

Talking about recovery after stroke: How do we do it, and can we do it better?

Louisa-Jane Burton

Submitted in accordance with the requirements for the degree of
Doctor of Philosophy

The University of Leeds

School of Medicine

Academic Unit for Ageing & Stroke Research

October 2023

The candidate confirms that the work submitted is his/her own, except where work which has formed part of jointly-authored publications has been included. The contribution of the candidate and the other authors to this work has been explicitly indicated below. The candidate confirms that appropriate credit has been given within the thesis where reference has been made to the work of others.

The work in Chapter 1 of this thesis has appeared in publication as follows:

Burton, L.J., Forster, A., Johnson, J., Crocker, T.F., Tyson, S.F., Wray, F. and Clarke, D.J. Experiences and views of receiving and delivering information about recovery in acquired neurological conditions: a systematic review of qualitative literature. *BMJ Open* 2021;11:e045297. DOI: 10.1136/bmjopen-2020-045297

I was responsible for the design, conduct, analysis and write-up of the systematic review. Co-authors David Clarke, Tom Crocker, Sarah Tyson, Anne Forster and Judith Johnson provided guidance on the design, conduct and analysis of the review and provided feedback upon the manuscript prior to submission. Anne Forster acted as second reviewer during screening; David Clarke and Judith Johnson acted as consensus reviewers. Co-author Faye Wray completed double-data extraction and quality assessment.

This copy has been supplied on the understanding that it is copyright material and that no quotation from the thesis may be published without proper acknowledgement.

The right of Louisa-Jane Burton to be identified as Author of this work has been asserted by her in accordance with the Copyright, Designs and Patents Act 1988.

Acknowledgements

I would like to express my sincere gratitude to my supervisors, Dr David Clarke, Prof Anne Forster, Dr Judith Johnson and Dr Tom Crocker, for sharing their invaluable expertise and insight at every stage of the research, as well as their support, encouragement and patience. I would particularly like to thank Dr David Clarke, who continued to encourage and inspire me into his retirement. I am also grateful for the help of Prof Sarah Tyson, who began this journey with me, and has provided support, encouragement and mentorship throughout my career.

I wish to thank my colleagues at the Academic Unit for Ageing & Stroke Research in Bradford. In particular, I am grateful to Deidre Andre (Information Specialist), who helped to develop the search strategy for my systematic reviews, and to fellow researchers Dr Faye Wray, Dr Mark Perry, Dr Gregg Rawlings and Ellie Grant, who assisted with duplicate screening, data extraction and quality assessment. I would also like to express gratitude to Dr Becca Hawkins for her sage advice, to Matthew Prescott for taking time to answer my numerous clinical questions, and to my stroke team colleagues (Dr Jess Johansson, Dr Seline Ozer, Dr Jen Airlie and Rosie Shannon) for providing encouragement and a sounding board for my ideas. I would like to thank fellow PhD student Sadia Ahmed, who has always been at the other end of a phone to share experiences, even on the Mondayest of Mondays.

I am grateful to those who participated in my research, particularly the stroke survivors and carers who devoted their time and shared their experiences with me, and the stroke unit staff at the NHS services who welcomed me on to their wards and contributed their professional knowledge.

I am deeply grateful to my family and friends, without whose support this work would not have been possible. I would especially like to thank my husband Matt for his constant love and belief in me. To my three PhD babies, Eva, Aaron and Mollie: I hope you will be proud of what Mummy has achieved. I am also grateful to my parents for their support and encouragement throughout my academic journey so far.

I would like to thank The Stroke Association, whose generous funding allowed me to complete a PhD in an area of research, which I truly believe has the potential to benefit the lives of stroke survivors and their families. Finally, this thesis is dedicated to Pat and to Josephine, whose experiences inspired me to embark upon this journey.

Abstract

Background: Survivors of stroke and their families report dissatisfaction with the information they receive about the expected timing and extent of recovery.

Aim: To develop an in-depth understanding of current practice in providing and receiving information about recovery in stroke units and explore patients', carers' and professionals' experiences and views, to inform development of a complex intervention to improve provision.

Methods: Current practice was explored using focused ethnographic case studies in two stroke units, including non-participant observations, interviews with patients, carers and professionals, and documentary analysis. Systematic literature reviews identified and synthesised existing literature relating to patients', carers' and professionals' views and experiences, and the effectiveness of existing strategies to improve provision. This work informed intervention development underpinned by behaviour change theory, with mixed-methods survey employed to gather professionals' feedback on identified strategies.

Results: A complex range of factors influenced the consistency, quality, and delivery of information about recovery, including the hospital and stroke unit environment, multidisciplinary team (MDT) working, the uncertainties of stroke recovery, and individual differences in patients' and carers' abilities and needs. Patients and carers reported mixed experiences of receiving information, and desired delivery to be positive, honest, proactive, and compassionate. Identified barriers to provision included professionals' perceived lack of skills and confidence and insufficient knowledge of the benefits. No strategies to deliver recovery information that had been proven effective in improving patient and carer outcomes could be identified from existing literature. Professionals perceived practical advice and demonstrations of communication skills, MDT support, and patient and carer accounts as feasible and effective strategies to address these barriers.

Discussion: Communication of information about recovery in stroke units continues to be sub-optimal and presents significant challenges for professionals. Further research is required to continue development of an intervention to support professionals to provide information more effectively.

Table of Contents

| | |
|---|------|
| <u>Acknowledgements</u> | ii |
| <u>Abstract</u> | iii |
| <u>Table of Contents</u> | iv |
| <u>List of Figures</u> | vii |
| <u>List of Tables</u> | viii |
| <u>List of Abbreviations</u> | ix |
| <u>Background</u> | x |
| <u>1.1 The problem of stroke</u> | x |
| <u>1.2 Post-stroke recovery</u> | x |
| <u>1.3 Stroke treatment pathways in the UK</u> | xii |
| <u>1.4 Information provision after stroke</u> | xiii |
| <u>1.5 Overview of thesis</u> | xv |
| <u>1.6 Thesis aims and objectives</u> | xv |
| <u>1.7 My perspective as a researcher</u> | xvi |
| <u>Section 1: Review of existing literature</u> | 1 |
| <u>Chapter 1 Systematic Review: The experiences and views of participants in conversations about recovery</u> | 3 |
| <u>1.1 Background</u> | 3 |
| <u>1.2 Review objectives</u> | 3 |
| <u>1.3 Methods</u> | 3 |
| <u>1.4 Results</u> | 7 |
| <u>1.5 Discussion</u> | 28 |
| <u>Section 2: Qualitative fieldwork</u> | 32 |
| <u>Chapter 2 Methods</u> | 34 |
| <u>2.1 Research design</u> | 34 |
| <u>2.2 Ethical considerations</u> | 38 |
| <u>2.3 Sampling</u> | 40 |
| <u>2.4 Recruitment</u> | 43 |
| <u>2.5 Data collection</u> | 45 |
| <u>2.6 Data analysis</u> | 49 |
| <u>2.7 Quality</u> | 53 |
| <u>2.8 Reflexivity</u> | 54 |
| <u>Chapter 3 Study context, data collected and participant characteristics</u> | 56 |
| <u>3.1 Background</u> | 56 |
| <u>3.2 Context</u> | 56 |

| | |
|--|------------|
| 3.3 Data collected | 62 |
| 3.4 Participant characteristics | 63 |
| 3.5 Reflections on recruitment and data collection | 72 |
| Chapter 4 Findings: What influences provision and receipt of information about recovery on stroke units? | 76 |
| 4.1 Background | 76 |
| 4.2 Analysis | 76 |
| 4.3 Discussion | 98 |
| Chapter 5 Findings: How do professionals experience providing information about recovery after stroke and what do they perceive as the key challenges? | 101 |
| 5.1 Background | 101 |
| 5.2 Analysis | 101 |
| 5.3 Discussion | 117 |
| Chapter 6 Findings: How do patients and carers experience receiving information about recovery after stroke and what information do they want to receive? | 119 |
| 6.1 Background | 119 |
| 6.2 Analysis | 120 |
| 6.3 Discussion | 138 |
| 6.4 Qualitative findings indicate the need for novel intervention development | 139 |
| Section 3: Complex intervention development | 142 |
| Chapter 7 Systematic Review: Effectiveness of existing interventions | 146 |
| 7.1 Background | 146 |
| 7.2 Development of the research question | 146 |
| 7.3 Methods | 148 |
| 7.4 Results | 152 |
| 7.5 Discussion | 169 |
| Chapter 8 Application of the Capability Opportunity Motivation model of Behaviour (COM-B) to identify potential promising behaviour change techniques | 173 |
| 8.1 Background and rationale | 173 |
| 8.2 The use of theory in complex intervention development | 173 |
| 8.3 The COM-B model and Behaviour Change Wheel | 175 |
| 8.4 Developing a complex intervention to improve recovery conversations using the BCW | 177 |
| 8.5 Discussion | 191 |

| | |
|--|------------|
| <u>Chapter 9 Survey study to establish healthcare professionals' views of potential behaviour change techniques</u> | 193 |
| <u>9.1 Background and rationale</u> | 193 |
| <u>9.2 Methods</u> | 193 |
| <u>9.3 Results</u> | 200 |
| <u>9.4 Discussion</u> | 214 |
| <u>9.5 Conclusions</u> | 221 |
| <u>Chapter 10 Discussion</u> | 222 |
| <u>10.1 Summary of main findings</u> | 222 |
| <u>10.2 Original contribution to knowledge</u> | 224 |
| <u>10.3 Comparison with existing literature, and implications for clinical practice and future research</u> | 225 |
| <u>10.4 Strengths and limitations</u> | 241 |
| <u>10.5 Dissemination</u> | 243 |
| <u>10.6 Implications for intervention development</u> | 243 |
| <u>10.7 Conclusions</u> | 244 |
| <u>References</u> | 247 |
| <u>Appendices</u> | 278 |

List of Figures

| | |
|---|-----|
| <u>Figure 1.1 Example of how codes generated from initial line-by-line coding were grouped into categories</u> | 7 |
| <u>Figure 1.2 PRISMA diagram of included studies</u> | 8 |
| <u>Figure 1.3 Relationship between descriptive and analytical themes</u> | 19 |
| <u>Figure 2.1 Stages in the Framework approach (88)</u> | 51 |
| <u>Figure 2.2 Example of how codes generated from initial line-by-line coding were grouped into categories (patient/ carer data)</u> | 52 |
| <u>Figure 4.1 Themes</u> | 77 |
| <u>Figure 5.1 Themes</u> | 102 |
| <u>Figure 6.1 Themes</u> | 121 |
| <u>Figure 6.2 Updated MRC framework for developing and evaluating complex interventions, reproduced from Skivington et al., 2021, pp. 4 (205)</u> | 144 |
| <u>Figure 7.1 PRISMA diagram of included studies</u> | 153 |
| <u>Figure 7.2 Bar chart used in Rahn et al.'s study to display prognostic information (reproduced from Kasper et al., 2017, pp 800 (235))</u> | 165 |
| <u>Figure 8.1 The Behaviour Change Wheel, reproduced from Michie et al., 2011, pp. 7 (262)</u> | 176 |
| <u>Figure 9.1 Twitter advertisement</u> | 196 |
| <u>Figure 9.2 Professional background of study participants</u> | 201 |
| <u>Figure 9.3 Age group of study participants</u> | 201 |
| <u>Figure 9.4 Number of years worked in stroke care by study participants</u> | 202 |
| <u>Figure 9.5 Importance of identified barriers to study participants</u> | 203 |

List of Tables

| | |
|---|-----|
| <u>Table 1.1 Inclusion criteria</u> | 4 |
| <u>Table 1.2 Characteristics of included studies</u> | 10 |
| <u>Table 1.3 Included studies: Patient and carer demographics</u> | 14 |
| <u>Table 1.4 Included studies: Healthcare professional demographics</u> | 16 |
| <u>Table 1.5 Methodological quality of included studies</u> | 18 |
| <u>Table 3.1 Site descriptions</u> | 58 |
| <u>Table 3.2 Site staffing levels</u> | 61 |
| <u>Table 3.3 Number of observed professional meetings at each site</u> | 62 |
| <u>Table 3.4 Patient participant characteristics</u> | 66 |
| <u>Table 3.5 Carer participant characteristics</u> | 67 |
| <u>Table 3.6 Professional participant characteristics</u> | 68 |
| <u>Table 3.7 Detailed patient participant characteristics</u> | 70 |
| <u>Table 7.1 Inclusion criteria</u> | 149 |
| <u>Table 7.2 Included studies: Trial design and participant characteristics</u> | 156 |
| <u>Table 7.3 Details of study interventions, structured according to TIDieR checklist</u> | 158 |
| <u>Table 7.4 Risk of bias assessment</u> | 162 |
| <u>Table 8.1 Behavioural diagnosis for the target behaviour of providing information about recovery</u> | 181 |
| <u>Table 8.2 Behavioural diagnosis using the COM-B model, suggested intervention functions and associated Behaviour Change Techniques</u> | 185 |
| <u>Table 9.1 Distribution of survey link by professional bodies</u> | 197 |
| <u>Table 9.2 Percentage of participants rating each barrier as very or extremely important; and percentage of participants who rated each proposed Behaviour Change Technique as likely to be feasible or very feasible, and likely to be useful or very useful</u> | 204 |
| <u>Table 9.3 Suggested core components of a professional-focused intervention to improve provision of information about recovery</u> | 213 |

List of Abbreviations

| | |
|-----------------|---|
| APEASE | Affordability, Practicability, Effectiveness and cost-effectiveness, Acceptability, Side-effects/ safety, and Equity (criteria) |
| ASU | Acute Stroke Unit |
| BCT | Behaviour Change Technique |
| BCW | Behaviour Change Wheel |
| COM-B | Capability Opportunity Motivation model of Behaviour |
| COMFORT | Communication, Orientation, Mindfulness, Family, Ongoing, Reiterative, Team (protocol) |
| COVID-19 | Coronavirus Disease 2019 |
| DMD | Disease Modifying Drug |
| ESD | Early Supported Discharge |
| HASU | Hyper-Acute Stroke Unit |
| MDT | Multidisciplinary Team |
| MCA | Mental Capacity Act |
| MRC | Medical Research Council |
| MS | Multiple Sclerosis |
| NHS | National Health Service |
| NICE | National Institute for Health and Care Excellence |
| NIHSS | National Institutes of Health Stroke Scale |
| OT | Occupational Therapist |
| PICO | Population, Intervention, Comparison, Outcome |
| PT | Physiotherapist |
| RCT | Randomised Controlled Trial |
| SCI | Spinal Cord Injury |
| SLT | Speech & Language Therapist |
| SPIKES | Setting up, Perception, Invitation, Knowledge, Emotions with Empathy, Strategy/ Summary (protocol) |
| STARs | Stroke Training and Awareness Resources |
| TBI | Traumatic Brain Injury |
| TDF | Theoretical Domains Framework |
| TIDieR | Template for Intervention Description and Replication |

Background

This section provides important context to the studies reported in this thesis, describing current stroke care in the UK and outlining the known issues relating to provision and receipt of information about post-stroke recovery.

1.1 The problem of stroke

Globally, stroke is the second most common cause of mortality and a leading cause of disability (1). It is estimated that one in every four people over the age of 25 will experience a stroke within their lifetime (2); in the UK this amounts to more than 100,000 strokes every year (3). The World Health Organisation defines stroke as:

“Rapidly developed clinical signs of focal (or global) disturbance of cerebral function, lasting more than 24 hours or leading to death, with no apparent cause other than of vascular origin.” (4) pp. 114

Stroke can result from a blockage (ischemic stroke) or a bleed (haemorrhagic stroke), which causes cell death by disrupting the blood supply to the brain. Although its effects are determined by its type, size and location, stroke has the potential to result in a wide range of difficulties, including physical, visual, communication and swallowing, continence, and cognitive problems (5). Additionally, many survivors experience pain, fatigue and psychological problems such as low mood and anxiety (6). These potentially long-lasting effects can limit survivors’ abilities to undertake daily activities and restrict participation, as well as impacting their quality of life (7). Stroke can also significantly impact the lives of their families, who may take on additional caring responsibilities. This can result in carer burden and psychological difficulties, such as anxiety and low mood, and reduced quality of life (8, 9).

1.2 Post-stroke recovery

Although around 13% of patients with stroke still do not survive their hospital admission (10), improvements in acute care have resulted in decreasing mortality rates over recent decades (11). These advances have however resulted in an increasing number of individuals living with the long-term effects of stroke, currently thought to be around 1.2 million in the UK (3). For survivors, the road to recovery can be long; research has slowly refocussed on rehabilitation and treatments for these individuals to identify how the best outcomes can be achieved (12).

Understanding of the processes and mechanisms underlying post-stroke recovery has increased in recent decades. Early after stroke, most patients undergo some spontaneous functional recovery (13), as the brain seeks to recover through the repair of cells that were not irreversibly damaged (restitution) and the reorganisation of neural pathways (substitution) (14, 15). Such spontaneous recovery is usually however incomplete. The extent and rate of individual recovery also varies, based on a range of factors, including medical aspects, e.g., lesion size and location; demographics, such as age; existing comorbidities; and symptom severity (16-18). The brain's ability to reconfigure, referred to as neuroplasticity, can however be exploited and enhanced by experience, e.g., intensive therapy (19). Recovery may also occur through compensation, during which patients learn to modify their behaviour within the constraints of their residual impairments (14), e.g., completing tasks with their non-dominant hand where the dominant hand is affected. Post-stroke rehabilitation therefore seeks to support spontaneous recovery and enhance neuroplasticity through the provision of task-based practice and re-learning, alongside teaching patients compensatory strategies to improve their function (14).

It is now generally accepted that greater intensity of therapy results in improved outcomes (20-22), and there is some evidence for a dose-response relationship, i.e., the more rehabilitation provided, the greater the benefit (20, 21). Guidelines therefore recommend minimum amounts of therapy to be received by patients with stroke, although the specific 'dose' remains somewhat arbitrary, guided by expert consensus rather than evidence (23). The timing of rehabilitation is also important. Animal models suggest a phase of heightened neuroplasticity occurring during the weeks and early months after the acute event, during which spontaneous recovery can be most effectively enhanced by external input (13, 19). Although it was previously thought that recovery outside of this period was unlikely (24), research has now demonstrated that for some, rehabilitation can result in continuing recovery in the months and years after this initial period (25, 26) (particularly for language (27) and cognitive impairment (28)). However, improvements tend to be activity- rather impairment-based, suggesting the mechanism is compensatory (19). To take advantage of this critical window, the bulk of rehabilitation is thus targeted during the early weeks and months after stroke (see 1.3).

Despite increasing knowledge about the process and mechanisms of post-stroke recovery, individual trajectories can be unpredictable, largely due to the wide range of factors that can influence outcomes. Predictions are largely based on clinical judgement, taking these factors into account (29). However, an increasing body of

research has focused on identifying early predictors of outcome, often through the application of standardised tools, which could inform predictions for individual patients (29). However, these tools are not widely used in clinical practice (29, 30), and achieving predicted outcomes remains dependent on a variety of factors, not least frequency and intensity of therapy (31), such that their accuracy for individual patients remains variable (18).

1.3 Stroke treatment pathways in the UK

The treatment of stroke changed significantly in the last decades of the twentieth century, with significant enhancements in acute care causing a shift from the idea that “*nothing can be done*” (pp. 51) to help patients (32), towards improved outcomes. Research informed the introduction of treatments, such as thrombolysis and, more recently, thrombectomy, as well as the reorganisation of pathways, which have resulted in improved survival and outcomes for eligible patients (33-36).

In the UK, as mandated in clinical guidelines, patients with stroke receive care and rehabilitation in hospital-based stroke units. A stroke unit has been described as a geographically discrete ward, where patients receive care from a co-ordinated multidisciplinary team (MDT), who have expertise in stroke and access to specialist education and training (37). The benefits of stroke unit care have been well-documented since the 1990s, and include reductions in mortality, disability, and institutionalisation compared with treatment on general medical wards (38). The mechanisms underlying these benefits are however less well understood. Stroke units can vary significantly in their organisation and processes, as well as the expertise and numbers of staff (39), making it challenging to identify which of their features result in improved outcomes (40). The stroke unit however represents the primary location of post-stroke care and treatment for many patients, on which ~80% of patients spend ≥90% of their hospital stay (10).

Post-acute stroke treatment is typically followed by a period of rehabilitation, which, in line with the biopsychosocial model of illness, aims to target the functional impairments and activity limitations caused by the stroke, as well as to address psychological challenges including adjustment and enhance social participation and quality of life (41). Rehabilitation is a complex intervention, delivered by a MDT primarily comprising physiotherapists, occupational therapists and speech and language therapists, working alongside stroke-skilled nurses and doctors. Therapists provide a range of interventions as appropriate to patients’ needs and guided by the patient’s own goals

for recovery. Alongside restoring function and compensating for deficits to increase activity, therapy aims to prevent complications and deterioration, and promote well-being (42). Whilst it is recommended to continue for as long as it remains beneficial to the patient, discharge from hospital generally occurs when patients are deemed medically stable and safe to continue their rehabilitation in the community (43). Around a third however leave hospital still requiring help with everyday activities (3). Whilst most patients are still discharged home, around one in ten require institutional care, e.g., in a nursing home or care facility (44). Discharge is typically navigated through a process of shared decision-making between professionals, patients and their families, to determine discharge destination and how any on-going care needs might be met.

Following discharge from the stroke unit, patients may continue their recovery at home, working towards ongoing goals with the support of community-based services. For those with mild to moderate disability, this is often facilitated by Early Supported Discharge (ESD) services, which aim to expedite hospital discharge by providing therapy at a similar frequency and intensity as an in-patient stroke unit within the patient's own home, beginning within 24 hours of discharge (45). Those experiencing more severe disability may receive support from a community stroke team, though typically at a lower frequency (43). Following the culmination of ESD therapy, patients may transition into the care of this team to continue their rehabilitation. Rehabilitation can therefore continue for a period of six months or more (43), after which patients enter a chronic phase and are usually required to self-manage any continuing effects of their condition. However, there remains significant local variation in stroke services across the UK, particularly with regards to ESD, which can impact the frequency and intensity of community-based rehabilitation received by individual patients (46).

1.4 Information provision after stroke

A suggested core component of stroke unit care is the provision of information and education to patients and their families (47). UK guidelines have strongly advocated for the provision of information to patients since the 2000s, with the aim of promoting health literacy and intervention compliance, as well as empowering patients to take control of their healthcare, and supporting engagement in shared decision-making (48). A recently updated Cochrane review identified that active provision of information after stroke may be beneficial in reducing survivors' and carers' symptoms of anxiety and depression, and improving survivors' quality of life (49). The 2007 National Stroke Strategy included the provision of information, advice and support as a marker of a quality service, acknowledging the importance of providing individualised, accessible

information to stroke survivors (including those with communication difficulties, such as aphasia) and their families across the pathway (50). However, until the most recent iteration, although UK stroke guidelines have recommended provision of information, limited detail has been offered on the types of information, who should provide it, and when (45).

