectivity in the participants.

RESULTS

Factors identified for each of the participant groups are presented below alongside the main points that define the factors

Stroke Survivors
n=17

Factor 1
'Willing but less able'

- Not impossible to move more but it's hard work
- Support from family, friends and carers is essential

Factor 2
'I'm still a person'

- Psychological aspects of coping with a mobility disability are more difficult to deal with than the physical

Factor 3
'I know the importance, but what's the point'

- Know they should move, their mobility does not stop them but yet they still think there is no point

Informal Carers
n=12

Factor 1
'Practice makes perfect'

- They may not be able to do much now but without trying and practising they will never get better
- Although they help and support, the stroke survivor is ultimately responsible

Factor 2
'Fait Accompli'

- It is extremely hard to be a carer – a big transition from family member to carer
- They don't have a choice but to sit for long periods, their mobility problems do stop them from moving

Factor 3
'With time comes adaptation and acceptance'

- Learn how to adapt the environment and processes to enable more independence
- Experience in how to safely encourage movements and exercise

Healthcare Professionals
n=20

Factor 1
'We're all in this together'

- Everyone should be involved in the reduction of sedentary behaviour. It's a team effort

Factor 2
'Therapy gets people moving'

- Functional movement should be the focus of therapy not exercise
- Fatigue is a major barrier to movement

Factor 3
'Focused on the barriers'

- Reducing sedentary behaviour should first address the barriers then apply the tools (e.g. goal setting)
- Complexity of barriers highlights the need for longer term therapy

Factor 4
'Keep moving no excuses'

- Everyone should move more and exercise – mobility problems are not a barrier
- Family and friends are key to help stroke survivors to move

CONCLUSIONS

- Consensus across groups:
  - ➢ It is important to keep moving and reduce time spent sitting.
  - ➢ It is not impossible to reduce sedentary behaviour but very difficult in these stroke survivors with complex barriers
  - ➢ Uncertainty over what 'sedentary behaviour' is – consensus belief that it is lack of exercise

REFERENCES

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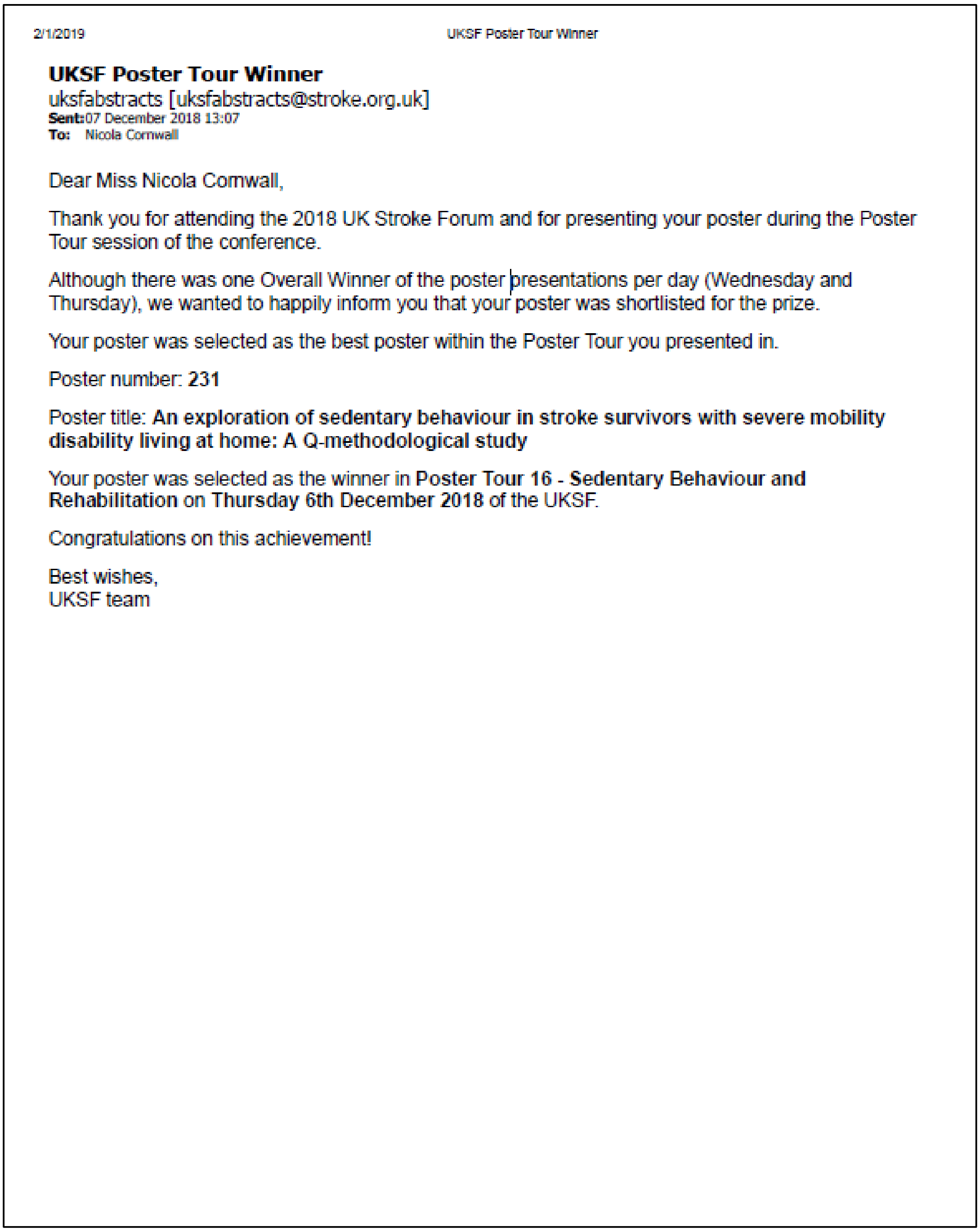

2/1/2019 UKSF Poster Tour Winner

UKSF Poster Tour Winner
uksfabstracts [uksfabstracts@stroke.org.uk]
Sent: 07 December 2018 13:07
To: Nicola Cornwall

Dear Miss Nicola Cornwall,

Thank you for attending the 2018 UK Stroke Forum and for presenting your poster during the Poster Tour session of the conference.

Although there was one Overall Winner of the poster presentations per day (Wednesday and Thursday), we wanted to happily inform you that your poster was shortlisted for the prize.

Your poster was selected as the best poster within the Poster Tour you presented in.

Poster number: **231**

Poster title: **An exploration of sedentary behaviour in stroke survivors with severe mobility disability living at home: A Q-methodological study**

Your poster was selected as the winner in **Poster Tour 16 - Sedentary Behaviour and Rehabilitation** on **Thursday 6th December 2018** of the UKSF.

Congratulations on this achievement!

Best wishes,
UKSF team