Despite the outlined policy drive towards increased information provision, stroke survivors and their families consistently report receiving insufficient information in a range of areas (51-55); a recent systematic review identified inadequate information as the most common unmet need post-stroke (52). A commonly reported need is for information about recovery and prognosis, reported by both patients and carers (51, 53, 56-60). It has been suggested that receipt of such information can promote involvement in decision-making about care and treatment (51), and adjustment to potential continuing disability (58, 61). It is also necessary to help patients and families negotiate discharge from the stroke unit, informing plans about their future lives (62, 63). As a result, the 2023 UK clinical guidelines have now introduced recommendations around the sharing of information about stroke-related impairments and prognosis, to manage patients and carers' expectations of goal achievement and outcomes, and underpinning collaborative discussion about appropriate treatment pathways including stroke unit rehabilitation and ESD (23).

Despite the asserted benefits, research suggests that patients with stroke and their families do not receive enough information about post-stroke recovery (53, 56, 58, 64), and in a recent UK survey, more than one in seven stroke survivors reported they did not feel stroke unit professionals helped them to understand recovery (65). Information about recovery comprises both generic information about the recovery process and tailored information about the extent and timescale of a patient's potential functional improvements. Providing tailored information has two components: professionals must first develop a prognosis, and then communicate it to patients and families (66, 67). There is evidence that stroke unit professionals find prognostic formulation challenging, due to the uncertain trajectory of post-stroke recovery and range of factors that can influence it (68, 69). The development of new tools is beginning to inform such conversations (indeed their use is now cautiously recommended (23)), however their implementation into clinical practice has been slow (29) and training is required for professionals to use them effectively. Professionals also report that communicating tailored predictions is difficult, particularly where it involves breaking bad news (68). In order to benefit from rehabilitation, it is felt necessary for patients to be motivated to actively participate in therapy (70). Some studies suggest that professionals worry that

providing information about a potentially negative outcome, e.g., prolonged disability, will reduce patients' engagement and thus negatively influence their outcome (69, 71). Conversely, Wiles et al. described how physiotherapists were also concerned about providing over-optimistic information, which could subsequently result in disappointment should the patient's hopes for recovery not be realised; they avoided providing information as a result (69). Whilst information about medical prognosis is commonly provided by doctors, the role of providing information about functional recovery in stroke is often undertaken by other MDT members, such as therapists. Opportunities for training in discussing recovery, particularly in breaking bad news, are however scarce, resulting in a lack of confidence (63, 68).

1.5 Overview of thesis

Despite increasing policy directives and growing scientific knowledge about post-stroke recovery, it appears that patients' and carers' needs for information remain unmet. Limited research has considered the experiences and perspectives of patients with stroke, their families and professionals on this issue, and no interventions could be identified which aim to improve the provision of information about post-stroke recovery. Much of the existing literature, e.g., Wiles et al.'s work (69, 72), is now decades old, pre-dating policy shifts aimed at improving communication of health-related information. In this thesis, I seek to update the literature, developing an understanding of current practice in talking about recovery after stroke, assessing what can be learned from other neurological conditions, and beginning development of a complex intervention to support professionals to provide information more effectively. My studies focus on the stroke unit environment, as a mandatory component of the post-stroke pathway and the place where conversations about recovery typically begin.

1.6 Thesis aims and objectives

Aims

- 1) To develop an in-depth understanding of current practice in providing and receiving information about recovery on stroke units, including the experiences of those involved, and the barriers and facilitators to provision and receipt;
- 2) To use this knowledge to develop an intervention designed to improve provision of information about recovery on stroke units.

Objectives

- 1) To synthesise the currently available evidence relating to experiences of providing and receiving information about recovery in the context of stroke and other acquired neurological conditions (Chapter 1);
- 2) To develop an in-depth understanding of the factors impacting provision and receipt of information about recovery in stroke units (Chapters 2-4);
- 3) To understand the experiences and needs of professionals, patients and carers relating to discussions about recovery (Chapter 2-6);
- 4) To review existing evidence to identify approaches or strategies to providing information about recovery in stroke or other neurological conditions which have been proven effective in improving patient/ carer outcomes (Chapter 7);
- 5) To begin development of an intervention aiming to improve provision of information about recovery on stroke units informed by behaviour change theory (Chapter 8);
- 6) To gather professionals' feedback on the likely feasibility and usefulness of the proposed intervention strategies (Chapter 9);
- 7) To synthesise the knowledge gained through objectives 1-6 to make recommendations for further intervention development (Chapter 10).

1.7 My perspective as a researcher

In this section, as part of my reflexive account, I briefly describe the personal journey that led to this research, acknowledging the influence of my experiences on my choice of research area, as well as my ontological and epistemological perspective.

I identify as a white British female and was raised in a working-class environment in the north-east of England. This research was conducted over a six-year period (2017-2022) when I was aged ~32-37 years. I completed my undergraduate degree in psychology in 2006, and my Masters in clinical neuropsychology in 2007. I worked clinically in the NHS until 2010 in in-patient, and community-based, neurological rehabilitation, as a rehabilitation assistant and an assistant psychologist, respectively. I subsequently moved into stroke rehabilitation research, working as a research assistant on a range of projects, primarily including qualitative and mixed methods, but also assisting within randomised controlled trials and undertaking systematic review work. The commonality across most of my research experiences is in its applied and pragmatic nature, taking place within the complexities of healthcare environments. My research motivation is to improve clinical practice, and thus the experiences of both those receiving and providing care (rather than to seek expansion of knowledge in its

own right). To achieve this, I believe it is important to use the methods most appropriate to the research questions and as such I am not committed to a single ontology or epistemology: I am a pragmatist.

The topic of the research reported here was driven by both my previous research and clinical experience. Having spent time engaging in non-participant observations in stroke units, I struggled to watch conversations between professionals, stroke survivors, and families about recovery, finding them at times awkward and even distressing. Comments expressing frustration and difficulty with the dearth of information about recovery raised by patients and carers caused me to reflect on my clinical experiences, and recall moments during which I had struggled when asked to provide such information myself as a junior MDT member. Although these experiences inspired me to pursue this topic, I also had an increased awareness of their potential impact on my focus and interpretations and bore this at the forefront of my mind throughout the research process, taking care to examine my own potential personal biases.

The data collection and analysis methods employed in my doctoral work are largely those I have previously used and am therefore familiar with (ethnographic case-study, Framework analysis, survey), and are based on my experiences of 'what works'. However I have also used this opportunity to explore new methods to inform my development as a researcher, such as systematic review of qualitative literature and behaviour change techniques. Although traditionally research (particularly methods) is reported in the third person to convey objectivity, my epistemological views about the way in which knowledge is constructed by researchers through both their decisions about methodology and design, and interpretations of the data they collect, has led to my use of the first person when reporting my studies. I return to questions of ontology and methodology in Chapter 2 and reflexivity in Chapters 2-3.

Section 1: Review of existing literature

Before embarking on a journey to explore the provision and receipt of information about recovery on stroke units, it was important to establish what was already known about the topic, to inform research planning and prevent unnecessary replication. Systematic review of the literature is a structured method, which aims to combine, interpret and draw conclusions from, the aggregated findings of existing research (73, 74). Key features include the use of a pre-planned protocol, which documents a systematic approach aiming to identify all studies which meet specific inclusion criteria, and appraisal of the quality of the extracted evidence (73). This approach therefore seeks to minimise bias.

The popularity of systematic reviews grew with the rise of evidence-based healthcare, which aims to facilitate best practice and equitable care by using research evidence alongside patients' values to inform clinical decision-making (75). Systematic reviews facilitate this through increasing access to the latest research for clinicians and policy makers, who may lack the time and access to stay abreast of the huge volume of developing evidence in their field (73, 76). Early synthesis focused on combining quantitative evidence from randomised clinical trials to draw together evidence of their effectiveness (77). More recently, methods for the synthesis of mixed-methods and qualitative literature have been developed (78). Qualitative studies often centre on patients' experiences of healthcare or the attitudes and beliefs of those involved in its delivery, which can identify areas for improvements (79). Additionally, they can shed light on the reasons why interventions may or may not be effective, and barriers to implementation (80). However, studies are often small by design, aiming to elicit rich and in-depth understanding of particular phenomena (79, 80). As well as summarising available literature and making it more accessible, synthesis should produce evidence that is more than the sum of the parts of the individual studies (80).

Qualitative studies are particularly useful for exploring the topics of providing information about prognosis and breaking bad news, enabling the exploration of the perceptions and experiences of conversation participants in a potentially sensitive area (81). As a result, an extensive body of research exists. Most studies however relate to cancer and palliative care settings, where such discussions typically relate to life expectancy or decisions about treatments of which the aim is curative or life-prolonging. In stroke, the focus is somewhat different; some recovery is nearly always possible, typically representing an upward trajectory. The challenge for those prognosticating is in the identification of the likely extent and time-frame of such

recovery, which may have an unpredictable course (82). Similar issues are evident in some other neurological conditions, such as traumatic brain injury (TBI) and spinal cord injury (SCI), where conversations about recovery share a similar focus (83). 'Bad news' in these cases may relate to prognostic information that is likely to be perceived as negative by patients and their families, e.g., that the patient may not regain as much independent function as hoped or that recovery will take longer than expected.

Initial scoping searches identified only a small number of studies specifically considering the experiences and views of participants in conversations about recovery following stroke. Scoping searches were therefore extended to wider neurological conditions, to identify what could be learned in clinical areas where the issues were likely to be similar to those encountered in stroke care. Some of the identified conditions were however progressive disorders, where there is a progressive deterioration in functioning with no known cure, such as dementia or Motor Neurone Disease. Discussions about prognosis in these cases thus appeared more similar to those in cancer, focusing on treatments to delay or slow the progression of symptoms. The size of the literature within such conditions was also significant; for example, a recent review exploring the experiences of those involved in giving and receiving the bad news of a diagnosis of dementia alone included 52 studies (84). As a result, the review presented here focused on synthesising the experiences and views of participants in conversations about recovery and breaking bad news in acquired neurological conditions.

Chapter 1 Systematic Review: The experiences and views of participants in conversations about recovery

1.1 Background

This chapter reports a systematic review of qualitative studies exploring the experiences and views of patients with acquired neurological conditions, their carers, and professionals, when providing and receiving information about recovery.

1.2 Review objectives

The review aimed to report and synthesise the views, perspectives, and experiences of patients with acquired neurological conditions, their carers, and healthcare professionals about the provision and receipt of information about recovery, including discussion of prognostic information, which may include 'bad news'. The research questions were:

- How do patients with acquired neurological conditions and their carers experience receiving information about recovery, including bad news, and what do they think about it?
- How do healthcare professionals working in acquired neurological conditions experience delivering information about recovery including bad news and what are their views about it?

1.3 Methods

The review was prospectively registered on the International Prospective Register of Systematic Reviews (ref: CRD42017081922).

1.3.1 Eligibility criteria

Eligibility criteria are outlined in Table 1.1. Papers presenting the views of healthcare professionals working across multiple neurological conditions, rather than a specific condition, e.g., in neurorehabilitation, were considered suitable for inclusion, as it was deemed that the views of these professionals were relevant to the research questions.

Table 1.1 Inclusion criteria

| | |
|----------------|--|
| Study designs: | Qualitative studies presenting empirical data, including (but not limited to) those collecting data via interviews, focus groups or questionnaires permitting free text responses. Descriptive studies, editorials and opinions papers were excluded. |
| Participants: | Human adults (≥ 18 years), where $\geq 50\%$ participants either: <ul style="list-style-type: none"> • Had a diagnosis of an acquired neurological condition, including stroke, traumatic brain injury, spinal cord injury or peripheral nerve lesions, or brain tumour (no restrictions according to time post-diagnosis). • Cared for someone with one of the diagnoses listed above. • Were a healthcare professional involved in the care of people with one of the diagnoses listed above. |
| Interventions: | Not applicable |
| Comparators: | Not applicable |
| Outcomes: | Not applicable |
| Setting: | No restrictions were employed according to setting (in-patient, community, outpatient, or primary care). |
| Language: | English language. |

1.3.2 Search strategy

Electronic databases (Medline, EMBASE, AMED, CINAHL, PsycINFO, Web of Science and the Cochrane library) were searched from their time of inception to July 2019.

Search strategies were created with assistance from an Information Specialist. Search terms were developed through an iterative process, involving repeated pilots. A search strategy for one database is available in Appendix A; this was adapted to the Medical Subject Headings (MeSH) terms and syntax requirements of each database. Searches were limited to English language (due to resource limitations) and human adults. No study design filters were employed.

Previous authors of systematic reviews aiming to identify papers relating to provision of recovery information and breaking bad news have identified challenges in keyword searching, resulting from the variety of language used in this field (85). For example, authors have referred to “*prognostic awareness*” pp. 1 (86) or “*difficult conversations*” pp.93 (87). Therefore, to ensure the searches were as comprehensive as possible, a

wide range of keywords were selected, and backwards and forwards citation searching of included articles were employed.

1.3.3 Data management and study selection

Search results from each database were combined, and de-duplicated in EndNote. I screened titles and abstracts for eligibility against the inclusion criteria using a piloted in/ out decision sheet, with 20% independently screened by a second reviewer (a supervisor). Full texts were obtained for each paper deemed to meet the inclusion criteria and for those where there was uncertainty. Full text review was conducted by two independent reviewers (myself and a research colleague) using a Microsoft Access database, where decision-making and reasons for exclusion were recorded. Discrepancies between reviewers were discussed and referred to a third reviewer (a second supervisor) where agreement could not be reached.

1.3.4 Data extraction

Data were extracted from the selected papers, using a standardised form. Extracted data included study aims, sampling techniques and size, participant demographic information (age, gender, diagnosis), country, study setting, and methodology (data collection and analysis methods). Data were extracted from all included studies by two independent reviewers (myself and a research colleague) and compared to check agreement.

1.3.5 Critical appraisal of included studies

In recent decades, attempts have been made to quantify and judge the quality of qualitative research through the development and use of research checklists (88). These checklists include a selection of quality indicators and their use may improve the quality of study reports (89). However, they can be challenging to apply due to the diversity of methods used in qualitative research (90) and there is no consensus about the most appropriate checklist to use (91).

In this study, critical appraisal was completed using a checklist covering the core domains of quality in qualitative research (the National Institute for Health and Care Excellence (NICE) public health guidance quality appraisal checklist (92)), which assesses fourteen domains including study design and appropriateness of qualitative methods, clarity of the study aims, data collection methods including triangulation, consideration of context, the role of the researcher, analytical methods, conclusions

and ethics. It was chosen because of its specific development by a national body, for the purpose of assessing the quality of research for inclusion in UK guidelines (92). Included studies were graded in three categories according to whether all or most of the checklist items were fulfilled (++), some of the items were fulfilled (+), or few or none of the items were fulfilled (-) (92).

Each included study was scored independently by myself and a second reviewer (a research colleague). I then compared both sets of scores and discussed areas of disagreement with the second reviewer. Where consensus could not be reached, a third reviewer was consulted (a supervisor). In this study, quality was assessed to reveal possible limitations to included studies, rather than for the purposes of exclusion. The results of lower quality studies were examined to confirm that they did not contradict the findings of higher quality studies, and that these studies did not contribute disproportionately to the conclusions. This was to ensure that the synthesis results were not biased by lower quality studies and therefore lower the risk of drawing unreliable conclusions.

1.3.6 Data synthesis

In addition, all text labelled as 'results' or 'findings', including participant quotations and author-generated analytical themes was extracted from included studies into qualitative data management software (QSR NVivo v10). Thematic synthesis (93) was selected for this study because it can be applied to review questions aiming to make recommendations for interventions (94), and moves from initial line-by-line coding of data presented in individual studies, to subsequent development of descriptive, and then analytical, themes (93). Its detailed procedure addresses questions relating to transparency in qualitative synthesis by clearly linking the findings of primary studies to the review conclusions (93).

In this study, I inductively free-coded extracted data line-by-line. The codes generated were grouped and organised into descriptive themes (see Figure 1.1), before being evaluated for repetition and condensed to form a coding framework, which was subsequently reapplied to the included studies. The coded findings were exported from NVivo and displayed in a Framework matrix in Microsoft Excel, to facilitate comparison of the views and experiences of healthcare professionals, patients, and carers; and to assess whether and how views and experiences might vary, depending on neurological condition and participant type. Summaries were produced for each descriptive theme, and were then considered against the review objectives to develop

analytical themes (93). Development was iterative and founded upon links between the descriptive themes and their implications on patients', carers', and professionals' experiences and views of the provision and receipt of recovery information (93). Preliminary results were discussed with my supervisors during the coding process, and throughout the development of themes. I prepared a draft summary of findings, which I circulated amongst my supervisors, who suggested other potential interpretations. Following amendments, a final stage of reading through all included studies ensured that findings were representative of the original studies.

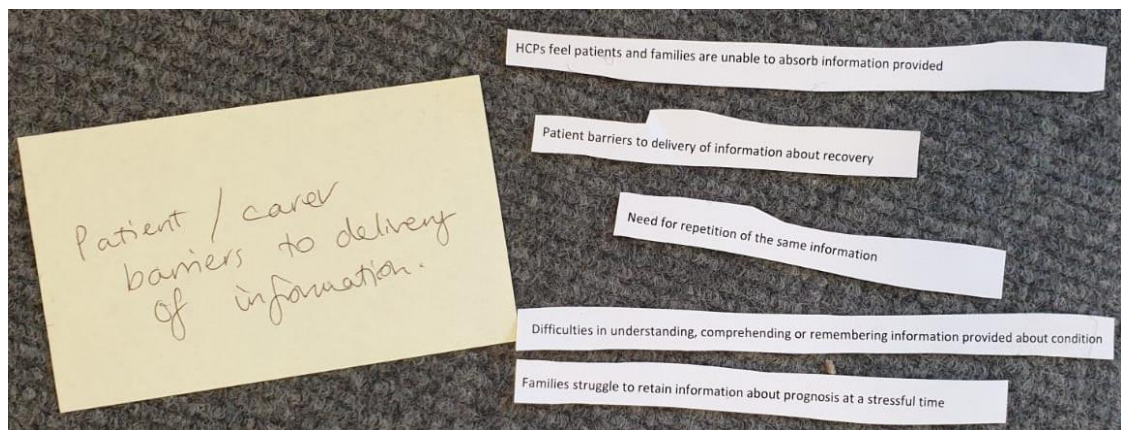


Figure 1.1 Example of how codes generated from initial line-by-line coding were grouped into categories

1.4 Results

1.4.1 Study selection

Following removal of duplicates, the searches identified 9,105 articles for title/ abstract screening (see Figure 1.2). Full texts of 145 papers were retrieved for review, and 30 papers reporting 28 studies were retained for inclusion. Two studies were reported in two papers each: Lefebvre and Levert (95, 96) and Wiles et al (69, 72).

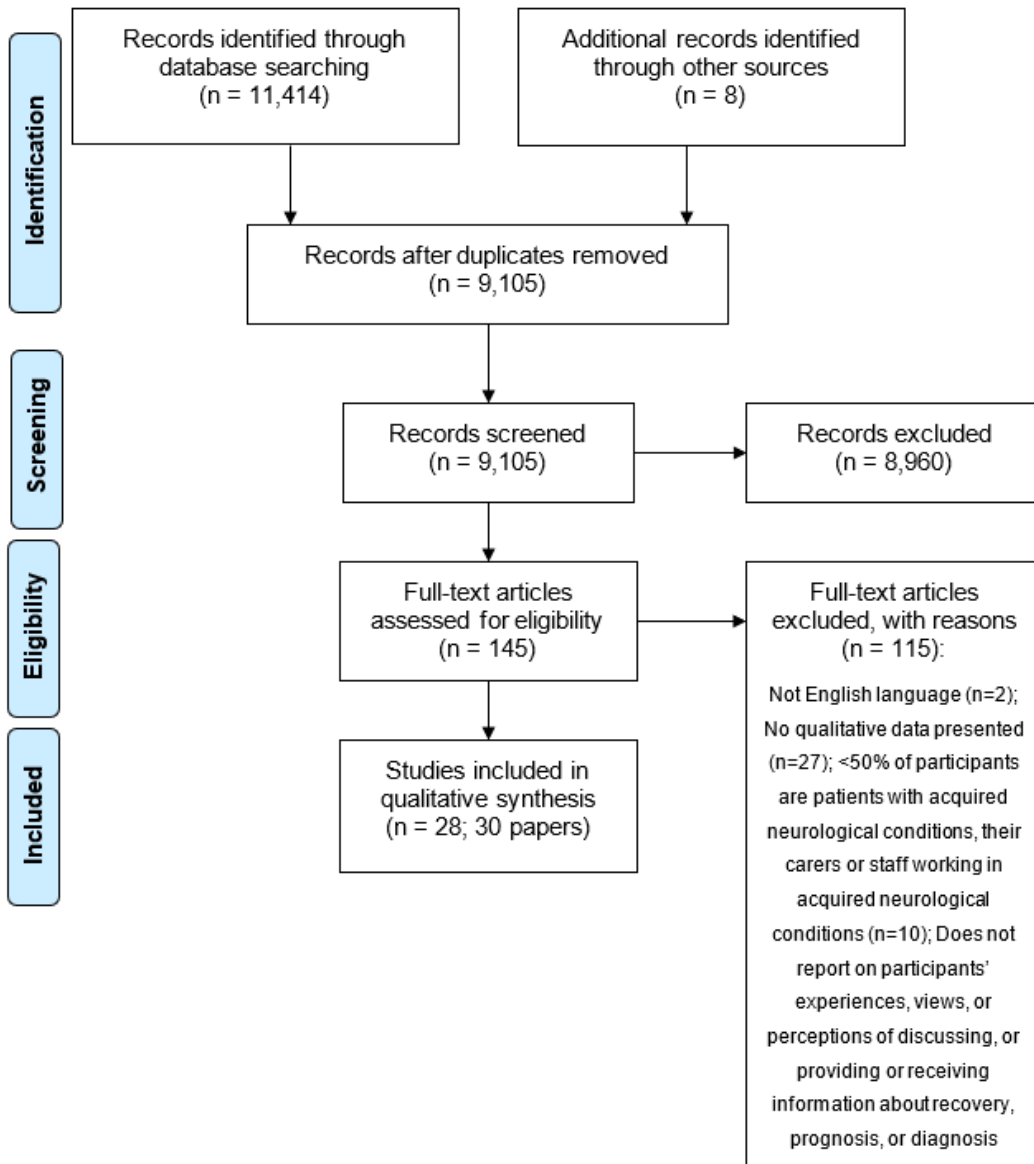


Figure 1.2 PRISMA diagram of included studies

1.4.2 Study characteristics

The 28 included studies were conducted in eight different countries: Nine in the USA (71, 97-104), six in the UK (62, 63, 68, 69, 72, 83, 105), five in Australia (106-110), three in Canada (111-113), two in Italy (114, 115), one each in Sweden (116) and Turkey (117), and one in Canada and France (95, 96) (see Table 1.2). Included studies most frequently came from the stroke literature (n=10) (62, 68, 69, 71, 72, 98, 104, 107, 109, 110, 116), whilst similar numbers came from Traumatic Brain Injury (TBI) (n=6) (95-97, 100, 101, 103, 112), Spinal Cord Injury (SCI) (n=5) (99, 111, 114, 115, 117), and multiple neurological conditions (n=5) (63, 83, 105, 106, 113), with a minority from the brain tumour literature (n=2) (102, 108). Of the five papers considering multiple neurological conditions, four included only professionals, who

worked with patients with a range of neurological diagnoses. These included professionals working in TBI and SCI rehabilitation (83), occupational therapists working in neurology settings (63), neurological physiotherapists (105), and speech and language therapists working with patients with aphasia (106). The latter three papers contained no further information about the diagnoses of the patients with whom the professionals worked. The fifth paper included patients, carers, and professionals in palliative neurology, citing a range of conditions including stroke, TBI, brain tumours, amyotrophic lateral sclerosis and muscular dystrophies (113).

Roughly equal numbers took place in the in-patient setting (n=10) (62, 71, 83, 97, 100-102, 104, 111, 116) and community (n=11) (68, 98, 99, 103, 107-110, 112, 114, 117), whilst a minority took place across multiple settings: in-patient and out-patient (n=2) (69, 72, 113), in-patient and community (n=3) (63, 95, 96, 115), and two included professionals from a range of settings, including in-patient, out-patient and community (105, 106). Of note, two studies were conducted in palliative care settings; one involved multiple neurological conditions (described above) (113), the other involved TBI (101).

Five studies included data from only individuals with the condition (99, 107, 110, 114, 117), four reported views of only carers (97, 102, 104, 115), and four included perspectives of both individuals with the condition and carers (98, 103, 108, 109). Seven included only professionals, including physiotherapists (105), occupational therapists (63), speech and language therapists (106), nurses (111), doctors and nurses (116), a mixture of therapists (68), or a wider mix of professionals (83). Three included individuals with the condition and professionals (62, 69, 71, 72), one included carers and professionals (100), and four included all three groups (95, 96, 101, 112, 113). Participant demographic data from the included studies are presented in Table 1.3 and Table 1.4.

In terms of data collection methods, most studies used semi-structured interviews (n=17) (63, 71, 97, 98, 100, 101, 104-106, 108-110, 112, 114-117) and three used focus groups (95, 96, 103, 107). One used a survey (99), and one analysed a video-taped observation (62). Six used mixed-methods: three employed focus groups and interviews (83, 111, 113); one each used interviews and questionnaires (102), observations and interviews (69, 72), and a questionnaire and observations (68).

Table 1.2 Characteristics of included studies¹

| Authors | Condition | Stated aim | Country | Service setting | Perspective | Sampling method | Sample size | Time after event | Data collection | Methodology/ Data analysis | Quality rating |
|-----------------------------|--------------|--|-----------|--|--|----------------------------|----------------|------------------------------|---|-------------------------------------|----------------|
| Applebaum et al, 2018 (102) | Brain tumour | <i>"To understand what informal caregivers of patients with malignant glioma understand about their loved one's prognosis, how they derived this information, what additional information they would like, and the existence of discrepancies in prognostic understanding between informal caregivers and patients with malignant glioma."</i> Pp. 818 (102) | USA | Inpatient Neurology service at a Cancer Centre | Carer (Patient) | Not stated | 32 (32) | In-patient | Mixed - methods. Interviews and follow-up questionnaire | Inductive thematic textual analysis | - |
| Becker & Kaufman, 1995 (71) | Stroke | <i>"To examine illness trajectories from two vantage points, that of older persons who have had a stroke and that of physicians who care for stroke patients."</i> Pp. 165 (71) | USA | Community hospital | Patient Healthcare Professional | Not stated Snowball | 36 20 | In-patient | Semi-structured interviews | Content analysis | + |
| Bond et al, 2003 (97) | TBI | <i>"To discover the needs of families of patients with severe traumatic brain injury during the families' experience in a neurosurgical ICU."</i> Pp. 64 (97) | USA | Neurological ICU | Carer | Convenience | 7 | In-patient | Interviews | Content analysis | + |
| Ch'ng et al, 2008 (107) | Stroke | <i>"To explore long term perspectives on coping with recovery from stroke, to inform the design of psychological interventions."</i> Pp. 1137 (107) | Australia | Stroke support groups | Patient | Purposive | 26 | Community: 6 months-12 years | Focus groups | Thematic analysis | + |
| Conti et al, 2016 (115) | SCI | <i>"To explore the experience of caregivers of individuals with SCI analysing the final phase of hospitalisation and</i> | Italy | SCI unit | Carer | Purposive | 11 | In-patient and community | Interviews | Phenomenology: Giorgi method | ++ |

¹ ICU=Intensive Care Unit; (T)BI=(Traumatic) Brain Injury; SCI=Spinal Cord Injury; OT=Occupational Therapist. Participants in parentheses were recruited to the study but did not participate in the qualitative element, therefore results from these participants have not been included in the analysis. *Inferred from author's description; ** A second paper from the same study was also used in the analysis, which considered only the Canadian data from healthcare professionals (n=29) and carers (n=19); ***A second paper from the same study was also used in the analysis, which considered the process of discharge and included only the patients who had completed data at the third time=point (n=13 patients and n=21 healthcare professionals)

| | | | | | | | | | | | |
|---------------------------------|--------|--|-----------|---|-------------------------|--|----------|-------------------------------------|----------------------------|---|----|
| | | at 6 months from discharge, to highlight their needs during hospitalisation as well as emotional experiences, reactions to difficulties resulting from being back home, and subsequent positive and negative aspects related to discharge." Pp. 160 (115) | | | | | | | | | |
| Dams-O'Connor et al, 2018 (103) | TBI | "To learn about the experiences individuals with BI have in seeking and accessing healthcare (both primary and speciality care), from the 'patient' or insider perspective, in order to better understand how providers and health systems can improve care for their patients with BI." Pp. 432 (103) | USA | Medical centres and support groups | Patient Carer | Convenience | 44 1 | Community: 0.8-66.3 years | Focus groups | Content analysis | + |
| Danzl et al, 2016 (98) | Stroke | "To examine rural Appalachian Kentucky stroke survivors' and caregivers' experiences of receiving education from health care providers with the long-term goal of optimising educational interactions and interventions for an underserved population." Pp 13 (98) | USA | Discharged patients from medical centres and rehab network (flyers/ mailshot) | Patient Carer | Convenience* | 13 12 | Community: 1-14 years | Semi-structured interviews | Content analysis | + |
| Dewar, 2000 (111) | SCI | "To explore nurses' perceptions of their role in delivering bad news in an acute spinal cord injury unit and to describe their experiences, difficulties, and needs as professionals." Pp. 325 (111) | Canada | Acute spinal cord unit | Healthcare professional | Convenience* | 22 | In-patient | Focus groups, 1 interview | Grounded theory – constant comparison method | - |
| El Masry et al, 2013 (109) | Stroke | "To explore the psychosocial aspects of the experiences, concerns, and needs of caregivers of persons following stroke." Pp. 357 (109) | Australia | Discharged patients from neurology unit, speech therapy department and rehab hospital | Patient Carer | Purposive (maximum variation and theoretical sampling) | 10 20 | Community: >3 months | Semi-structured interviews | Interpretive phenomenological analysis: Thematic analysis | ++ |
| Garrino et al, 2011 (114) | SCI | "To assess the perception of care by patients with SCI by collecting important data in order to determine whether an integrated and personalised care pathway could be effective." Pp. 67 (114) | Italy | Discharged patients from SCU | Patient | Purposive* | 21 | Community: >3 months post-discharge | Semi-structured interviews | Narrative approach: Content analysis | - |

| | | | | | | | | | | | |
|------------------------------------|-------------------------|--|-------------------|---|---|---|--|--|--|---|---|
| Gofton et al, 2018 (113) | Neurological conditions | <i>"To develop a conceptual understanding of the specific characteristics of palliative care in neurology and the challenges of providing palliative care in the setting of neurological illness."</i> Pp. 226 (113) | Canada | Academic medical centre | Patient Carer Healthcare professional | Not stated Not stated Purposive | Not stated | In-patient and Out-patient – palliative | Dyadic patient/ carer interviews Focus groups | Grounded theory – constant comparison method | + |
| Grainger et al, 2005 (62) | Stroke | <i>"To explore the practice of bad news delivery in a specific healthcare setting."</i> Pp. 42 (62) | UK | Stroke rehabilitation ward | Patient Healthcare professional | Not stated | 1 1 (part of larger study) | In-patient rehabilitation | Video-recorded interaction | Ethnography: Conversation analysis | - |
| Hersh, 2003 (106) | Neurological conditions | <i>"[To discuss] speech pathologists' reports about how they discharge their clients with chronic aphasia; [to explore] the process of weaning in order to define its nature and raise awareness of it as a common aspect of clinical practice."</i> Pp. 1007 (106) | Australia | Practicing SLTs | Healthcare professional | Not stated | 20 | In-patient/ Out-patient and community | Semi-structured interviews | Grounded theory | - |
| Kirshblum et al, 2016 (99) | SCI | <i>"To determine when, by whom, and in what setting persons with neurologically complete traumatic SCI want to hear of their prognosis."</i> Pp. 155 (99) | USA | Medical rehabilitation facilities | Patient | Convenience | 56 (45 complete d qualitative component) | Community: >3 months | Online survey with open and closed questions | Thematic analysis | - |
| Lefebvre & Levert, 2006 (112) | TBI | <i>"To investigate the experiences of individuals who had sustained a TBI, their families, the physicians and health professionals involved, from the critical care episodes and subsequent rehabilitation."</i> Pp 711 (112) | Canada | Hospital rehabilitation centres; paramedical organisation and victims association | Patient Carer Healthcare professional | Purposive (Maximum Variation Sampling)* | 8 14 36 | Community: mean 2.8 years | Semi-structured interviews | Thematic analysis* | + |
| Lefebvre & Levert, 2012** (95, 96) | TBI | <i>"To explore the needs of individuals and their loved ones throughout the continuum of care and services, from the point of view of everyone affected by the experience of a TBI. including individuals, their loved ones, and the health care professionals involved in their care."</i> Pp. 198 (96) | Canada and France | Not stated Acute care, rehabilitation or social reintegration | Patient Carer Healthcare professional | Convenience | 56 34 60 | Community: mean=4.3 years In-patient/ community | Focus groups | Thematic content analysis | + |
| Lobb et al, 2011 (108) | Brain tumour | <i>"To understand patient experiences of high-grade glioma and to describe their information and support needs."</i> Pp 316 (108) | Australia | Tertiary centre for neurological cancers | Patients Carer | Purposive | 19 21 | Community: within 1 year of diagnosis | Semi-structured interviews | Grounded theory – constant comparison method | + |
| Maddern & Kneebone, 2019 (110) | Stroke | <i>"To explore the experience of stroke survivors when receiving bad news from</i> | Australia | Community stroke clubs | Patients | Convenience* | 10 | Community: 2-4 years, mean=6.2 years | Semi-structured interviews | Interpretive phenomenological analysis, Thematic analysis | + |

| | | | | | | | | | | | |
|--------------------------------------|-------------------------|--|--------|---|---|-------------------------------------|----------------|---------------------------------------|---|--|----|
| | | <i>medical practitioners.</i> " Pp. 1 (110) | | | | | | | | | |
| Ozyemisci-Taskiran et al, 2018 (117) | SCI | <i>"To investigate the process of breaking bad news from the perspective of spinal cord injury survivors."</i> Pp. 347 (117) | Turkey | Discharges from in-patient rehabilitation | Patients | Not stated | 14 | Community: 1–19 years, mean=7.5 years | Semi-structured interviews | Content analysis | - |
| Peel et al, 2019 (83) | Neurological conditions | <i>"To explore health professionals' lived experiences of having difficult conversations surrounding rehabilitation potential; to explore different strategies used to support these difficult conversations; and to identify how future practice could be improved."</i> Pp. 1 (83) | UK | Regional neuro-rehabilitation unit within an acute hospital | Healthcare professional | Convenience* | 15 | In-patient | One focus group; 5 individual interviews | Phenomenological approach: Thematic content analysis | + |
| Phillips et al, 2013 (68) | Stroke | <i>"To address the seemingly neglected area of BBN within stroke care, by documenting a collaborative consultation undertaken to support this skill within a multidisciplinary community stroke rehabilitation team."</i> Pp. 695 (68) | UK | Multidisciplinary community stroke team for early discharge | Healthcare professional | Self-selecting* | 5 | Community | Case study of consultation. Self-report questionnaire, qualitative observations | Not stated | - |
| Quinn et al, 2017 (100) | TBI | <i>"To explore key communication preferences and practices by stakeholders (surrogates and physicians) for the outcome prognostication during goals-of-care discussions for critically ill TBI patients."</i> Pp. 155 (100) | USA | Level-1 trauma centres | Carer Healthcare professional | Purposive Purposive and snowball | 16 20 | In-patient | Semi-structured interviews | Content analysis | + |
| Rejno et al, 2017 (116) | Stroke | <i>"To deepen the understanding of stroke team members' reasoning about truth telling in end-of-life care due to acute stroke with reduced consciousness."</i> Pp. 100 (116) | Sweden | Combined acute and rehabilitation stroke unit teams | Healthcare professional | Convenience sample | 15 | In-patient | Interviews | Content analysis | ++ |
| Schutz et al, 2017 (101) | TBI | <i>"To explore how family members, nurses, and physicians experience the palliative and supportive care needs of patients with severe acute brain injury receiving care in the neuroscience intensive care unit."</i> Pp. 170 (101) | USA | Neuro-ICU | Patient Carer Healthcare professional | Purposive | 15 16 31 | In-patient – palliative care | Semi-structured interviews | Thematic analysis | ++ |
| Sexton, 2013 (63) | Neurological conditions | <i>"To answer the question, 'What are the experiences of occupational therapists when having bad news"</i> | UK | Neurological OTs | Healthcare professional | Convenience | 10 | In-patient and community | Semi-structured interviews | Phenomenology: Thematic analysis* | ++ |

| | | | | | | | | | | | |
|--------------------------------------|------------------------------------|--|-----|---|------------------------------------|--------------|------------|--|---|------------------------------------|----|
| | | <i>conversations with disabled people regarding long-term neurological disability?" Pp. 270 (63)</i> | | | | | | | | | |
| Soundy et al, 2010 (105) | Neurological conditions | <i>"To 1) explore the meanings of the different types of hope that neurological physiotherapists give to patients to consider, 2) give greater depth to the role of hope in clinical practice, 3) present the dilemmas of physiotherapists hope for their patient, and 4) illustrate how different disease prognoses may influence hope." Pp. 80 (105)</i> | UK | Neurological physiotherapists | Healthcare professional | Purposive | 9 | In-patient, out-patient and community: Clinical specialists and educators in one UK city | Semi-structured interviews | Categorical-content analysis | ++ |
| Wiles et al, 2002, 2004 *** (69, 72) | Stroke | <i>"To explore the factors, associated with physiotherapists' provision of information, that may contribute to patients' high expectations of physiotherapy." Pp. 842 (69)</i> | UK | 3 acute Trusts | Patient Healthcare professional | Not stated | 16 26 | In-patient and out-patient | Longitudinal case studies – semi-structured interviews and observations | Grounded theory: Thematic analysis | ++ |
| Zahuranec et al, 2018 (104) | Stroke – intracerebral haemorrhage | <i>"To examine surrogate decision maker perspectives on provider prognostic communication after intracerebral haemorrhage." Pp. 956 (104)</i> | USA | 5 health system/ hospital/ medical centre sites | Carer (Patient) | Convenience* | 52 (52) | In-patient: Median days from admission to interview = 35.5 | Semi-structured interviews | Thematic analysis* | + |

Table 1.3 Included studies: Patient and carer demographics²

| Authors | Perspective | Sample size | Age range | Mean age | % female |
|---------------------------------|------------------|-------------|---------------------|--------------------------|------------------|
| Applebaum et al 2018 (102) | Carer | 32 | Not stated | Average=50 | 64 |
| Becker & Kaufman, 1995 (71) | Patient* | 36 | 48-105 | Not stated | 64 |
| Bond et al, 2003 (97) | Carer | 7 | 41-61 | Not stated | 71 |
| Ch'ng et al, 2008 (107) | Patient | 26 | 22-79 | 60.9 | 54 |
| Conti et al, 2016 (115) | Carer | 11 | 28-80 | 57.4 | 73 |
| Dams-O'Connor et al, 2018 (103) | Patient Carer | 44 1 | 23-72 Not stated | Not stated Not stated | 58 Not stated |
| Danzl et al, 2016 (98) | Patient | 13 | 42-89 | 63.4 | 69 |

² *A second paper from the same study was also included, with 19 carers, age range=28-67, mean 50.6 years; **A second paper from the same study was also included, with 13 patients of the same age range/mean age, 61.5% female. *Study also included healthcare professionals (see Table 1.4).

| | | | | | |
|--------------------------------------|--------------------|---|--|--------------------------|--------------------------|
| | Carer | 12 | 38-75 | 55.9 | 58 |
| El Masry et al, 2013 (109) | Patient Carer | 10 20 | 41-50=2; 61-70=4; 71-80=3; 81-90=1 31-40=2; 41-50=2; 51-60=3; 61-70=5; 71-80=5; 81-90=3 | Not stated Not stated | 20 80 |
| Garrino et al, 2011 (114) | Patient | 21 | 34-63 (F); 19-70 (M) | Not stated | 24 |
| Gofton et al, 2018 (113) | Patient• Carer | Not stated Not stated | Not stated Not stated | Not stated Not stated | Not stated Not stated |
| Grainger et al, 2005 (62) | Patient• | 2 (part of larger study) | Not stated | Not stated | 100 |
| Kirshblum et al, 2016 (99) | Patient | 56 (45 completed qualitative component) | 18-30=10 31-40=17 41-50=17 50+=12 | Not stated | 13 |
| Lefebvre & Levert, 2006 (112) | Patient• Carer | 8 14 | 18-29=5, 30-39=1, 40-49=2 18-29=3; 30-39=3; 40-49=4; 50-59=10; 60+=2 | 28.4 46.4 | 25 64.3 |
| Lefebvre & Levert, 2012* (95, 96) | Patient• Carer | 56 34 | Not stated Not stated | Not stated Not stated | 30 59 |
| Lobb et al, 2011 (108) | Patients Carers | 19 21 | Not stated 30-39=2; 40-49=2; 50-9=10; 60-69=6; 70+=1 | Not stated Not stated | 37 81 |
| Maddern & Kneebone, 2019 (110) | Patients | 10 | 61-84 | 63.4 | 30 |
| Ozyemisci-Taskiran et al, 2018 (117) | Patients | 14 | 25-57 | 37.2 Median=35.5 | 7 |
| Quinn et al, 2017 (100) | Carer• | 16 | Not stated | 57 | 56 |
| Schutz et al, 2017 (101) | Patient• Carer | 15 16 | Not stated Not stated | 46.1 Not stated | 33 69 |
| Wiles et al, 2002, 2004** (69, 72) | Patient• | 16 | 41-79 | 66 | 62.5 |
| Zahuranec et al, 2018 (104) | Carer | 52 | Not stated | Median=55 | 60 |

Table 1.4 Included studies: Healthcare professional demographics³

| Authors | Perspective | Sample size | Professional roles | Age range | % female | Years of experience in practice | Years of experience with condition |
|-----------------------------------|-------------------------|--------------------------|---|------------|------------|--|--|
| Becker & Kaufman, 1995 (71) | Healthcare professional | 20 | Physicians | 32-78 | 20 | Not stated | Not stated |
| Dewar, 2000 (111) | Healthcare professional | 22 | Nurses | 22-54 | Not stated | Mean=7.4 | Mean=4.6 |
| Gofton et al, 2018 (113) | Healthcare professional | Not stated | Physicians 5 nurses 6 allied health professionals (SLT, OT, PT) | Not stated | Not stated | Not stated | Not stated |
| Grainger et al, 2005 (62) | Healthcare professional | 1 (part of larger study) | OT | Not stated | 100 | Not stated | Not stated |
| Hersh, 2003 (106) | Healthcare professional | 20 | SLT | Not stated | 97 | >20 = 12; 5-20 = 14; <2 = 4 | Not stated |
| Lefebvre & Levert, 2006 (112) | Healthcare professional | 36 | Nurse=16.1%; PT=9.7%; OT=6.5% SLT=3.2%; Remedial teacher=3.2%; Psychologist=6.5%; Social worker=12.9%; Special educator=6.5%; Psychosocial coordinator=3.2%; Physician=29% | Not stated | Not stated | Mean=12 <5=16.1%; 6-10=19.4%; 11-15=35.5%; 16-20=25.8%; >20= 3.2% | Mean=8.2 <5=32.3%; 6-10=32.3%; 11-15=25.8%; 16-20=9.7% |
| Lefebvre & Levert, 2012* (95, 96) | Healthcare professional | 60 | 13 psychology/ neuropsychology; 7 OT 6 social work; 5 nursing; | Not stated | 68.3 | Average= 15.75 | 1-30 |

³ SLT=Speech and Language Therapist; OT=Occupational Therapist; PT=Physiotherapist; *A second paper from the same study was also included, with 29 healthcare professionals of the same professions, average experience in rehabilitation=13 years, no other demographics available. **A second paper from the same study was also included, with 21 PT, no other demographics available.

| | | | | | | | |
|------------------------------------|-------------------------|----|--|-----------------------------|------------|-----------------------|---|
| | | | 4 health care aid; 3 PT; 2 kinesiology; 2 SLT; 2 clinical coordination; 2 rehabilitation counselling | | | | |
| Peel et al, 2019 (83) | Healthcare professional | 15 | Physicians, nurses, OT, PT, SLT, psychologists | Not stated | 80 | Not stated | <1=5, >10 years=4 |
| Phillips et al, 2013 (68) | Healthcare professional | 5 | 2 OT, 1 PT, 1 SLT, 1 rehabilitation assistant | Not stated | 100 | 8-38 | Not stated |
| Quinn et al, 2017 (100) | Healthcare professional | 20 | Physicians | Mean age=47 | 35 | Not stated | Median (speciality practice)=11, range=2-40 |
| Rejnö et al, 2017 (116) | Healthcare professional | 15 | 4 physicians, 11 nurses | Mean age=48 | 73 | Not stated | Median: 11 |
| Schutz et al, 2017 (101) | Healthcare professional | 31 | Physicians Nurses | Not stated Mean age=44.7 | 19 80 | Median=4 Median=18 | Not stated |
| Sexton, 2013 (63) | Healthcare professional | 10 | OT | 21-30=3, 31-40=5, 41-50=2 | 90 | 11 (range=2-27) | 6.9 (range=1-13) |
| Soundy et al, 2010 (105) | Healthcare professional | 9 | PT | Mean age=43.2 | 100 | Not stated | 4-17 (median=10) |
| Wiles et al, 2002, 2004** (69, 72) | Healthcare professional | 26 | PT | Not stated | Not stated | Not stated | Not stated |

1.4.3 Quality assessment

Table 1.5 details the methodological quality of included studies. Most (n=20) were scored + or ++, suggesting that all/ most or some of the criteria were met, and where there was insufficient description, the conclusions would be unlikely to change. Of the eight studies deemed to be of lower quality, four lacked richness of the data presented (98, 99, 114, 117). In four, the context from which the data were drawn was unclear (68, 106, 111, 113), and in three, the analysis did not appear sufficiently rigorous (68, 111, 117). In three studies, research methodology was not adequately justified (62), data collection methods were not clearly described (62), methods were felt to be unreliable (111), or the links between the findings and conclusions were unclear (99).

Table 1.5 Methodological quality of included studies

| | Appropriate | Not sure | Inappropriate |
|--|-------------------|---------------------------------|-----------------|
| 1 Theoretical approach: appropriateness | 28 | 0 | 0 |
| | Clear | Mixed | Unclear |
| 2 Theoretical approach: clarity | 24 | 4 | 0 |
| | Defensible | Not sure | Indefensible |
| 3 Research design/ methodology | 10 | 17 | 1 |
| | Appropriately | Not sure/ Inadequately reported | Inappropriately |
| 4 Data collection | 14 | 13 | 1 |
| | Clearly described | Not described | Unclear |
| 5 Trustworthiness: role of the researcher | 4 | 24 | 0 |
| | Clear | Not sure | Unclear |
| 6 Trustworthiness: context | 15 | 9 | 4 |
| | Reliable | Not sure | Unreliable |
| 7 Trustworthiness: reliable methods | 7 | 20 | 1 |
| | Rigorous | Not sure/ not reported | Not rigorous |
| 8 Analysis: rigorous | 16 | 9 | 3 |
| | Rich | Not sure/ not reported | Poor |
| 9 Analysis: rich data | 17 | 7 | 4 |
| | Reliable | Not sure/ not reported | Unreliable |
| 10 Analysis: reliable | 9 | 19 | 0 |
| | Convincing | Not sure | Not convincing |
| 11 Analysis: convincing | 23 | 5 | 0 |

| | Relevant | Partially relevant | Irrelevant |
|---------------------------------------|-------------|------------------------|---------------|
| 12 Analysis: relevance to aims | 24 | 4 | 0 |
| | Adequate | Not sure | Inadequate |
| 13 Conclusions | 24 | 3 | 1 |
| | Appropriate | Not sure/ not reported | Inappropriate |
| 14 Ethics | 19 | 9 | 0 |
| | ++ | + | - |
| Overall assessment | 7 | 13 | 8 |

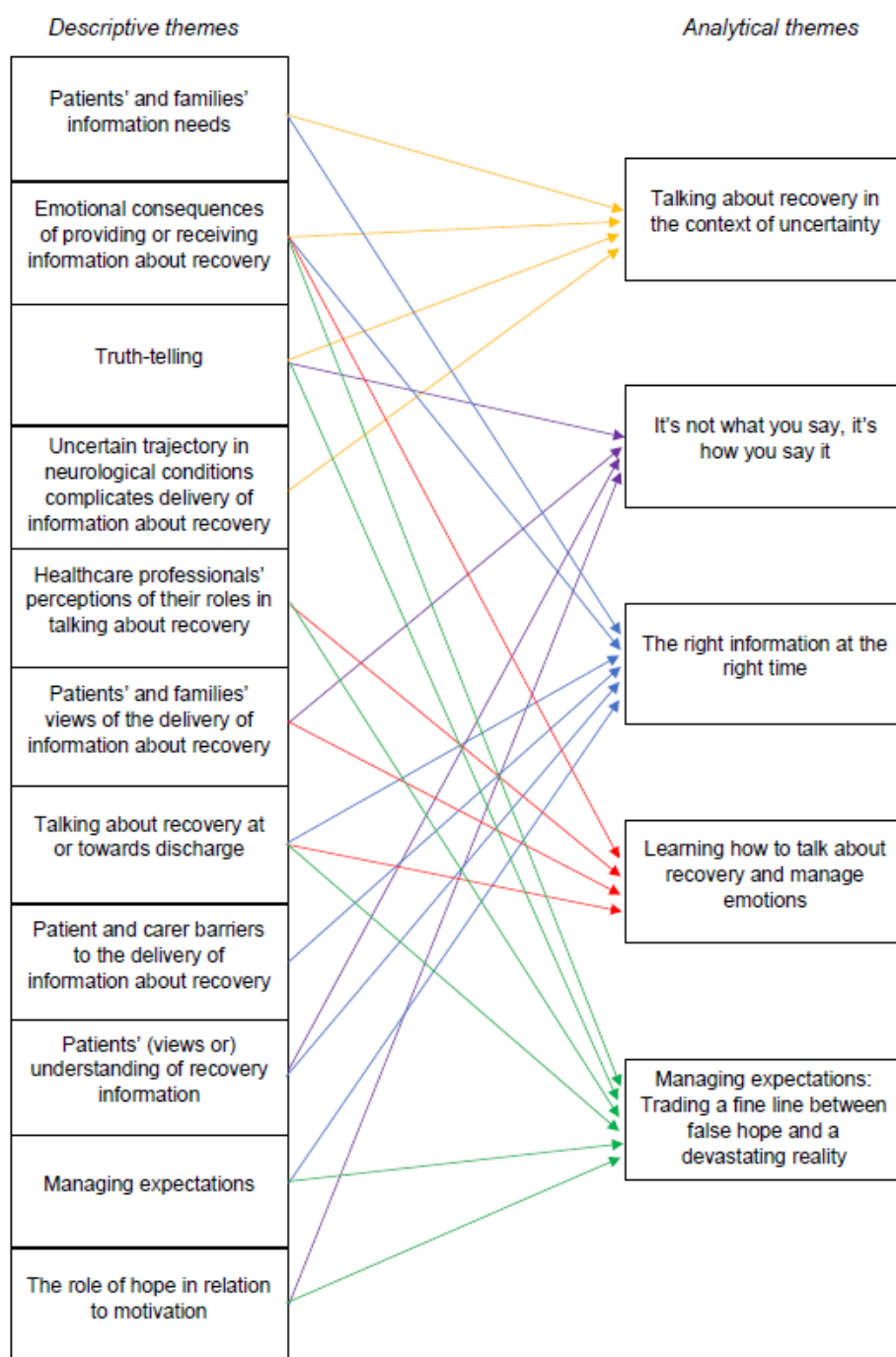


Figure 1.3 Relationship between descriptive and analytical themes

1.4.4 Thematic synthesis

Eleven descriptive themes were generated from the synthesis, and were used to develop five analytical themes (93), reflecting patients', carers', and professionals' experiences of receiving and providing information about recovery. Themes are outlined in Figure 1.3; the five analytical themes are considered in detail below:

1.4.5 The right information at the right time

In general, patients and carers across studies wanted to receive information about their diagnosis and recovery prognosis from their treating clinical teams (71, 95-97, 114, 115). This usually included information about the nature of the patient's condition, the cause, available treatments, and the prognosis or long-term prospects. However, there was some variation in what was deemed to be the 'right' information across conditions and individuals. Patients with SCI particularly wanted clear information about their diagnosis (114, 115), whilst patients with stroke and TBI commonly wanted information about their recovery potential, including how long this would take and their long-term outcome (71, 95-97). In contrast, some patients with tumours did not wish to receive prognostic information (usually in relation to a life-limiting condition) (102, 108):

"[.] when we met with the doctor, it seemed she wanted to reveal to us where we stood, and I interrupted her, and said that I really do not want to, I cannot hear that so please do not share that with me." Carer, brain tumour (102)

Overall, a source of dissatisfaction for patients and carers across numerous studies was a feeling that they did not receive enough information from their healthcare teams (95, 96, 98, 100, 103, 107-110, 112, 115, 117). Complaints included professionals not being proactive in providing information (98, 112), or not providing timely information (95, 96, 103, 110). Patients and carers described negative emotions associated with not receiving information including frustration (95, 96, 100, 115), worry (110), carer stress (115), delay in acceptance and adjustment (112), and decreased trust in, and poorer relationships with, their treating professionals (100, 112). Consistency in approach and language across different professionals was viewed as essential, with concerns raised when different professionals provided incongruous information (97, 100, 104).

The timing of information provision was also a key concern for patients and carers. In the acute phase after TBI, stroke or SCI, e.g., in the emergency room, information was often provided to families, due to the medical status of the patient. However, even where patients were medically stable, the nature of an unexpected neurological event

or diagnosis meant that they or their families often felt unable to understand or retain information effectively in the early period after the event, due to their emotional state of mind, i.e., feeling overwhelmed, or in shock (95, 96, 98, 103, 107, 108, 112):

“In [the hospital], my wife was away for a moment when the nurses were doing their rounds, but my mom was there. And they gave her a bunch of handouts. . . And I think they may have explained a little bit about brain injury. But my mom wasn’t quite in the head-space to remember all of it at the time. [...]” Patient with TBI (103)

Some patients and carers accepted these limitations and described how they wanted information to be repeated at different time-points (103). For professionals however, this presented a challenge: they were aware of these difficulties (95, 96, 111, 112), but feared complaints from patients and carers who felt that information was not satisfactorily provided (112). Suggested strategies to manage this situation included repetition of information at different times (98, 103, 112), provision of written materials (103), and providing staff details for patients and families to contact if they had questions at a later time (103).

Professionals agreed that the timing of information about recovery potential needed to be right for the individual patient and carer, suggesting that they needed to be ‘ready’ to hear it (63), or they risked causing anger or distress (68). Some studies, particularly those involving stroke survivors, suggested that some patients could reject or deny information about recovery provided when they were not ready to hear it, particularly where it was perceived to be negative and challenged their hopes of returning to their previous lifestyle (68, 69, 72, 110, 117):

“I just thought, I’ll be all right, I’ll be all right... the people told me that you will get aphasia and that you’re going to have that for the rest of your life and I thought, yeah, I’ll be over that in a couple of weeks’ time, and never did [get over it].” Patient with stroke (110)

Some professionals felt that the most important time to provide information was during rehabilitation (although of note, no studies included the rehabilitation of patients with brain tumours), when patients received therapy to help them re-gain their independence, with some suggesting ‘drip-feeding’ it over time (83, 106, 111), or providing it in the context of a formal meeting (83):

“In the back of your mind, you’ve got some rough plan of “I don’t think she is really going to ever get functional verbal speech” so you do your other stuff along the way to try and bring them to that point as well.” Speech & Language Therapist (106)

In some cases, the practicalities of discharge forced therapists to discuss recovery towards the end of rehabilitation (69, 72), particularly where a patients' home environment was deemed unsuitable or their care needs had increased (62, 63):

"The patient perhaps isn't safe to go home anymore ... and we were recommending placement, and that's always hard to discuss with people."
Occupational Therapist, In-patient neurology (63)

Where patients and particularly carers felt they didn't receive the right information about recovery from professionals, they sought it from other sources (95, 96, 102, 117). Most commonly, alternative sources included use of the internet (83, 95, 96, 102, 117), and books and newspapers (95, 96, 105). Human sources of information included fellow patients and their families (83, 117), and skilled relatives or friends (95, 96, 110, 117). Occasionally, professionals expressed concern about the use of additional sources, worrying that information could provide false hope, particularly where the information did not pertain to the individual's specific case (83, 105).

1.4.5.1 Managing expectations: Treading a fine line between false hope and a devastating reality

This theme relates only to studies in TBI, SCI, stroke and general neurology settings; none of the included studies considered rehabilitation after brain tumour.

Although professionals felt that during rehabilitation was the best time to discuss recovery potential, this was sometimes problematic. During rehabilitation, patients were mostly engaged in therapy and motivated to work hard. Whilst professionals endeavoured to be realistic in the information they provided, they were aware that receiving potentially 'bad news' about how much (or how little) a patient might achieve in the long-term could be distressing and demotivating. As a result, they were concerned about the impact negative information could have on patients' mood, hope and, subsequently motivation to participate in rehabilitation (63, 68, 71, 83, 105, 111); a feeling echoed by some patient and carer participants (110). Professionals feared that a loss of motivation could result in a negative prediction becoming a self-fulfilling prophecy:

"I just don't want to sort of squash their hope ... they sort of give up a lot and also they don't maintain their home exercise programme."
Occupational Therapist, community rehabilitation (115)

These fears could result in professionals being unwilling or hesitating to discuss recovery with patients and families (63, 71).

At the opposite end of the spectrum, professionals also feared that a failure to manage patients' and families' expectations about recovery and provide realistic information could foster 'false hope,' and allow patients and carers to maintain expectations of a return to life as they had experienced it before their neurological event (63, 69, 72, 100, 101, 105, 112). They worried that patients, and their carers, would be disappointed or distressed if their hopes for recovery were not realised (69, 72, 100, 105). As a result, professionals knew they must provide some realistic information to manage patients' and carers' expectations, but expressed that they must do so in a way that nurtured their patients' hope and motivation; this was presented as a careful and challenging balance (68, 69, 72, 83, 105, 106, 111):

"You wouldn't want to give them too high hopes, but then you also want to encourage them [...]" Neurological physiotherapist (105)

Professionals described several strategies they used to manage the expectations of patients and carers. In the acute phase, they could provide written information about the role of rehabilitation and what could be provided by their service (83). During rehabilitation, therapists described how realistic goal-setting (63, 105, 106) and repetition of information about recovery in different forms (written, via keyworker or outreach service) (83) could help to manage expectations about what it might be possible to achieve. Where expectations were effectively managed, professionals described benefits in enabling carers to plan for the future (63) and in facilitating discharge (106); however where patients maintained what professionals deemed to be unrealistic hopes for recovery, they felt this limited adjustment to disability (69, 72).

Underlying discussions about recovery often appeared to be an assumption made by patients that they would make a full recovery, and that their main route to recovery was through rehabilitation. Where this was the case, they perceived discharge as an end to their recovery, and expressed disappointment if it occurred before their recovery expectations were met (69, 72). In contrast, professionals understood recovery as a long-term process, with its conclusion likely involving adaptations to a patient's previous lifestyle.

In a minority of studies however, it wasn't simply the outcome of rehabilitation about which professionals and patients were observed to have incongruous ideas, but also their understanding of the process. Whilst professionals described that what could be achieved through therapy was mediated by spontaneous neurological recovery, only two studies described how this was conveyed to patients and carers (69, 71, 72), and this concept was rarely mentioned by patient and carer participants (69, 72, 98).

Patients and carers therefore, placed much emphasis on patients' motivation and effort within rehabilitation, which could result in feelings of failure if their expected level of recovery was not achieved (95, 96). Rather than discussing the complexities of rehabilitation and/ or recovery with patients and carers, professionals attempted to bring patients' and carers' expectations and perspectives about recovery closer to their own so that they were 'on the same page' (62, 101). Strategies employed by professionals at discharge when patients felt they had not achieved their expected recovery included negotiation of a finite number of treatment sessions or the use of objective measures to demonstrate to the patient that they were no longer making progress and thus persuade them that more therapy would not be beneficial to their recovery (69, 72, 106).

1.4.5.2 It's not what you say, it's how you say it

Where professionals feared both giving false optimism and destroying hope, patients and carers described how important hope was to them (102). Where information about recovery was provided, patients and carers felt that professionals should deliver it with compassion and empathy (95, 96, 98-100, 108, 110, 117), as well as positivity, allowing them to maintain hope and motivation (95, 96, 99, 101, 108-110, 117):

"I think they need to be more in empathy with the patient rather than just a number." Patient with stroke (110)

They wanted positive messages, including a focus on the function the patient retained, rather than what they had lost (99, 108):

"I would prefer the initial statement to be addressing the positive aspect of the condition. e.g., 'you are capable of doing almost all you did before the accident'." Patient with SCI (99)

This presentation of 'good news' alongside bad news was observed (62), and also acknowledged as a strategy by some professionals (111). Patients and carers expressed a need to feel listened to and understood, with their distress acknowledged (98, 103, 110, 117). A private setting for information provision was important, and patients valued being able to choose whether their families were present or not (99, 117). Sometimes, however, patients and carers felt professionals were too negative in the messages they gave, resulting in distress, anxiety, fear or anger (101, 109). Where bad experiences were recounted, they involved receiving incongruous information from different professionals (97, 100, 104), overhearing information (117), not being given an opportunity to ask questions (95, 96, 110, 117), or the use of complex medical terminology, which limited their understanding of the information (95, 96, 104).

Patients and carers also described a desire for truthful and honest information about recovery (95-97, 99-101), and professionals felt that telling the truth was important to build relationships, gain families' trust and maintain their own credibility (111, 116):

"I can take the bad news. Just don't tell us things that are not true and think that we need to hear happy things." Carer, TBI (97)

For professionals, a consistent approach to conveying information could help patients to process and understand what had happened to them, accept residual disability, and adjust to necessary lifestyle changes (83, 105, 106). It was also crucial to developing a trusting relationship between patients, carers, and professionals (95, 96, 112). The use of inconsistent language between professionals and the expression of different viewpoints could have negative effects on carers, including causing distress and confusion (104), causing them to doubt the truth of what professionals were telling them (97, 104), triggering arguments amongst families (97), and resulting in stress and anxiety in decision-making (100, 104). In some studies, participants suggested having one key contact in the patient's family and one on the healthcare team, or providing written information, could aid consistency (83, 95-97).

1.4.5.3 Learning how to talk about recovery and manage emotions

Most professionals described a role in talking about recovery (except for brain tumours; no included studies involved professionals working with patients with brain tumour), and in breaking bad news, including physicians and therapists (63, 68, 71, 83, 101, 106), although none advocated a team approach. Nurses did not take outright ownership of this role, choosing to defer to physicians or therapists (101, 111), although some described how the round-the-clock nature of their work meant they were well-placed and available to answer patients' questions when information provided by other professionals had had time to 'sink in' (111).

Although therapists described a role in talking about recovery, they described lacking sufficient training or confidence, worried patients would not listen to them and felt uncomfortable answering questions outside of their expertise (63, 68, 83). In terms of the knowledge and skills required, therapists and nurses felt communication skills were important to effectively discuss recovery with patients and families, as well as knowledge about, and ability to predict, potential outcomes (63, 68, 83, 105, 111).

Most felt that learning to break bad news was experience-based, rather than provided via formal training (63, 83), although some expressed an unfulfilled need for training (63, 68, 83, 112). Where training was desired, therapists wanted it to be led by experienced colleagues, and suggested techniques such as role-play, supervision and

debriefing, and reflective practice. Provision of staff support groups (63) and access to clinical guidelines were also felt to be important (83). In terms of content, therapists wanted training to include the grieving process and breaking bad news (83). Access to training was not discussed by physicians in the included studies, perhaps because such training is now commonly provided as part of medical education.

Where professionals (therapists, nurses, and physicians) talked about their experiences delivering information about recovery, and particularly, breaking bad news, they often described an emotional cost. Their emotional reactions ranged from awkwardness and discomfort, to worry and stress, as well as feelings of responsibility or failure (63, 69, 72, 83, 111-113):

“We are dealing with long term disability and we’re almost dealing with the acute stages of anger and coming to terms, [it] can be really emotionally hard for the therapist as well.” HCP, in-patient neurorehabilitation (83)

“I wonder if there is a sense ... almost that you have failed the patient.”
Occupational Therapist, in-patient neurology (63)

Professionals described that these conversations became easier with experience and identified reflective practice and debriefing with team members as ways to manage their emotions (63, 83, 111).

Patients and carers also described their emotional responses to discussions about recovery. This was often related to receiving ‘bad news’ and included shock (at diagnosis) (108, 112), fear (110), anger (110, 117), distress (107, 110, 117), and anxiety (107). In some cases, the way that information about recovery or bad news was presented provoked a negative emotional response, for example, where patients felt the professionals provided the information in a rushed or patronising manner, they could experience anger or anxiety (110). In addition to delivering information about recovery, professionals described a role in managing the resulting emotional reactions of patients and carers (68, 69, 72, 83, 111, 112, 116). They described how strategies such as detaching themselves from the situation and talking about their own feelings could help (112), however some described withholding information or avoiding having conversations with patients or carers to limit their emotional response (112, 116).

1.4.5.4 Talking about recovery in the context of uncertainty

Before being able to convey information about recovery and prognosis to patients and carers, and thus meet their information needs, professionals must feel able to make predictions about how the trajectory of an acquired neurological condition might progress for a specific individual. To do this, some described using clinical evidence or

results of medical investigations, whilst others relied on their previous clinical experience; however, they often felt that outcomes were still uncertain (69, 71, 72, 105, 113). Across studies, professionals discussed how uncertainty impacted their ability and willingness to share their predictions with patients and their families. They described how, although they might have a hunch or an instinct about how much recovery a patient was likely to achieve based on their previous experience, it was not always possible to generalise across cases, and they might encounter exceptions (71, 105, 106):

“I do find that most families, or the person themselves wants to know how much is this going to improve . . . how quickly that's going to happen? And I usually say ‘well, I don't know, everybody is different’ and in my own mind I have probably already got a gut feeling of how much change they are going to make, as in actual change on testing . . . but it is not usually something that I would verbalise . . . because you do get the surprises.”
Speech and Language Therapist (106)

Professionals dealt with this uncertainty in different ways. Many were afraid to convey predictions about recovery to patients and their families for fear of being wrong, and therefore giving false hope, causing disappointment and anger if their predictions did not come to pass; or quashing hope unnecessarily (69, 72, 111-113). They feared that the information provided would be ‘used against them’ by patients and carers and worried about damaging relationships (69, 72, 100, 112). As a result, some professionals described how they might avoid or delay providing information about recovery (68, 69, 72, 101, 106, 112); which did not go unnoticed by patients (112, 114). Many provided vague information or made attempts to convey the uncertainty they faced (69, 71, 72, 95, 96, 100, 106, 112):

“The prognosis is never certain, and when you don't know, you have to tell them you don't know.” HCP, TBI (95)

“I just own it. I just say I'm not sure [...] Usually I'll have a hunch, that it is going to go one way or the other, but I readily and openly cop to not being sure and not knowing.” Physician, Critically-ill TBI (100)

Some professionals felt that sharing their uncertainty could instil realism in patients and families, thus avoiding false hope, but could help patients to maintain the hope that they needed to keep them engaged and motivated in rehabilitation (71, 105, 106).

The extent to which patients and carers accepted the uncertainty presented to them varied across individuals. Whilst some were able to accept it (69, 71, 72, 104, 114), others found uncertainty resulted in feelings of frustration, worry and confusion (95, 96, 104, 109, 112, 115):

“I don't know what he is going to be able to do. It made me anxious I guess is probably the best way to describe it. I wanted answers and they really

were not able to give me answers.” Carer of patient with intracerebral haemorrhage (104)

The inability to see what the future might hold could make them feel helpless and impotent; the trajectory appeared outside of their control, and the endpoint was unclear (71, 115).

However, some families did find hope in the uncertainty presented to them (101, 104). The ‘not knowing’ of what may occur gave them space to hope for a positive outcome. Some described sympathy for the professionals, who they believed were trying their best in an uncertain situation (114):

“Doctors never committed themselves by saying you will never walk again. However, the poor things really didn’t know what to say.” Patient with SCI (114)

From the perspective of professionals, some felt that patients and carers generally could understand the uncertainty they were facing as professionals, whilst others accepted that uncertainty could cause frustration or distress (106, 112).

1.5 Discussion

1.5.1 Summary of main results

This review included 28 studies (30 papers) from across a range of acquired neurological conditions, and synthesis of this literature has provided significant insights into the views and experiences of those involved in conversations about recovery. In particular, this study has demonstrated the difficulties inherent in talking about recovery after neurological events. Although patients and carers desire more information about an individual’s potential for recovery, a triad of factors impact professionals’ efforts to meet these needs, namely the uncertain trajectory of recovery, a desire to maintain patients’ hope and motivation in rehabilitation, and typically an absence of training to discuss recovery and break bad news. Where information is provided, patients and carers emphasise that it should be delivered honestly, with kindness and compassion, and most of all, positivity.

1.5.2 Comparison with existing reviews

This is the first systematic review to synthesise the qualitative literature exploring patients’, carers’ and professionals’ views and experiences of discussing recovery in acquired neurological conditions. Most previous studies have reviewed the literature relating to communicating prognosis and breaking bad news in life-limiting illnesses, particularly cancer, or palliative care (e.g., Matthews et al. (118)). Whilst these reviews

reveal that patients' and carers' preferences for receipt of this information are similar, including honesty, empathy and positivity in communication (118-120), the importance of maintaining therapeutic engagement is likely to be more pertinent in rehabilitation settings, such as those encountered in neurology. The review reported here suggests particular challenges are faced by professionals resulting from the need to discuss the realistic potential for a negative outcome with the maintenance of motivation for continuing active engagement in therapy. Challenges in communication arising from the consequences of neurological events, e.g., cognitive and language problems, are also specific to this clinical area, and require special consideration from professionals.

Previous reviews of breaking bad news have frequently focused on recommendations or interventions to improve its delivery, and are primarily aimed at doctors (121, 122). This review is one of the first to highlight the experiences of professionals other than doctors in providing information about recovery and breaking bad news. Research is increasingly acknowledging the role played by therapists and nurses in breaking bad news; a recent metasynthesis of fourteen studies considering the experiences of multidisciplinary professionals working in a range of conditions similarly identified the emotional costs associated with breaking bad news, reporting widespread feelings of anxiety, stress and sadness, and fear of patients' reactions (123). As in this review, the authors recognised the lack of emotional support available and characterised the act of breaking bad news as an individual one, rather than a team effort (123). An absence of training was however not reported, perhaps because most of the included studies (9/14) still included doctors, who likely receive routine education in this area (123).

1.5.3 Strengths and limitations

Synthesis of qualitative studies using rigorous methods has facilitated understanding and comparison of the perspectives of the three groups of participants in recovery conversations. Whilst qualitative studies are by nature context-specific, and frequently based on a small number of cases than are quantitative studies (79), the use of thematic synthesis has facilitated 'going beyond' the results of the included studies, to present new perspectives and advance knowledge (124).

A limitation of systematic review methodology is that the validity and relevance of review findings are dependent on the quality and reporting of the included studies. Appraising the quality of qualitative research is a contentious issue, both in terms of whether and how it should be completed (125). In this study, a widely-used tool designed to assess the quality of evidence to make recommendations for inclusion in

public health guidance was employed (92). Although quality assessment was not used to exclude studies from the review, all the included studies were considered worthy of inclusion, as they made a valuable contribution to the synthesis.

Systematic searching of the literature using a robust search strategy, including backwards and forwards citation searching was a strength of this study, reducing the likelihood that relevant articles were missed. However the use of inconsistent terminology in this field, and in qualitative research in general, means this remains a possibility. Additionally, the inclusion of only studies published in English (due to resource limitations) and conducted in Western countries may have resulted in the omission of the experiences of patients, carers, and professionals reported in different languages, and from other cultural backgrounds.

The searches for this review were conducted in 2019; more studies have been published since this date, which would have been eligible for inclusion. In a series of linked studies, Cheng et al. describe the experiences of patients with post-stroke aphasia, their carers, and SLTs in receiving and delivering information about recovery, respectively (126-128). Similarities between these studies and the themes identified in this review include patients' desire for information about recovery despite tensions due to the emotional reactions caused by conversations and the desire to remain hopeful (127); challenges for professionals, including balancing hope with realism, a relative absence of training and reliance on clinical experience (126); the perceived importance of timely information and the therapeutic benefits to discussing recovery, including to support adjustment (126); and the inadequacy of information for carers (128). These studies also highlight the specific challenges reported by patients with aphasia and their carers (127, 128), which have not arisen in this review as no studies specifically considered their perspectives. These include the experience of aphasia as an "*invisible impairment*" pp. 880 (127), which could cause some patients to doubt the information they were provided due to their perceptions of the hidden extent of their problems. Additionally, interviews with carers revealed a preference for information about how recovery could be maximised rather than information about outcomes (128). However, overall, participants' experiences appeared broadly similar to those reported in other studies in this review.

1.5.4 Implications for clinical practice and research

It is unsurprising that the findings of this review indicate that patients and carers report unmet needs for information: This finding is common within the neurological literature

(56, 129, 130). However, these results suggest that it may be unclear whether information provision did not occur or whether information was provided but patients and carers were unable to retain or understand it, due to the shock of diagnosis; cognitive or communication problems resulting from neurological damage; or complexities in medical language. This identifies a need for future studies to utilise observations of clinical practice alongside interviews to ascertain this.

In highlighting the work of professionals other than doctors in providing information about recovery and breaking bad news, these findings also emphasise the need for increased clarity and guidelines about the roles of MDT members in this area. This is important to ensure consistency in information delivery and that those involved in delivering this information possess the relevant skills and confidence to do so. Interventions to improve professionals' communication skills may benefit from the inclusion of models and strategies designed to support the delivery of bad news in ways which meet patients' and carers' needs for empathy and compassion, e.g., the SPIKES protocol (131). Training incorporating these models using techniques such as role play and group discussions, have been demonstrated to be effective in increasing clinicians' confidence (132, 133) and patient satisfaction (134), therefore their absence in all but one of the included studies (68) is perhaps surprising. More research is required to understand how multidisciplinary teams work together to coordinate the delivery of recovery information to patients and their families, and to identify how the training and emotional support needs of professionals might best be met.

Section 2: Qualitative fieldwork

The findings of the systematic review presented in Chapter 1 revealed the need for further research to explore the provision and receipt of information about recovery, from the perspectives of those involved in these conversations, particularly in stroke care. The use of multiple methods of data collection was particularly indicated, to develop an understanding of the root causes of patients' dissatisfaction with the amount of information provided and their understanding of it. To date, no research in stroke care has explored the contemporaneous experiences of patients, carers and multidisciplinary professionals. Only a handful of studies have been conducted in the in-patient setting (62, 69, 71, 72, 116), with a single study including observations of practice alongside participants' self-reported views; this was published ~20 years ago (69, 72). Stroke care has changed dramatically over the last two decades: improvements in acute management and reorganisation of pathways have significantly improved survival rates and outcomes (34, 135). While positive, this has increased the number of those experiencing its long-term effects (136), potentially changing the landscape for conversations about recovery in stroke units.

This section of my thesis details a qualitative study, in which I aimed to explore current practice relating to the provision and receipt of information about post-stroke recovery in stroke units, including how, when, and why such information is provided, and the perspectives, experiences and views of patients, carers, and healthcare professionals, using non-participant observation, interviews, and documentary analysis.

My objectives were:

- To develop an understanding of how, when, and why information about recovery is provided to patients and carers in the in-patient stroke unit setting;
- To identify the information patients and carers want and need about recovery after stroke;
- To explore how patients and carers feel about the prognostic information they receive;
- To develop an understanding of the perspectives of healthcare professionals, including their perceived ability to make predictions about stroke recovery, how they feel about sharing this information with patients, carers and other members of the multidisciplinary team (MDT), and whether and how training to deliver such information is provided;
- To explore the barriers and facilitators to providing and receiving information about recovery.

In Chapter 2, the methodological approach and study design will be described; subsequently Chapters 3-6 will detail the study findings, organised in line with the study objectives and beginning with a description of the context and participants.

Chapter 2 Methods

In this chapter, I detail my selection of the methodological approach and research design to address my aims and objectives.

2.1 Research design

2.1.1 Methodological approach and study design

At the beginning of this thesis, I introduced myself as a pragmatist, unwedded to a particular traditional ontological standpoint, and unlike those who identify as positivists (believing that a stable, measurable reality exists) or align with interpretative or constructionist ontologies (who consider reality to be interpreted or social constructed) (79). For the latter, views of reality lend themselves to epistemological beliefs about how knowledge can be accessed, which inform the selection of corresponding research methods. As a result, positivism is irrevocably tied to quantitative research, whilst interpretivism and constructionism are associated with qualitative study; the so-called 'paradigm wars' (137). It has been argued however that strict allegiance to a particular ontology or epistemology can constrain method selection, discounting those that might be best employed in a given situation (138, 139). In contrast, pragmatists focus more closely on the selection and combination of methods that most appropriately fit the research question posed (88, 140). Methods are viewed as part of a toolkit to address "*practical problems*" pp. 130 (141) and such problems can be approached in a range of different ways; thus pragmatism lends itself to mixed-methods research, particularly in healthcare (141).

Consistent with this stance, I therefore took a pragmatic approach to study design. As my objectives related to 'how' and 'why' provision of information about recovery occurs (rather than 'how much') (79), the research lent itself to the use of qualitative methods. Having already identified the need for multiple data sources and methods to triangulate the views of participants involved in conversations about recovery, as well as address inconsistencies in previous reports, I looked to identify methods that met this criteria. In line with my objectives, it was also necessary to study the behaviour within its natural setting to identify 'what happens' (requiring naturalistic observation) and to use techniques that could elicit a rich understanding of the problem from different perspectives to ascertain 'how participants feel about it' (in-depth interviews thus seemed appropriate).

Ethnography appeared to meet my needs. There is no standard definition of ethnography (142), which Hammersley and Atkinson suggest is the result of a range of influences within its history and its adoption within various disciplines (143). Atkinson and Hammersley however describe that ethnographies have four qualities in common, including: 1) a focus on understanding the nature of social events and interactions; 2) involving data that is 'unstructured'; 3) in-depth exploration of a single or few cases; 4) analysis focused on developing understanding and explaining the "*meanings and functions of human actions*" pp. 11 (144). As a result, the product is a rich account of participants' understanding and experiences of a particular phenomenon; how they make sense of it (90). Ethnography typically employs participant observation as the primary method of data collection, however data is also collected through interviews and artefacts (143). This requires the researcher to act as the research instrument (143); the process of data collection and analysis is therefore influenced by their choices and interpretations (e.g., who, where, when and what to observe, what questions to ask, etc.) (143, 145). Quantitative researchers, who seek to eliminate this subjectivity, might view this as a disadvantage. As a result, reflexivity ("*critical self-reflection of the ways in which researchers' social background, assumptions, positioning and behaviour impact on the research*" pp. ix (146)) is an important feature of ethnographic study (discussed further in 2.8).

The appeal of ethnography in this study was threefold: it requires the collection of data from multiple sources (143), lends itself to a range of analysis methods, and I had been involved in ethnographic studies before and so had some experience. However, traditional ethnography, derived from anthropology, involves a researcher embedding themselves into the field for extended periods of time (143); this was infeasible within the scope of my PhD studies. Ethnography has however evolved over recent years; modern methods include organisational, rapid and focused ethnography, amongst others (147). These interpretations typically require shorter periods of time spent in the field, can occur in familiar as well as unfamiliar contexts, and are usually employed alongside case study designs (147, 148). Case study typically involves a small number of settings, although numerous definitions of case study exist (148). Yin defines it as "*an empirical method that investigates a contemporary phenomenon (the "case") in depth and within its real-world context, especially when the boundaries between phenomenon and context may not be clearly evident.*" (pp. 48) (149). Combination of organisational ethnography (such as focused ethnography) and the case study approach permits researchers to develop in-depth holistic understanding of phenomena in its natural context within and between sites (147).

Focused ethnography has been particularly highlighted as appropriate for developing in-depth understanding of specific healthcare phenomena, centring on *“investigating specific beliefs and practices of particular illnesses, or particular healthcare processes, as held by patients and practitioners”* pp. 2 (150). It can be used to study different contexts and organisational practices, as well as helping to identify potential opportunities for improvement (147, 150, 151) (unlike traditional ethnography, which typically seeks to develop knowledge in its own right (144)). As a result, studies have been conducted in a wide range of health settings including palliative care (152), general practice (153) and intensive care (154). Although it is usually not possible to achieve the same degree of immersion into the field as is required by traditional ethnography (148), such studies represent an efficient method of collecting data in a short time-frame, often focused on specific events (150). It was thus selected as a robust approach for this study. The shorter time-frame and concentration on specific phenomena demanded greater background knowledge (as in the literature review I had already completed (151)) prior to beginning fieldwork, however I was aware this could lead to potential biases; reflexivity was therefore all the more important (155) (see 2.8).

The methods used in focused ethnographic case study research, typically observations, interviews and collection of documentary data, fit well with the aims of my study. Observation involves data collection in which *“the qualitative researcher systematically watches people and events to find out about behaviours and interactions in natural settings”* pp. 182 (156). It can be undertaken as a participant or non-participant. As neither a professional nor patient/ carer, I could not be an active participant in the stroke unit setting. However, in line with the focused ethnography method (150), I sought to align myself with Gold’s definition of *“observer-as-participant”* pp. 221 (157), in recognition that although observation was the primary reason for my presence, that mere presence could impact the behaviour of those under observation. It also accurately reflects my awareness of the role I played in the interpretation and analysis of what was observed (158).

The primary benefit of conducting observations in healthcare research is that it enables the researcher to identify behaviours outside of participants’ own consciousness (156). Observation also has advantages over interviews in allowing the researcher to discern participants’ actual behaviour, as opposed to their own potentially-biased reports of their conduct, which can be influenced by their recollections or social desirability (156). That is not to say that observation cannot result in change in behaviour as a result of participants’ awareness of the observer’s presence (the so-called Hawthorne effect (159)); participants may view the observer as an expert or critic (143), which may make

them anxious or try to behave in ways they believe to be desirable. For example, in this study, this could have led to greater or fewer conversations or questions about recovery than would usually be undertaken. Longer periods of time in the field can therefore be beneficial, as it is likely that participants find it difficult to maintain behavioural adaptations, as can the building of rapport (143). Data triangulation is another method in which this problem can be allayed (e.g., comparing documentary and observational evidence) (160), although some caution against its use in establishing validity, due to difficulties in establishing which source is 'correct' (90).

A second key method employed in ethnography is in-depth interview. Interviews can be both formally undertaken or can take the form of informal conversations with participants during periods of observation (143). Andreassen et al. argue that interviews are particularly important in focused ethnography, due to the more limited undertaking of observations (155). Typically focused around the specific phenomena of interest (151), they enable researchers to access concealed information about participants' thoughts, feelings and beliefs, as well as potentially validating observational data (161). In this study, formal interviews exploring participants' views and experiences of providing and receiving information about recovery were conducted following completion of observations, in an attempt to limit the impact of my questioning on participants' behaviour. Despite this, informal conversations with participants during observations were useful in understanding participants' contemporary experiences and thoughts at times when information was provided or was desired. This was particularly beneficial in the stroke unit setting, as participants frequently struggled to recall these instances when asked at formal interviews which took place some time later, particularly where they experienced cognitive difficulties.

The collection of documentary evidence and artefacts is also a common feature of ethnographic research (143). Documents relevant to healthcare can include hospital policies and procedures, patient records, and assessment results (150), and can be paper-based or electronically-held. Exploration of such evidence can elicit in-depth understanding of the role they play within social interaction (162), provide contextual information about the settings in which they are constructed or used, and oppose or provide support for participants' accounts or observations (143), although it is important to reflect on the extent to which they merely represent the opinions of the author (163). In this study, I examined written information provided to patients and carers, typically in the form of leaflets; searched for ward policies providing guidance to professionals in providing information about recovery; and reviewed patients' clinical records. These clinical records not only functioned as records of diagnoses, prognoses, conversations

and decision-making, but as an alternative or adjunct to verbal communication between health professionals.

2.2 Ethical considerations

Ethical approval was sought from Health Research Authority, and the study was reviewed and approval granted by the Yorkshire & the Humber (Bradford-Leeds) NHS Research Ethics Committee (Ref: 19/YH/0009; see Appendix B). Approvals from each participating NHS Trust were gained via the appropriate Research and Development department; a letter of access for research was provided at one site (as it was not my employing Trust). Examples of ethically approved documents are available in Appendices C-E. The main ethical issues are summarised below.

2.2.1 Informed consent

Informed consent is a cornerstone of research practice, requiring the provision of adequate information for potential participants to make a choice about whether or not they wish to be involved (88). In this study, such information was primarily provided in written materials detailing the aims and procedures, funding source, risks and benefits of participation, and maintenance of confidentiality (e.g., Appendix C). Through this information, I sought to emphasise the voluntary nature of participation and right to withdraw without giving a reason. Written informed consent was sought prior to participation. Meaningful communication of research information can be challenging in the in-patient stroke population however, due to the range of impairments that can result from the condition (164). For example, visual deficits can impact reading of written materials, aphasia can affect comprehension and/ or expression of a patient's wishes, and cognitive difficulties may affect understanding and the ability to evaluate risks and benefits. Additionally, gaining written consent can be difficult following upper limb activity limitations.

Challenges in providing informed consent can be a barrier to research participation, with those with some stroke-related difficulties, e.g., aphasia, frequently excluded (165, 166). This can lead to the under-representation of specific groups, including those with aphasia and cognitive impairment, and those with more severe strokes or comorbidities (167, 168). Historically, such exclusion served to protect the vulnerable from exploitation, however more recently the importance of providing all individuals the opportunity to participate in research has been recognised (169). Such difficulties are prevalent within the in-patient stroke population, e.g., ~30%, and >50%, of patients experience aphasia (170), and cognitive impairment (171), respectively. Therefore,

excluding patients with these problems from research not only risks biasing study results and denies their right to contribute, but also represents a missed opportunity to understand, and learn how to improve, their experiences (165). In the context of this study, the inclusion of those with cognitive and communication difficulties was particularly important, to understand the impact of these challenges on how information about recovery was provided and received.

As a result, steps were taken to encourage the participation of those with stroke-related difficulties in this study. In line with recommendations, every effort was made to support potential participants to actively decide whether they wished to participate (172). This included the development of aphasia-friendly and large-print information sheets and consent forms. I also spent time reading aloud and discussing study information with patients and engaging them alongside their family members to facilitate understanding. Despite these efforts, the nature of stroke-related impairments left the potential for some potential participants to lack the capacity to consent to participate. This study complied with the Mental Capacity Act (MCA), which provides a framework, outlining guidance and best practice for establishing whether someone has the capacity to provide informed consent (172). It states that potential participants are assumed to have capacity to consent, unless it is proven that they do not (172). In this study, where a patient was judged to lack the capacity to provide informed consent for study participation, an option was provided for a proxy (close relative/ friend) to provide assent on their behalf, based on their beliefs about the patient's wishes prior to becoming incapacitated. This process is described in 2.4.3.

2.2.2 Confidentiality

Confidentiality is another key component of conducting research with human participants. This refers not only to the non-disclosure of participants' inclusion in the research study, but also to maintaining the anonymity of their data, such that they could not be identified (88). The nature of qualitative research, involving rich description and small sample sizes can make it challenging to hide the identities of those taking part, both in terms of settings and participants (173). Although balancing confidentiality with providing rich description can be challenging, (88), in this study I aimed to protect the anonymity of the participants using pseudonyms, both for individual participants and for stroke units (subsequently referred to as 'Summerfield' and 'Brownside'). Protecting the confidentiality of professionals in study reports was particularly challenging where their characteristics may have revealed their identity, e.g., where there was a single professional of a specific banding working in the stroke unit.

The confidential storage of participants' personal data is also important in healthcare research. In the UK, regulations for the use and storage of identifiable personal data are laid out in the Data Protection Act 2018 (174), which was adhered to in this study. In line with common practice, paper-based identifiable participant data (consent forms, contact details) were securely stored separately from linked (anonymised) study data. Audio-recordings (e.g., of interviews) were recorded on encrypted audio-recorders and transcripts were anonymised as soon as possible following transcription; observational fieldnotes were written using participants' pseudonyms. Data from patients' clinical records were collected electronically using a standardised form, immediately anonymised, and securely stored alongside other collected data (audio-recordings, transcripts and fieldnotes) on a secure drive on the NHS server.

Although I represented myself as a PhD student, my ID badge identified me as an NHS employee and as such I felt it particularly important to reassure patient and carer participants that their views about the care they received would not be shared with those who provided it, such that they felt able to freely express their opinions. However, there are important limits to confidentiality (88), which participants were made aware of through information sheets prior to consenting to participate in the study. Examples of situations where confidentiality might be deliberately broken included where I had concerns about the practice observed in hospitals or where participants disclosed information, which caused me to suspect abuse or harm. Fortunately, these circumstances did not arise, but should they have, my plans to manage this included following NHS safeguarding policies and discussing my concerns immediately with my supervisors. Should my supervisors have agreed my concerns were justified, I would have contacted relevant individuals, e.g., the acute Trust, community team, the patient's General Practitioner or social services.

2.3 Sampling

Unlike quantitative research, which seeks to study a representative sample of the population in question, qualitative research requires careful selection of a participants with a particular characteristic or feature, to facilitate exploration of the research objectives (88). Smaller sample sizes are common, with the emphasis on developing a detailed understanding of individuals' views and experiences of the phenomenon in question (173). In this study, I sought to identify and sample those involved in conversations about recovery, namely patients who had had a stroke and their carers (as information recipients), and healthcare professionals (as information providers).

The question of 'how many' participants or units (interviews, observations, etc.) is controversial and a common concern for researchers (79). The concept of data saturation has widely been highlighted as essential in qualitative research (175), from its origins in grounded theory research (176) to its application across a range of approaches. Saturation refers to the idea that data collection should cease only when no new information is generated that contributes to the identified categories or their dimensions (176). Some have however argued that saturation has been poorly defined in the literature, and there is a dearth of guidance to estimate the sample size that may be required to achieve it (177, 178). In addition to achieving saturation, other considerations for sample size have been outlined. These include practical considerations, such as resource constraints, e.g., researcher time and budget (88). In this study, I employed purposive and heterogeneous sampling methods to ensure diversity of cases, facilitating richness and detailed understanding, within the constraints of my resources, which were limited by my available time.

2.3.1 Selection of settings

Settings were eligible for inclusion if they provided stroke rehabilitation. I purposively selected wards in different hospitals, to explore variability in how information about recovery was provided. To deliver the in-depth study required within the available resources, I aimed to select two sites. Based on my previous experience in stroke units as a researcher in other studies I was aware that information delivery could be variable, and hypothesised this variability may be due to factors including staffing levels and patient length of stay.

I approached senior staff at two local sites (lead therapists and stroke consultants), who acted as "gate-keepers" (143). Although I obtained formal permissions to conduct the study through each Trust's Research and Development department, support from gate-keepers in each setting was important in facilitating access to the units and participants. Based on my previous experiences, I focused my attention on engaging with senior therapists and stroke consultants, whom I believed would most likely be involved in conversations about recovery. These preconceptions, which meant I did not specifically engage with senior nurses may however have led to greater suspicion about my presence on the wards, and more limited participation, from nursing staff as the study progressed (later discussed in 3.5.1). Initial discussions with these gate-keepers revealed different approaches to the provision of information about recovery to stroke survivors and their families; one site had lower staffing levels and a shorter length of stay than the other, in line with the variability I sought. Both agreed to participate, and I did not pursue other settings.

Prior to starting the study, I visited each unit to familiarise myself with the unit staff, environment, and processes, and to enable me to adapt my observational framework.

2.3.2 Participant sampling

In line with ethnographic methods, I employed a purposive approach to sampling. I approached professionals identified as having a role in discussions about recovery to take part. Although I aimed to recruit at least 15 professionals from each setting, this was flexible to ensure that all those involved in discussions about recovery with the recruited patient participants could take part should they wish. I then invited a heterogeneous sample of ten of the recruited professional participants from each setting to participate in interviews. Heterogeneous sampling is used in qualitative research to enable inclusion of participants with a wide range of views and experiences, based on factors the researcher hypothesises will be important to facilitate detailed exploration of the research questions (88). In this study, my selections were based on professional background and experience levels, to explore potential divergence in professionals' perspectives according to these factors whilst identifying central themes across groups.

As I was interested in exploring and comparing the perspectives of stroke survivors, who had had a range of experiences and views, I again employed purposive sampling for this participant group. I hypothesised that person-specific factors, including age, pre-morbid functioning and comorbidities, post-stroke impairment levels, including cognitive and communication ability, could impact patients' views about how much and the type of information they desired, as well as their experiences of how information was tailored to their individual needs. I therefore sampled stroke survivors heterogeneously according to these factors, through discussions with the MDT. A carer (family member or close friend) of each participant was also approached where available.

2.3.3 Participant inclusion criteria

In line with study aims, eligibility criteria were broad. Patients were eligible if they had a confirmed primary diagnosis of new stroke and were receiving care/ rehabilitation at a participating site. Carers of participating patients were also eligible. Professionals were eligible if they provided care or rehabilitation at a participating stroke unit.

Participants in all three groups were eligible if they were:

- English-speaking;

- Aged ≥ 16 years;
- Able and willing to provide informed consent for observation of their participation in episodes of rehabilitation in the stroke unit in which patients' progress or recovery might be discussed;
- Able and willing to provide informed consent for participation in a semi-structured interview about the provision/ receipt of information about post-stroke recovery.

Consultee declaration was permitted for stroke survivor participants who lacked capacity to provide informed consent, although those lacking capacity were not interviewed (see 2.4.3).

2.4 Recruitment

2.4.1 Healthcare professionals

Initially, I employed a blanket approach to recruitment of professionals at each site, with all those who were potentially eligible being invited to take part. To do this, I identified regularly occurring meetings, e.g., MDT meetings, and provided verbal information and participant information sheets before inviting questions. I asked those who were interested to approach me following the meeting to discuss and provide written consent. My reasoning for employing such a strategy was based on my previous experiences of observation in hospitals; I was aware that additional members of staff could join episodes of care unexpectedly and wanted to be prepared, to prevent any missed opportunities for observation. I attempted to stay abreast of changes within the team throughout the study, identifying any new members who may be eligible and proactively providing information about the study and seeking consent.

2.4.2 Patients and carers

I sought help from local research practitioners in each setting to identify potential study participants, alongside support from the MDT. At Summerfield, research practitioners conducted daily screening of potentially eligible patients and alerted me to those who were eligible. At Brownside (where patient turnover was slower), I attended board round meetings two to three times per week where MDT members identified eligible patients.

At both sites, a clinical team member (research practitioner or MDT member) briefly introduced the study to each patient, before gaining consent for me to provide further information. Where possible, I attempted to make my first approach in the presence of

a family member. I gave verbal information about the study, and provided a participant information sheet if interest was expressed. During this discussion, I highlighted that study participation would not directly benefit the patient and emphasised the voluntary nature of participation. I provided an opportunity for questions and advised the potential participant to discuss participation with someone close to them; I would subsequently return to discuss informed consent if they wished to participate. If the patient was deemed to have capacity to consent and expressed a desire to participate, they were asked to sign a consent form (see Appendix D). Where a patient was unable to read or sign the consent form due to stroke-related or prior physical difficulties, consent was witnessed by a family member. Where it was felt that the patient lacked the capacity to consent, the process of consultee declaration was discussed (see 2.4.3).

Recruited patient participants were asked if they had a carer (family member or friend) who might also wish to participate, and carers were recruited following a similar process.

2.4.3 Capacity

As previously discussed, all potential participants were assumed to have the capacity to consent, unless it was proven that they did not, in line with the MCA (172); all attempts were made to assist each individual to make the decision themselves. The MCA states that an individual lacks capacity to make a specific decision if they are unable to understand, retain and weigh up information relevant to the decision, and communicate their decision. Assessment of these factors was undertaken following provision of time to consider the information and discuss it with a family member/friend. I asked the participant to briefly summarise the study to assess understanding, before communicating their decision about whether or not to participate. Where the patient had communication difficulties, this was facilitated by using yes/no questions, e.g., “Do you have to take part in this study?” or “Will taking part in this study involve being watched while you have therapy?” or engaging a Speech & Language Therapist in supporting communication. In addition, I consulted treating members of the MDT and a member of the patient’s family where possible.

Where I felt that a patient lacked the capacity to provide informed consent to participate, a Consultee Declaration was sought. In these cases, in collaboration with the MDT, I identified a close family member or friend of the patient and provided them with information about the study, asking them to advise on the patient’s potential participation, taking into consideration the patient’s opinions and wishes. Patients who

were deemed to lack capacity (and for whom a consultee declaration was provided) were only involved in the observational component of the study, and not approached for participation in a semi-structured interview, as I felt it unlikely that they would be able to make a meaningful contribution and did not wish to cause distress by asking them about experiences for which they may not have detailed memories. However, their carers were invited to take part in interviews.

As I was aware that capacity could fluctuate in the time following stroke, I checked each participant's understanding and gained consent before each observation and interview. I had intended that, if a participant lost the capacity to consent during the study, they would be subsequently withdrawn or a Consultee Declaration sought if appropriate (data collected before this date would be retained for inclusion). Should I have believed a patient had re-gained capacity I would have sought written consent from the participant, which could potentially include participation in an interview. However, neither of these situations arose. I was however careful to take note of any signs of objection to observation or distress from a research participant, and should this have arisen, would have considered withdrawing the participant from the study.

2.5 Data collection

2.5.1 Sample characterisation data

Sample characterisation data were collected at the time of recruitment. Demographic data for patients included age, gender, ethnicity, time since stroke, and stroke severity (admission National Institutes of Health Stroke Scale (NIHSS (179))). I had intended to collect admission independence in activities of daily living (Barthel Index (180)), should it have been available, however neither site routinely collected it. Carer data included age, gender, ethnicity and relationship to the patient. Data from staff included age, gender, ethnicity, professional background and grade, time since qualification and years of experience in stroke care.

2.5.2 Observational data

I undertook observations over a continuous period at each site, for four months at Summerfield (March to June 2019) and three months at Brownside (August to October 2019). I had initially intended to spend a maximum of six weeks at each site, however found it was not possible to recruit the desired number of patient participants, and collect the in-depth data I required, during this time and thus extended the data collection period at both sites. I planned to observe on three to four days per week at a

range of times, including evenings and weekends, although in practice most observations were during therapists' working hours as this was interactions between professionals and patients/ carers most frequently occurred. Observations were based on a qualitative framework (see Appendix F) informed by guidance from Spradley (181); I expanded on my fieldnotes following each observation and maintained a reflexive diary (see 2.8).

Collection of observational data in each setting initially began with familiarisation with the environment and MDT members; I spent time on the ward, observed routine meetings and shadowed professionals to learn about ward routines. Preliminary descriptive general observations explored overall service processes, including the identification of site-specific opportunities for sharing information about recovery, e.g., family and MDT meetings, and the availability of more informal opportunities to discuss individual patient recovery, both between MDT members and with patients and families. Observations were undertaken in therapy rooms and gyms, day rooms, meeting rooms and bed areas, with permission from the Principal Investigator at each site. Personal information relating to patients or carers was only recorded if they specifically consented to participate in the study. Posters (e.g., Appendix E) describing the nature of the research were placed at the entrances to the ward and to each bay, alerting patients and carers to my presence; similar posters alerting professionals were placed in staff areas.

General observations were focused on description of general activities routinely involving interactions between MDT members and patients and/ or their carers. I recorded descriptions of:

- Environmental conditions in which activities and interactions between professionals, patients and carers took place, including perceived barriers and facilitators;
- Interactions between professionals, particularly in relation to discussing individual patients' recovery and how this might be communicated;
- Activities relating to sharing information about recovery between professionals, patients, and carers;
- Concerns and views of professionals, patients, and carers, relating to recovery and provision/ receipt of information.

Summaries of dialogue were recorded, where appropriate. Verbatim recordings of dialogue were recorded only from participants who had provided written informed consent; the content of recurring dialogue which related to the aims of the study was not deemed to require consent.

These *descriptive observations* subsequently progressed to more *focused observations* (181) of interactions between patients, carers and professionals, where information about recovery and prognosis was likely to be discussed, including therapy sessions, formal family, goal-setting, or discharge-planning meetings, and more informal opportunities for discussion, as identified in the general observations. Formal meetings were audio-recorded, with participants' consent. In cases where a family meeting attendee did not wish to participate, I had intended to discuss options, including continuing with observation and audio-recording but removing their input from fieldnotes and transcripts; observing but not audio-recording the meeting and removing their input from fieldnotes; or not observing the meeting. However, this situation did not arise. The initial intention was not to transcribe family meeting recordings, but to use them as an *aide-memoir*. However, as I took a period of maternity leave between collecting and analysing the data, the recordings were transcribed to enhance my recollection. The transcripts were used to supplement the fieldnote data, in the same way as audio-recordings (only the fieldnote data were coded). The ethics committee was notified of this activity, although it was not felt that a formal amendment was required.

During observations, due to the potentially sensitive nature of the interactions, I tried to position myself in a physically unobtrusive location and did not participate in discussions. Following the observations, where appropriate, I subsequently approached the participants (patient, carer or professional) individually on an informal basis, to explore their views or seek clarification. Participants were advised these informal conversations comprised part of data collection in the participation information sheet; at times they also sought me out following experiences of information delivery to actively contribute their views to the research.

2.5.3 Interview data

I aimed to interview patients and carers around four to six weeks after hospital discharge, to allow enough time for them to process and make sense of (but still recall) their experiences. I began conducting interviews with professionals following completion of my observations at each site, as I did not want my questioning to impact on subsequently observed behaviour, and to allow me to explore issues highlighted during observations. At the beginning of the interview, participants were reassured about the confidentiality of their responses and how their data would be managed. Patients and carers were advised that it was not unusual to become emotional when talking about their experiences; all participants were advised that they could stop the interview at any time and that they did not have to answer any questions they did not

wish to. Participants were offered an opportunity to ask questions before consent was gained to begin the interview.

Interviews were semi-structured, with a topic guide employed flexibly. The topic guides (Appendices G-H) were developed to explore areas highlighted through the previous systematic review work and areas of interest from observations, and used flexibly to allow participants to introduce their own relevant ideas. I used prompts to encourage the participant to speak in more detail and to draw their attention to aspects that they did not spontaneously discuss in response to open questions (88).

Interviews were audio-recorded and transcribed verbatim for analysis.

2.5.3.1 Patients and carers

Patients and carers were given the opportunity to be interviewed separately or together. I gave this issue serious consideration, concerned that the presence of patients could inhibit carers discussing their views for fear of causing distress; however, research suggests that the presence of a carer can provide communication and emotional support for the stroke survivor and facilitate recall of events during their acute admission (182). As a result, the approach I took was to encourage the patient and carer to decide what was best for them. In line with accepted approaches, participants were also encouraged to select the time and location of their interviews (183). Given the sensitive nature of the topic, and the convenience for those with potentially on-going disabilities and continuing input from healthcare professionals and carers, I was unsurprised that all opted to be interviewed in their own homes.

Interviews explored expectations about recovery, how and when information about recovery was provided, how the stroke survivor/ carer felt about this and their preferences for receipt of information. Carers were asked about their experiences of receiving information about recovery and how this information shaped their expectations of the stroke survivor's potential for recovery. To include as many patients as possible, including those with aphasia, the interview methods were adapted if required, e.g., using images.

2.5.3.2 Healthcare professionals

Interviews with healthcare professionals were held in a quiet, private area convenient to the participant (usually their place of work), to limit disruption to their clinical work. The focus of the interview was to elicit professionals' views and experiences of

discussing recovery on the stroke unit, including decision-making about whether, when, how, and to whom information was provided. Other questions related to hospital policies relating to the provision of information and any training or guidance they had received. I was also interested in what they perceived as barriers and facilitators to information provision, as these could directly impact the development and subsequent implementation of an intervention.

2.5.4 Documentary data

Documentary data were collected from the patient's medical record following their discharge from the stroke unit, using a standardised form. This aimed to ensure that only data which were relevant and necessary to answer the research questions were obtained. These included documentation of:

- The patient's presenting complaint and diagnosis;
- Results of initial assessments and goals;
- Observed interactions between patients/ carers, and professionals;
- Information about recovery provided to the patient/ carer (including family meetings);
- MDT communication related to the patient's progress (MDT meetings, board rounds);
- Information provided at discharge.

The date and professional role of the healthcare professional who made the entry were also collected. Data were collected from throughout the patient's in-patient stay to develop an understanding of how, what, when, and by whom information was provided over time.

In both settings, patient records were held using the same electronic system and I attended training in its use at Summerfield (my home Trust). At Brownside, supervised access to the electronic system was facilitated by research practitioners.

Written information provided to patients, e.g., leaflets or booklets, and written advice provided to professionals in relation to providing information, e.g., relevant ward policies, were also sought.

2.6 Data analysis

In ethnography, it is common for data analysis to take place contemporaneously with data collection (143). I developed analytical memos throughout the research process, noting ideas for on-going exploration and theorising about the meanings attached to

interactions and events. In terms of formal analytical processes, ethnography lends itself to different types of analysis and researchers may select methods which best fit their data collection techniques. I selected Framework analysis as my primary method of data analysis in this study for a several reasons: Firstly, the approach can involve deductive analysis, appropriate to this study due to having predefined objectives (79). Secondly, it provides a structured and transparent method of managing, and systematically and rigorously interrogating, large amounts of data (90), whilst facilitating within- and between-case analysis (184). This enabled me to draw comparisons between the views and experiences of patients with varying stroke severities, lengths of stay and backgrounds; as well as between professionals from different professional groups, of varying levels of seniority and from different sites. Thirdly, my own previous experience in using the method also likely influenced my choice; whilst the method has been described as time-consuming (88), having previously used it, I was familiar with the process, time requirements and use of software to support it.

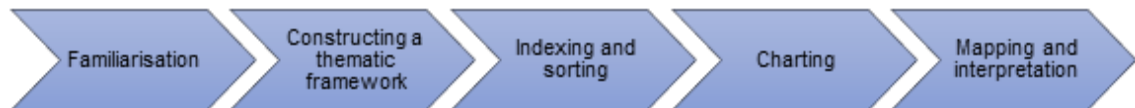
Sample characterisation data were managed within IBM SPSS Statistics 27 and summarised using descriptive statistics. All qualitative data were managed within NVivo (v.11).

2.6.1 Data from observations and interviews with healthcare professionals

Observational fieldnotes and transcripts from interviews with healthcare professionals were analysed using the Framework approach (88). This five-stage method (see Figure 2.1) involves initial familiarisation with the data, followed by identification of a thematic framework. In this study, I applied the thematic framework used to code data in my earlier qualitative systematic review (Chapter 1), and further developed it using an iterative process during the familiarisation stage (a combined deductive and inductive approach). During a third stage of indexing, the data were coded according to the framework with code descriptions expanded and new codes added where needed, to capture all data relevant to the research questions. In a fourth stage of charting, data were displayed within matrices, using Microsoft Excel, with columns representing each code and rows representing cases (see Appendix I for a sample). Summaries of participants' views on each code were developed, staying as close to the original text as possible. Finally, I compared and contrasted the views and experiences of the participants in an interpretation stage, developing overall summaries for each code and examining them for areas of commonality and difference. Throughout the analysis process, I developed analytical memos (also stored in NVivo) to capture any

emerging insights, concepts, or issues. I discussed emerging findings with my supervisors and research colleagues (some of whom were health professionals with experience of working in stroke care), which served to challenge my interpretations and help me to consider alternative explanations.

Figure 2.1 Stages in the Framework approach (88)



2.6.2 Patient and carer data (from interviews, focused observations and documentary evidence)

The Framework approach was also used to analyse patient and carer data. However, during data collection, and confirmed during the familiarisation stage of analysis, it became apparent that the issues raised by patients and carers were (perhaps unsurprisingly) somewhat different to those that emerged from interviews with professionals. As a result, patient/ carer interviews, patient-specific observations and documentary data from patient records were managed in a separate NVivo file (see Appendix J for a screenshot). My aim in including the observational and documentary records alongside patient/ carer reports was to develop an understanding of each patient's journey, to interpret how these experiences shaped their views and recollections when interviewed, but also to facilitate triangulation between sources. I began inductively coding the patient/ carer interview transcripts (with a focus on my research objectives specifically relating to patient/ carer views and experiences), before stepping back to group similar codes and form a thematic framework (see Figure 2.2). This framework underwent iterative development as I progressed to apply it to further transcripts, observations and documentary data. As with the analysis of professionals' interview transcripts, matrices displaying the coded data were created, with three consecutive rows for each patient participant (or patient/ carer pair) for the observational, documentary and interview data coded to each sub-theme. Managing the data in this way allowed me to begin to triangulate between the data sources, drawing comparisons between what I observed, professionals' documentation, and the patient/ carer's views and recollections. I was however careful not to treat any of these sources as the objective 'truth'; rather to view them as different interpretations/ recordings of events, e.g., my own perspective, that of the professionals, and that of the patient/ carer, respectively. Again, throughout the analytic process, I completed

memos, which included my interpretations of the variations between sources. In the final stage, each participant's comments and experiences related to each code were summarised, with a focus on comparing and contrasting views and experiences, particularly in light of factors I believed might impact their views/ experiences, such as stroke severity and presence of cognitive or communication difficulties. Emerging findings were again discussed informally with my supervisors and research colleagues.

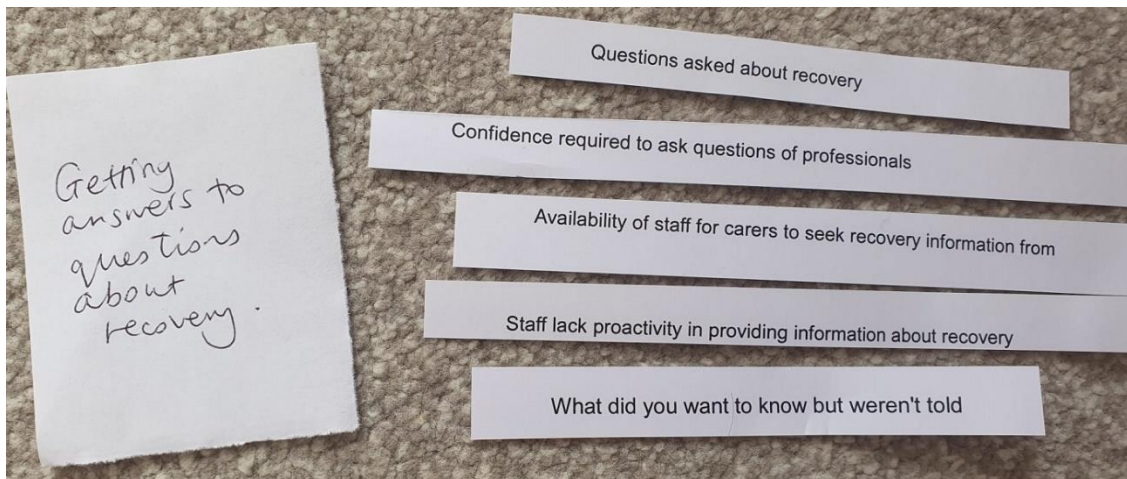


Figure 2.2 Example of how codes generated from initial line-by-line coding were grouped into categories (patient/ carer data)

2.6.3 Triangulation

As a final stage in the analysis process, I created a third NVivo file, in which I could compare and contrast the coded data from the professionals' interviews and general observations with the patient and carer dataset (focused observations, interviews, and documentary analysis). I looked across the codes generated from each dataset and grouped codes together according to the research question they addressed. I then read through all of the data relating to each research question to identify areas of similarity and difference, thus allowing me to compare and contrast the views and experiences of professionals, patients, and carers. I created memos during this process, highlighting initial ideas (particularly where data related to more than one research question) and identifying how data from different sources might challenge my interpretations and emerging findings from my earlier analysis, before developing my final themes.

2.7 Quality

Assessing quality in qualitative research is a complex and controversial topic (125). Researchers have long debated whether concepts traditionally applied to quantitative research such as reliability and validity are useful or require adaptation to qualitative methodologies (90, 185). In applied health research in particular, it is important that quality can be judged so that findings can be used effectively to improve patients' experiences of care. This relies on some notion of generalisability, where the findings of one study can be effectively used to influence practice in similar settings or within the wider population (88).

Lincoln and Guba's criteria to demonstrate trustworthiness in qualitative research (credibility, dependability, confirmability and transferability) (186) were considered in the planning and delivery of this research. *Credibility* refers to the extent to which the findings represent a true or believable account of the participants' views and experiences, achieved through the study conduct and reports (186). In this study, I employed a range of strategies to address this. Firstly, I sought to develop familiarity with each setting, through prolonged engagement (186), conducting observations of a range of activities at a variety of times, over a three-to-four month period. This also facilitated the development of rapport with study participants, allowing them to become comfortable with my presence. Secondly, I sought out ways to challenge my emerging interpretations of the data. During data collection and analysis, I engaged in peer debriefing (186), discussing my early hypotheses and explanations with my supervisory team, and with research and clinical colleagues, who acted to critically question my interpretations. The use of the Framework approach, which facilitates within- and cross-case analysis (88), helped to highlight deviant views and observations within the collected data, allowing me to explore those which appeared to contradict my interpretations (125). Finally, the triangulation of data collection methods (observations, interviews, documents) and sources (patients, carers, professionals) allowed me to assess similarities and identify discrepancies, closely examining how they contributed to my overall explanations to develop a more comprehensive understanding (187).

Dependability requires the clear documentation of the research process, to enable the reader to assess whether procedures undertaken were systematic and repeatable (188). I sought to achieve this through preparation of a detailed protocol and through establishing an audit trail. I logged decisions taken during data collection, such that the work could be replicated. *Confirmability* refers to the extent that the researcher represents the experiences of participants as objectively as possible (186), which can

be achieved by demonstrating that the findings are clearly derived from the data rather than the researcher's own views (188). True objectivity is rarely possible in qualitative research, particularly in ethnography, as the researcher forms a part of the world being studied (143) and thus at least some influence is unavoidable. However, in this study, I sought to minimise the impact of bias through the use of methodological and source triangulation, and attempted to acknowledge and present potential sources of bias, considering how they might have influenced data collection and analysis. To do this, I maintained a reflexive diary throughout data collection and analysis and endeavoured to openly present my own preconceptions and decision-making alongside study findings (see 2.8 for further discussion of reflexivity).

Lincoln and Guba's fourth criterion is *transferability*, which relates to the degree to which findings can be applied to other similar groups or contexts, akin to the notion of generalisability in quantitative research (186). Thick description of the context and comprehensive reporting of participants' views and understandings can enable the reader to draw their own conclusions about whether the findings can be applied in other settings (125, 189). Contextual information including detail about the selected settings and data summarising the sample characteristics are presented in Chapter 3; care has also been taken to demonstrate how these findings compare to those in contexts of varying similarity (190).

2.8 Reflexivity

Whilst it was once thought that researchers could be a separate and objective observer of the world they studied, it is now widely accepted that they are a part of that world, and that their personal views, feelings, reactions, focus, and decision-making impact the data they collect, and their interpretations and reporting of it (191). Additionally, their personal characteristics can impact how they are viewed and received by participants in the field. Researchers are therefore encouraged to reflect on these attributes and actively and consciously consider their impact throughout the research process through practise of reflexivity (148). Acknowledgement and reporting of potential biases, and their impact, can make reports of findings more convincing and are central to claims of validity (192).

In my initial presentation of my background, I sought to describe my prior experiences such that the reader could begin to understand how these likely shaped the work I am undertaking. Such "*positioning statements*" pp. 192 (193) are common in qualitative research, however more critical reflection is required to acknowledge and understand

the role the researcher plays in developing the research outputs (143). During data collection, I used a reflective diary to record my reactions to being in the field, and my views and perceptions of what I saw and heard, keeping this separate from my fieldnotes, as recommended by Miles and Huberman (194). I also recorded my decisions about where I chose to focus my time and efforts, including my considerations in making these decisions, which I also discussed with my supervisors. Within my diary, I attempted to continuously evaluate the research process, making amendments where required (e.g., changes to the time periods spent at each site). This reflexive record-keeping continued throughout the analysis process, during which I developed memos (stored alongside the data in NVivo) to draw together ideas, hypotheses, and my developing interpretations of the data, which I also discussed in formal and informal supervision. I report my reflections from these sources later in Chapter 3.

Chapter 3 Study context, data collected and participant characteristics

3.1 Background

In this chapter I will describe the contexts in which data were collected, the range of data collected and the characteristics of study participants, alongside my reflections on the data collection process. In subsequent chapters, I will draw on the range of data collected (observational fieldnotes (supplemented by audio-recordings of family meetings), transcripts of interviews with patients, carers, and professionals, and documentary data) to address the study objectives. In Chapter 4, I will discuss the factors impacting provision and receipt of information about recovery on stroke units; Chapter 5 focuses on specifically on the experiences and views of professionals including the issues they face in this challenging area of clinical practice, whilst Chapter 6 identifies what is important to patients and carers and their interpretations of the messages they received.

3.2 Context

Two sites participated in the study (Brownside and Summerfield). During early discussions with therapy leads and stroke consultants at these two potential sites, I attempted to glean information about their approaches to provision of information about recovery. It became clear that one site (Brownside) appeared to place greater value on sharing information about recovery with patients and families and this was reflected in their ward processes (including a more formal and defined procedure for family meetings), whilst professionals at the other site (although keen to provide information) reported some challenges due to organisational factors and staffing levels. Alongside my initial data gathering about staffing levels and length of stay, I believed these sites represented sufficiently different approaches to allow meaningful comparisons to be drawn. The context of the selected units will initially be described, based primarily upon data collected through general observations and informal conversations with professionals.

3.2.1 Site descriptions

The two sites were situated in hospitals approximately ten miles apart, in separate NHS Trusts. Summerfield was a 35-bed stroke/ neurology ward, including hyperacute and mixed acute/ rehabilitation beds. The history of the stroke service was complex, having

previously comprised two separate wards: an acute ward at a large teaching hospital, and a separate rehabilitation ward at another smaller hospital (primarily providing out-patient and rehabilitation services). Approximately five years previously, the rehabilitation ward had been closed, and the service combined with the acute service at the larger hospital. However, many staff working on the rehabilitation ward were not retained, leading to a perceived shortage of rehabilitation nursing skills, and an increased focus on acute care. Brownside was a 12-bed rehabilitation ward set within a large 52-bed stroke unit, which also housed a Hyper-Acute Stroke Unit (HASU)/ acute stroke unit (ASU) and two other rehabilitation wards. The decision to focus recruitment and data collection on a single ward was taken following discussions with professionals at the site, who believed their approach to discussing recovery was distinctive to their ward, and to facilitate observational data collection. The sites are further described in Table 3.1.

Table 3.1 Site descriptions¹

| | Summerfield | Brownside |
|---------------------------------------|--|---|
| Site description | 35-bed stroke and neurology ward, comprising one six-bed hyperacute bay, plus 29 mixed acute/ rehabilitation beds organised into three 6/8-bedded bays and five side rooms. | 12-bed ward comprising two bays of four patients each and four individual side-rooms. Set within a wider stroke unit (52 beds), including a 14-bed hyperacute/ acute unit and 38 beds across two other further rehabilitation wards. |
| Turnover/ length of stay | ~900 patients admitted/ year. Average length of stay ~six weeks. | ~563 stroke admissions/ year (wider unit). Average length of stay ~three months. |
| Regular meetings of MDT | <p><i>Board rounds:</i> 30 mins on four days/ week. <40 patients discussed (stroke/ neurology including outliers). Attended by consultants, junior doctors, a nurse, a PT, an OT, and a discharge nurse. Held in a ward office. Medically dominated, focus on discharge planning and throughput.</p> <p><i>MDT meetings:</i> 90-min weekly meeting. ~35 patients discussed (stroke, including outliers). Attended by consultants, junior doctors, a nurse, a PT, an OT, an SLT, and a discharge nurse. Held in a ward office. Focus on medical concerns, updates from each discipline and discharge plans.</p> <p><i>Therapy planning meetings:</i> One two-hour weekly meeting. <40 patients discussed (stroke/ neurology, including outliers). Attended by all OT and PT staff. Held in therapy department. Focus on current treatment, goals, progress and therapy and discharge plans.</p> | <p><i>Board rounds:</i> 30 mins on four days/ week. 12 patients discussed. Attended by a consultant, a nurse, a PT, an OT, an SLT and a discharge nurse. Held in a ward office. Focus on concerns, progress, and discharge plans.</p> <p><i>MDT meetings:</i> 90-min weekly meeting. 12 patients discussed. Attended by a consultant, junior doctor, nurse, PT, OT, SLT, dietician discharge nurse and social worker. Held in stroke unit meeting room. Focus on current treatment, goals, progress, and therapy and discharge plans.</p> |
| Routine written information provision | <i>Rehabilitation file</i> provided to some rehabilitation patients (new initiative). Included generic information about stroke and other neurological conditions, and contact numbers for available services. A small section detailed generic | <i>Joint Care Plan</i> provided to all patients after admission to acute ward. Included standardised written information, including contact numbers for community services, and individualised sections completed by medics (diagnosis, risk factors), and therapists (deficits). Generic |

¹ MDT: Multidisciplinary Team; PT: Physiotherapist; OT: Occupational Therapist; SLT: Speech & Language Therapist

| | | |
|---|---|--|
| | <p>information about stroke recovery. No written information available for those discharged directly from HASU. No leaflets available on ward due to infection control.</p> | <p>published leaflets from a national charity (selected for individual patients) were also included (and placed on stands across the stroke unit).</p> <p><i>Leaflet</i> provided to all patients on ward admission, describing professionals' roles.</p> <p><i>Therapy diaries</i> provided for some patients (newly initiated by OT), including therapy activity, goal achievement and mood monitoring.</p> |
| Ward routines | <p><i>Ward rounds:</i> Daily for acute patients, twice weekly for rehabilitation patients.</p> <p><i>Protected mealtimes:</i> 12-1pm.</p> <p><i>Visiting times:</i> 2-4pm, 6-7pm.</p> | <p><i>Ward rounds:</i> Weekly for rehabilitation patients.</p> <p><i>Protected mealtimes:</i> 12-1pm.</p> <p><i>Visiting times:</i> Open visiting.</p> |
| Family meeting provision | <p>Meetings arranged as required for some rehabilitation patients. Chaired by consultant, attended by treating therapists (OT, PT, SLT), nurse (occasionally), discharge nurse and social worker (discharge planning only). Held in therapy department or ward-based meeting room. Meetings lasted ~30 mins. No structured process for organising.</p> | <p>Meetings held for all patients within the first two/three weeks of ward admission and every two/three weeks thereafter. Chaired by consultant, attended by treating therapists (OT/ PT/ SLT/ dietician), a nurse, a discharge nurse and social worker (discharge planning only). Held in day room or seminar room on stroke unit. Meetings lasted ~30 mins. Organised process for arranging meetings, one afternoon/ week set aside by staff to hold four meetings back-to-back.</p> |
| Location of therapy and other available quiet areas | <p>Therapists based off the ward in separate departments (OT/ PT, SLT). Therapy department on separate floor (OT/ PT) included a large gym, two smaller therapy rooms and therapy kitchen (shared with other services). Small bookable quiet room next to nurses' station. No day room on the ward.</p> <p>Most therapy took place at the bedside or therapy department, timetabled weekly (OT/PT only). Few therapy groups held. Family meetings held in ward quiet room or in therapy department.</p> | <p>Therapists based off the ward in separate department. Access to a large therapy room on the stroke unit (shared with other wards) for OT and PT. Therapy department included small bookable rooms, a therapy kitchen, and large gym (all shared with other services). Day room on each ward. Two meeting rooms on stroke unit and an office behind the nurses' station on each ward.</p> <p>Most therapy took place at the bedside, in the therapy gym or department, timetabled daily (OT/ PT only). No therapy groups but activities held in day rooms by separate staff. Family meetings held in day room or meeting room.</p> |

3.2.2 Staffing levels

Staffing levels at each site are detailed in Table 3.2. It is notable that the staffing levels at Summerfield were lower than at Brownside and the remit of some professionals was greater, e.g., SLT staff provided a service across the whole hospital and thus attended the stroke unit less frequently. Additionally, Summerfield relied more frequently on nursing staff provided by an agency, and locum consultants. Although staff at Brownside were generally allocated to a specific ward within the stroke unit, staff within each discipline were managed as one team, and there was flexibility for them to be moved across the wards to meet service demands; this rarely occurred during data collection. Brownside also had more static positions for therapists than Summerfield, meaning they accrued greater stroke experience.

At both sites, nurses worked similar patterns of shifts (early, late and night), with therapists typically working 08:00-16:00 Monday to Friday. A skeleton staff of one OT and one PT provided an assessment service for new admissions at weekends.

Table 3.2 Site staffing levels¹

| | Summerfield (35-bed stroke and neurology ward, plus outliers) | Brownside (12-bed rehabilitation ward; staff were moved flexibly across the whole stroke unit when required) |
|---|--|--|
| <i>Medical</i> | 5 consultants including one dedicated stroke rehab consultant, plus rotational junior doctors. | 1 dedicated ward consultant, but covered by another consultant for 1 in 4 weeks when the designated consultant worked on the HASU/ ASU, 1 part-time rotational junior doctor. |
| <i>Nursing</i> ² | (Stroke rehab beds only): 2.44 qualified nurses (daytime only; 1.11 overnight), and 4 care assistants (daytime only; 1.78 overnight) per 10 beds. Frequent use of agency staff to meet requirements. | 1.25 qualified nurses and 1.25 care assistants per 10 beds. Limited use of agency staff. |
| <i>Physiotherapy</i> | 1 part-time band 7 (therapy team leader), 2 full-time band 6s (yearly rotations), 1 full-time band 5 PT (6-monthly rotations). | 2 full-time band 6s (static), 1 full-time band 5 (6-monthly rotations). Therapists were managed and supervised by a full-time band 7, with responsibility for all stroke physiotherapy services. |
| <i>Occupational therapy (OT)</i> | 1 full-time band 7, 2 full-time band 6s (yearly rotations), 1 full-time band 5 PT (6-monthly rotations). | 1 part-time band 6 (static), 2 full-time band 5s (6-monthly rotations). Therapists were managed and supervised by a full-time band 7, with responsibility for all stroke OT services. |
| <i>Therapy assistants (OT/ PT only)</i> | 2 part-time. | 3 part-time (shared across whole unit). |
| <i>Speech & Language Therapy</i> | 1 full-time band 7, 2 full-time band 6s, 1 part-time band 5 (cover whole hospital, including stroke). | 1 full-time band 6 (but also covers clinics, other wards). |
| <i>Clinical Psychology</i> | No clinical psychology input. | No clinical psychology input at start of data collection, however new appointment made in October 2019. |
| <i>Other</i> | | 1 part-time activity co-ordinator, volunteers from The Stroke Association visiting one day per week. |

¹ (H)ASU: Hyperacute/ Acute Stroke Unit; PT: Physiotherapist; OT: Occupational Therapist

² Data from Sentinel Stroke National Audit Programme Acute Organisational Audit 2019 (195)

3.3 Data collected

Observational data were collected from March to June 2019 at Summerfield and August to October 2019 at Brownside. Overall, 83 hours of observations were undertaken across sites (48 at Summerfield, 35 at Brownside). Numbers of observed sessions are described in Table 3.3. Similar numbers of MDT and board round meetings were observed at each site. At Summerfield, it became clear that therapy planning meetings (OTs/ PTs) represented a further opportunity for professionals to share recovery predictions, prepare for discussions with patients/ carers and discuss the outcomes of conversations about recovery, and these became a greater focus of observations at this site. Similar numbers of individual patient therapy sessions were observed at each site, but greater numbers of family meetings took place at Brownside, providing more opportunities for observation. Consultant-led ward rounds were also identified as an opportunity for information about recovery to be shared with patients at Summerfield, however I was unable to negotiate access to these at Brownside, as the consultant did not feel they represented a forum for discussions about recovery.

Table 3.3 Number of observed professional meetings at each site

| | MDT meetings | Board rounds | Ward rounds | Therapy planning meetings | Therapy sessions | Family meetings |
|-------------|--------------|--------------|-------------|---------------------------|------------------|-----------------|
| Summerfield | 3 | 8 | 2 | 8 | 14 | 2 |
| Brownside | 3 | 7 | 0 | N/A | 14 | 6 |

3.3.1 Documentary data

Documentary data were collected from the electronic records of the 20 recruited patients, alongside written information routinely provided to patients/ carers (detailed in Table 3.1). No written policies relating to providing information about recovery were identified by professionals at either site.

3.3.2 Interview data

Thirteen individual interviews with patients and carers were conducted. All took place face-to-face, in patients'/ carers' own homes. Most involved a single patient (n=9) or carer (n=2). Two patients chose to take part in interviews alongside their carers (although in one case the patient was also interviewed alone). Mean interview length was 32.92 (sd=13.23) (range=23.09-61.29 minutes).

At Summerfield, most patient participants took part in interviews. One declined (no carer interviewed), and two lacked capacity to participate due to severe aphasia and cognitive impairment (n=2); their carers were interviewed alone. Some carers declined to participate in interviews (n=3). At Brownside, fewer patients (n=3) and no carers participated in interviews. This was primarily due to the longer length of stay at Brownside, such that some were not yet discharged (or 4-6 weeks post-discharge) by the close of the study period. The close of the study also coincided with the start of my maternity leave. A minor amendment to increase the duration of the study was accepted, to enable me to complete some interviews following the birth of my baby, however this was not possible, partly due to the start of the COVID-19 pandemic.

Nineteen interviews with professionals took place across both sites, following completion of observational data collection. Most took place in a quiet room at the hospital site where the participant worked. At Summerfield, interviews took place in meeting rooms in the hospital's training department (n=3) and research unit (n=3), or in a gym in the therapy department (the therapists' base; n=3). Interviews at Brownside took place in a day room (n=3) or a meeting room on the stroke unit (n=2). SLTs were interviewed in a therapy room in their department (n=3), and the consultant was interviewed in his office (n=1). One interview was completed by telephone, at the participant's request (n=1). Mean interview length was 46.13 (sd=12.96) minutes (range=28.5-78.43 minutes).

3.4 Participant characteristics

3.4.1 Observations

Eighty-four participants (20 stroke survivors, 17 carers and 47 staff) took part in observations across sites. At Summerfield, the sample comprised 19 professionals, ten patients and seven carers. At Brownside, more professionals participated (n=28), due to the greater numbers of staff and the flexible nature in which they were deployed across the wards, alongside similar numbers of patients (n=10) and carers (n=10). Participant characteristics are presented in Table 3.4, Table 3.5 and Table 3.6, with greater detail on patient participant characteristics in Table 3.7.

Most patient participants were white (n=18; 90%) males (n=11; 55%) and females (n=9; 45%). Participants at Summerfield were typically older (mean age 73 years vs 65 years at Brownside) and had a shorter mean length of stay (32 days vs 52 days at Brownside). Mean stroke severity, as measured by admission National Institutes of

Health Stroke Scale (NIHSS) (179), was moderately severe at both sites (~12 points), and around three quarters of patients at both sites were discharged home. Recruited carers were most commonly a child of the stroke survivor (n=7; 41%); smaller numbers were a spouse (n=3; 18%) or another relative (sibling, grandchild, niece/ nephew, parent; n=6; 41%).

Most professional participants were white (n=39; 83%) females (n=39; 83%), with similar numbers across sites. The make-up of the sample was generally representative of the stroke MDT, with higher numbers of OT and PT professionals. Nurses were under-represented (n=5; 11%), as a result of the focus on therapy sessions and their less frequent engagement in formal meetings (Summerfield only). Most participants had up to five years of experience in stroke care, however more professionals at Summerfield had less than one year of stroke experience, whilst more at Brownside had between one and five years. Around a quarter of the sample at both sites had more than ten years' experience.

3.4.2 Interviews

Of the ten patient participants who were interviewed across sites, 50% were female and mean age was 67.6 (sd=12.16) years. The sample included more participants with a left hemiparesis than right (70% vs 30%), with stroke severity ranging from mild to severe (mean NIHSS=9.22 (moderate-severe)). All were discharged home following their hospital stay. The four carer participants were all from Summerfield, were mostly female (n=3; 75%) and had a mean age of 50.25 (sd=11.79) years. They represented a spouse, two children and a grandchild of a patient participant.

Overall, in comparison with the sample as a whole, interviewed patient participants included a lower percentage of those who: had aphasia; had a higher mean admission NIHSS score (179) (indicating more severe stroke); had a shorter length of stay; and were discharged to institutional care. This is likely to reflect the impact of the two participants who had severe strokes and aphasia, such that they were unable to participate in interviews, and the challenges in conducting interviews at Brownside (although some of these patients would likely have also lacked the capacity to consent to participate). Interviewed patients at Brownside represent those with shorter hospital stays, and therefore milder strokes, and as a whole, patient interview data more strongly reflect the experiences of those receiving care at Summerfield.

Professionals were purposively sampled to participate in interviews, to reflect the typical make-up of the stroke unit MDT; not all recruited were invited to be interviewed. Nineteen professionals took part in interviews (Summerfield n=9 (47%); Brownside n=10 (53%)). Participants were mostly female (n=15; 79%) and white (n=17; 89%). Mean age was 31.47 (sd=7.83) years (range=22 to 45 years). Overall numbers from each discipline were generally representative of a typical stroke MDT, with similar numbers of OTs (n=6; 32%) and PTs (n=6; 32%) and fewer SLTs (n=4; 21%) and stroke consultants (n=2; 11%). Nurses were under-represented (n=1; 5%); a nurse could not be identified to participate in an interview at Summerfield. Participants had a range of experience levels; 6 (32%) were junior professionals, including those newly-qualified (NHS Agenda for Change band 5); 8 (42%) were more experienced professionals (band 6); and 5 (26%) were senior, highly specialist professionals (band 7 or consultant). Four (21%) had less than one year of experience in stroke care, ten (53%) had between one and five years, one (5%) had six to ten years and the remaining four (21%) had more than ten years.

Table 3.4 Patient participant characteristics¹

| | Observations | | | Interviews | | |
|--|---------------------------|------------------------|-------------------------------|-----------------------------|-------------------------|-----------------------------|
| | Summerfield (n=10) | Brownside (n=10) | Overall (N=20) | Summerfield (n=7) | Brownside (n=3) | Overall (N=10) |
| Female (%) | 5 (50%) | 4 (40%) | 9 (45%) | 3 (42.9%) | 2 (66.7%) | 5 (50%) |
| Ethnicity | | | | | | |
| - <i>White</i> | 9 (90%) | 9 (90%) | 18 (90%) | 6 (85.7%) | 3 (100%) | 9 (90%) |
| - <i>Pakistani</i> | 1 (10%) | 1 (10%) | 2 (10%) | 1 (14.3%) | - | 1 (10%) |
| Mean (sd, range) age (years) | 72.6 (13.86, 52-93) | 65.1 (11.21, 47-85) | 68.85 (12.86, 47-93) | 67.14 (12.14, 52-85) | 68.67 (14.84, 56-85) | 67.6 (12.16, 52-85) |
| Language ability on admission | | | | | | |
| - <i>Normal</i> | 4 (40%) | 1 (10%) | 5 (25%) | 3 (42.9%) | 1 (33.3%) | 4 (40%) |
| - <i>Dysarthria</i> | 3 (30%) | 4 (40%) | 7 (35%) | 3 (42.9%) | 1 (33.3%) | 4 (40%) |
| - <i>Aphasia</i> | 3 (30%) | 5 (50%) | 8 (40%) | 1 (14.3%) | 1 (33.3%) | 2 (20%) |
| Symptoms | | | | | | |
| - <i>Left hemiparesis</i> | 5 (50%) | 4 (40%) | 9 (45%) | 5 (71.4%) | 2 (66.7%) | 7 (70%) |
| - <i>Right hemiparesis</i> | 5 (50%) | 6 (60%) | 11 (55%) | 2 (28.6%) | 1 (33.3%) | 3 (30%) |
| Mean admission NIHSS score (sd, range) | 12 (9.12, 2- 25) (n=9) | 12.2 (9.85, 2- 29) | 12.11 (9.26, 2- 29) (n=19) | 9.67 (7.53, 2- 21) (n=6) | 8.33 (4.73, 3- 12) | 9.22 (6.44, 2- 21) (n=9) |
| Mean length of stay in days (sd, range) | 31.6 (27.98, 3-76) | 52.1 (46.43, 6-144) | 41.85 (38.77, 3-144) | 26.14 (24.96, 3-76) | 22.33 (25.74, 6- 52) | 25 (23.79, 3- 76) |
| Discharge destination | | | | | | |
| - <i>Home</i> | 8 (80%) | 7 (70%) | 15 (75%) | 7 (100%) | 3 (100%) | 10 (100%) |
| - <i>Residential care</i> | 0 (0%) | 3 (30%) | 3 (15%) | - | - | - |
| - <i>Nursing care</i> | 2 (20%) | 0 (0%) | 2 (10%) | - | - | - |

¹ sd=standard deviation; NIHSS=National Institutes of Health Stroke Scale

Table 3.5 Carer participant characteristics²

| | Observations | | | Interviews | |
|-------------------------------|---------------------------|----------------------------|-----------------------------|----------------------------|-----------------|
| | Summerfield (n=7) | Brownside (n=10) | Overall (N=17) | Summerfield/ Overall (N=4) | Brownside (n=0) |
| Female | 4 (57.1%) | 7 (70%) | 11 (64.7%) | 3 (75%) | - |
| Ethnicity | | | | | |
| - <i>White</i> | 7 (100%) | 9 (90%) | 16 (94.1%) | 4 (100%) | - |
| - <i>Pakistani</i> | - | 1 (10%) | 1 (5.9%) | - | - |
| Mean (sd, range) age (years) | 50.17 (9.88, 34-62) (n=6) | 57.57 (22.14, 30-90) (n=7) | 54.15 (17.34, 30-90) (n=13) | 50.25 (11.79, 34-62) | - |
| Carer relationship to patient | | | | | |
| - <i>Spouse</i> | 1 (14.3%) | 2 (20%) | 3 (17.6%) | 1 (25%) | - |
| - <i>Child</i> | 3 (42.9%) | 4 (40%) | 7 (41.2%) | 2 (50%) | - |
| - <i>Sibling</i> | 1 (14.3%) | 1 (10%) | 2 (11.8%) | - | - |
| - <i>Grandchild</i> | 1 (14.3%) | - | 1 (5.9%) | 1 (25%) | - |
| - <i>Niece/ nephew</i> | 1 (14.3%) | - | 1 (5.9%) | - | - |
| - <i>Parent</i> | - | 2 (20%) | 2 (11.8%) | - | - |
| - <i>Friend</i> | - | 1 (10%) | 1 (5.9%) | - | - |

² sd=standard deviation

Table 3.6 Professional participant characteristics³

| | Observations | | | Interviews only | | |
|---------------------------------|-----------------------|------------------------|------------------------|----------------------|---------------------|-------------------|
| | Summerfield (n=19) | Brownside (n=28) | Overall (N=47) | Summerfield (n=9) | Brownside (n=10) | Overall (N=19) |
| Female (%) | 16 (84.2%) | 23 (82.1%) | 39 (83%) | 8 (88.9%) | 7 (70%) | 15 (79%) |
| Ethnicity | | (n=27) | (n=46) | | | |
| - <i>White</i> | 16 (84.2%) | 23 (82.1%) | 39 (83%) | 8 (88.9%) | 9 (90%) | 17 (89.5%) |
| - <i>Indian</i> | - | 2 (7.1%) | 2 (4.3%) | - | 1 (11.1%) | 1 (5.3%) |
| - <i>Pakistani</i> | 1 (5.3%) | 1 (3.6%) | 2 (4.3%) | 1 (11.1%) | - | 1 (5.3%) |
| - <i>Chinese</i> | 1 (5.3%) | - | 1 (2.1%) | - | - | - |
| - <i>Other black background</i> | 1 (5.3%) | - | 1 (2.1%) | - | - | - |
| - <i>Filipino-British</i> | - | 1 (5.3%) | 1 (2.1%) | - | - | - |
| Mean (sd) age (years) | 34.63 (9.89; n=16) | 36.08 (12.37; n=26) | 35.52 (11.39; n=42) | 31.5 (8.05) | 33 (9.09) | 31.47 (7.83) |
| Professional background | | | | | | |
| - <i>PT</i> | 8 (42.1%) | 5 (17.9%) | 13 (27.7%) | 4 (44.4%) | 2 (20%) | 6 (31.6%) |
| - <i>OT</i> | 4 (21.1%) | 4 (14.3%) | 8 (17%) | 3 (33.3%) | 3 (30%) | 6 (31.6%) |
| - <i>SLT</i> | 1 (5.3%) | 6 (21.4%) | 7 (14.9%) | 1 (11.1%) | 3 (30%) | 4 (21.1%) |
| - <i>Therapy assistant</i> | 1 (5.3%) | 3 (10.7%) | 4 (8.5%) | - | - | - |
| - <i>Nurse</i> | 2 (10.5%) | 3 (10.7%) | 5 (10.6%) | - | 1 (10%) | 1 (5.3%) |
| - <i>Physician</i> | 1 (5.3%) | 2 (7.1%) | 3 (6.4%) | 1 (11.1%) | 1 (10%) | 2 (10.5%) |
| - <i>Social worker</i> | 2 (10.5%) | 3 (10.7%) | 5 (10.6%) | - | - | - |
| - <i>Discharge co-ordinator</i> | - | 1 (3.6%) | 1 (2.1%) | - | - | - |
| - <i>Dietician</i> | - | 1 (3.6%) | 1 (2.1%) | - | - | - |
| Experience level | | | | | | |
| - <i>Student</i> | 1 (5.3%) | - | 1 (2.1%) | - | - | - |

³ sd=standard deviation; PT: physiotherapist; OT: Occupational Therapist; SLT: Speech & Language Therapist

| | | | | | | |
|---|-----------|------------|------------|------------|---------|------------|
| - <i>Unqualified therapy assistant/ nurse</i> | 1 (5.3%) | 5 (17.9%) | 6 (12.8%) | - | - | - |
| - <i>Qualified junior therapist/ nurse (band 5)</i> | 4 (21.1%) | 6 (21.4%) | 10 (21.3%) | 2 (22.2%) | 4 (40%) | 6 (31.6%) |
| - <i>Experienced therapist/ nurse (band 6)</i> | 7 (36.8%) | 10 (35.7%) | 17 (36.2%) | 44 (44.4%) | 4 (40%) | 8 (42.1%) |
| - <i>Senior therapist/ nurse (band 7 or above)</i> | 3 (15.8%) | 2 (7.1%) | 5 (10.6%) | 2 (22.2%) | 1 (10%) | 3 (15.8%) |
| - <i>Consultant physician</i> | 1 (5.3%) | 2 (7.1%) | 3 (6.4%) | 1 (11.1%) | 1 (10%) | 2 (10.5%) |
| - <i>Social worker</i> | 2 (10.5%) | 3 (10.7%) | 5 (10.6%) | - | - | - |
| Experience in stroke care | | | | | | |
| - <i><1 year</i> | 9 (47.4%) | 4 (14.3%) | 13 (27.7%) | 3 (33.3%) | 1 (10%) | 4 (21.1%) |
| - <i>1-5 years</i> | 5 (26.3%) | 16 (57.1%) | 21 (44.7%) | 3 (33.3%) | 7 (70%) | 10 (52.6%) |
| - <i>6-10 years</i> | - | 1 (3.6%) | 1 (2.1%) | - | 1 (10%) | 1 (5.3%) |
| - <i>>10 years</i> | 5 (26.3%) | 7 (25%) | 12 (25.5%) | 3 (33.3%) | 1 (10%) | 4 (21.1%) |

Table 3.7 Detailed patient participant characteristics⁴

| Participant pseudonym | Site | Age | Pre-stroke function | Stroke severity | Impairments | LOS (days) | Discharge destination | Number of family meetings | Patient and/ or carer interviewed? |
|-----------------------|-------------|-------|---|-----------------|---|------------|-----------------------|---------------------------|------------------------------------|
| Adil | Brownside | <50 | Working, active, independent, lives with wife/ young family | Moderate | Global aphasia, cognitive impairment | 29-84 | Home | 2 | - |
| Ajay | Summerfield | 51-60 | Working, active, independent, lives with family | Mild | Left leg drift, facial droop, dysarthria, cognitive impairment (mild) | <7 | Home | 0 | Patient |
| Albert | Brownside | 85 | Retired, active, independent, lives with wife, carer for wife | Moderate | Left arm and leg weakness, dysarthria, left neglect | 29-84 | Home with POC | 2 | Patient |
| Anne | Summerfield | >80 | Retired, active, sheltered accommodation | Severe | Right arm and leg weakness, global aphasia, hemianopia, ataxia | 29-84 | Nursing care | 0 | Carer (Stacey) |
| Bill | Brownside | 71-80 | Retired, active, lives with wife | Severe | Right arm and leg weakness, hemianopia, global aphasia, dysphagia, dysarthria, low mood, cognitive impairment | >84 | Home with POC | 2 | - |
| Bob | Summerfield | >80 | Retired, active, lives with family support | Mild | Confusion, left leg weakness | <7 | Home | 0 | Patient |
| Brian | Brownside | 51-60 | Working, active, independent, lives with wife | Mild (evolving) | Left arm and leg weakness, dysarthria, visual disturbance, decreased insight, low mood, cognitive impairment (mild) | >84 | Home with POC | 2 | - |
| David | Summerfield | 71-80 | Retired, independent, active, lives alone | Mild | Left arm and leg weakness, dysarthria, left hemianopia | 8-28 | Home with POC | 0 | Patient |
| Diana | Brownside | 51-60 | Working, active, independent, lives with son | Mild | Visual difficulties, unsteady on feet | 8-28 | Home with POC | 1 | Patient |
| Ethel | Summerfield | >80 | Retired, active, sheltered accommodation, support from family | Severe | Right arm and leg weakness, global aphasia, cognitive impairment, ataxia | 29-84 | Nursing care | 1 | Carer (Karen) |

⁴ POC=package of care

| | | | | | | | | | |
|----------|-------------|-------|---|----------|--|-------|------------------|---|-----------------------------------|
| Frank | Brownside | 61-70 | Working, active, independent, lives with wife | Moderate | Right arm and leg weakness, dysarthria | 8-28 | Home | 0 | - |
| Janet | Summerfield | 51-60 | Working, active, independent, lives alone | Moderate | Left arm and leg weakness and inattention, dysarthria, low mood | 29-84 | Home with POC | 0 | Patient |
| John | Summerfield | 71-80 | Retired, active, independent, lives alone | Mild | Right arm weakness, unsteady on feet | <7 | Home | 0 | - |
| Lynn | Brownside | 61-70 | Retired, active, independent, lives with family | Mild | Right arm weakness, dysarthria | <7 | Home | 0 | Patient |
| Marie | Summerfield | 71-80 | Retired, active, supported living | Mild | Right arm and leg weakness | 8-28 | Home with POC | 0 | Patient |
| Marion | Brownside | 61-70 | Recently retired, active, independent, lives alone | Severe | Left arm and leg weakness, dysarthria, dysphagia, visual disturbance, cognitive impairment, low mood | >84 | Residential care | 3 | - |
| Peter | Summerfield | 61-70 | Working, active, independent, lives with family | Moderate | Left arm and leg weakness, neglect, decreased insight, cognitive impairment (mild), low mood | 29-84 | Home with POC | 2 | Patient/ patient and carer (Jean) |
| Ruth | Summerfield | 61-70 | Retired, active, independent, lives with family | Moderate | Right arm and leg weakness, expressive aphasia, cognitive impairment | 29-84 | Home with POC | 1 | Patient and carer (Adam) |
| Simon | Brownside | 71-80 | Retired, mobile with aid, admitted from intermediate care | Moderate | Right leg weakness, dysarthria | 8-28 | Residential care | 0 | - |
| Vivienne | Brownside | 61-70 | Working part-time, independent, lives alone | Severe | Right arm and leg weakness, right hemianopia, global aphasia, dysphagia, cognitive impairment | 29-84 | Residential care | 2 | - |

3.5 Reflections on recruitment and data collection

3.5.1 Acceptance into the field

I was aware that how I presented myself could have an impact on participants' behaviour. On arrival at the study sites, I introduced myself as a PhD student. Although if questioned, I described my previous roles in research and as a junior MDT member in rehabilitation settings, my approach was to not openly speak about my background; I did not want professionals to feel I was judging their practice and thus become guarded or change their behaviour. I wore plain clothes, and a name badge, which identified me as a member of NHS staff. I felt this was important to give me credence when recruiting participants, however it did mean that I was occasionally mistaken for a junior doctor, who also did not wear uniforms.

My experiences of observation differed between sites. At Summerfield, the busy, acute nature of the ward meant that I could remain relatively anonymous; I felt behaviour was less affected by my presence. Conversely at Brownside, the close-knit nature of the smaller team initially made me feel like an outsider. I was introduced to most staff by the consultant; my association with him appeared to make others initially wary. As I spent more time with them however, I felt they accepted me into their environment and began to speak more openly.

Overall, the study was met with enthusiasm by professionals. They saw the subject area as clinically relevant and challenging, and were keen to discuss their experiences. Therapy and medical staff appeared very comfortable being observed during therapy sessions; they had become accustomed to having another person present through their training and supervision practices. My previous experiences of working in rehabilitation settings (both clinically and as a researcher) meant that I was *au fait* with their language and able to engage in discussions about clinical problems, which helped to develop relationships and rapport, and lessened my status as an outsider. I noticed however that nurses appeared less comfortable and frequently (and appropriately) questioned me around the aims of the study and specifics of what I was recording. The large nursing team and use of agency staff made this more common at Summerfield; I therefore arranged to visit nursing handovers to discuss the study and for staff to become more familiar with my presence. However, I was still unable to recruit a nurse to interview. At Brownside, the relatively small team of ward-based nursing staff facilitated greater opportunities to build rapport. Additionally, I was somewhat able to

capitalise on my personal characteristics; by this stage, I was noticeably pregnant and found this a useful 'ice-breaker' in getting to know the (predominantly female) nursing staff. This development of rapport meant that more nurses engaged with the study at this site, resulting in a nurse agreeing to be interviewed.

3.5.2 Practical challenges

Although the study recruited to target, the number of eligible patients at Summerfield was fewer than anticipated and there were additional challenges. These included: 1) the number of patients admitted to the ward with a diagnosis other than stroke, limiting those eligible; 2) the number of patients for whom stroke was suspected but not yet confirmed, delaying approach; 3) the high ward turnover, which meant patients were sometimes discharged before consent could be taken (and limiting the potential opportunities to observe their care); and 4) the limited visiting hours, which meant I struggled to approach patients alongside a relative to discuss the study (my preferred approach, to both facilitate carer recruitment, and support capacity assessment). These challenges led to recruitment being extended over a longer period than had been intended (four months rather than six weeks), to ensure that the intended number of patients (n=10) were recruited. Similar issues were not encountered at Brownside, where turnover was slower, visiting times were unrestricted, and all ward-based patients had a confirmed diagnosis of stroke.

My observations of the care of recruited patients primarily focused around their therapy sessions and family meetings. Whilst these were planned in some way at both sites, the systems were different and the extent to which it was possible for staff to adhere to these plans in a busy clinical environment was variable. The weekly timetabling system at Summerfield meant that I could plan some of my time in advance to coincide with these sessions. At Brownside, daily planning meant I was reliant on conversations with individual therapists to learn when recruited patients were due to have therapy, and to ensure that the staff attending had consented to study participation. However, the necessary flexibility employed by professionals, sometimes making last-minute changes to the timetable following, e.g., a lack of room availability or being unable to access a patient due to medical investigations, meant that at times, I observed fewer sessions than I had hoped. Family meetings were usually planned in advance at both sites, however there were still occasions where impromptu meetings took place, or last-minute changes were made, which rendered me unable to observe them; this could feel frustrating.

Although I was aware that Brownside had a longer length of stay than Summerfield before attending the site, I had perhaps naively not anticipated the potential challenges for completing data collection, which resulted in some patient participants not being discharged quickly enough for me to interview them within the planned timeframe. In other circumstances, extending the study to permit completion of these interviews might have been feasible, however my impending maternity leave limited this option. Although I received permissions to continue the study following the start of my leave, these interviews were due to take place in 2020 and concerns about the beginning of the COVID-19 pandemic caused me to rethink my plans. I considered using telephone interviews, however given the sensitive nature of the topic, I felt this would be inappropriate. I was disappointed that the reported experiences of these patients would not contribute to my analysis, however fieldnote data from informal conversations with them during their in-patient stays about their views did inform my analysis. While they may have been more reticent to give their true opinions in the hospital environment and their perceptions may have changed following time to reflect on their experiences, this provided a concurrent indication of their views. Additionally I was able to review the clinical records of these patients, which contributed to my final analysis.

At the time of their interviews, patient participants had been discharged from hospital for a month or more, and for those with more severe stroke, the reality of potentially living with residual disability had begun to set in. For these participants in particular, discussion of recovery could invoke an emotional response; particularly where theirs had not been as complete or as fast as they had hoped. Due to the sensitive nature of the topic, I took steps to attempt to limit emotional distress during interviews. Participants (stroke survivors and carers) were advised that participation in the interview was voluntary, that it wasn't unusual to become upset when discussing their experiences, and that they could stop the interview at any time or refuse to answer any questions they did not wish to. I had previously interviewed stroke survivors and carers around this time-point, and was aware that such emotional reactions were not uncommon, and felt comfortable and prepared to offer support. In addition to reiterating the advice above and providing reassurance, I was able to use previously acquired skills in active listening, e.g., paraphrasing and using non-verbal cues to demonstrate understanding. In some cases (depending on my interpretation of the reason for the participant's distress), I also limited my questioning about their hospital-based experiences; instead I made efforts to emphasise the progress they had made and their continuing recovery journey. This strategy felt appropriate given the voluntary nature of the research, however I was aware that this could reduce the richness of the

data collected in this small number of cases. Following the interview, I engaged in 'debriefing', including asking the participant if they required further support with their mood, and if so, signposting them to local clinical or third sector services.

3.5.3 Personal biases

Throughout data collection and analysis, I attempted to remain aware of my personal biases and assumptions. Based on my literature review, I was aware of the potential challenges in providing and receiving information about recovery, which at times directed my observations and questioning. My previous experiences of observing interactions about recovery on other stroke units, which had sparked my interest in the topic, were also somewhat negative. I thus attempted to remain open-minded about the practice I might observe, reflecting on my assumptions and consciously considering similarities and differences between these experiences and my current observations. I was able to challenge some of these assumptions through informal conversations with professionals, e.g., through exploring their views to develop understanding about the types of information available to them and their decision-making about what they shared with patients and carers, and why.

Chapter 4 Findings: What influences provision and receipt of information about recovery on stroke units?

4.1 Background

This is the first of a series of chapters in which findings from my qualitative study will be discussed, relating to the following objectives:

- To develop an understanding of how, when, and why information about recovery is provided to patients and carers in the in-patient stroke unit setting;
- To explore the barriers and facilitators to providing and receiving information about recovery.

In this chapter, I will draw on observational, interview, and documentary data, including the perspectives of professionals, patients, and carers, in an attempt to develop an in-depth understanding of the factors influencing how, when, and why information about recovery is provided by stroke unit professionals to patients and their families. I will argue that a range of challenges relating to the hospital and stroke unit environment, multidisciplinary team (MDT) working, the uncertainties of stroke recovery and individual differences in patients' and carers' abilities and needs impact the consistency, delivery, and quality of information provided about recovery.

Through data collection, it became clear that conversations about recovery fell into three main areas:

- Discussions about the progress made or goals achieved since the stroke, i.e., recovery to date;
- General information about post-stroke recovery, including the process and timing;
- Tailored predictions about the extent or timing of recovery an individual patient might expect to make.

Although the aim of this study was focused around the latter two types of information provision; conversations relating to the former, which were much more commonly observed, are also discussed.

4.2 Analysis

Four main themes, and eight subthemes were constructed (see Figure 4.1).

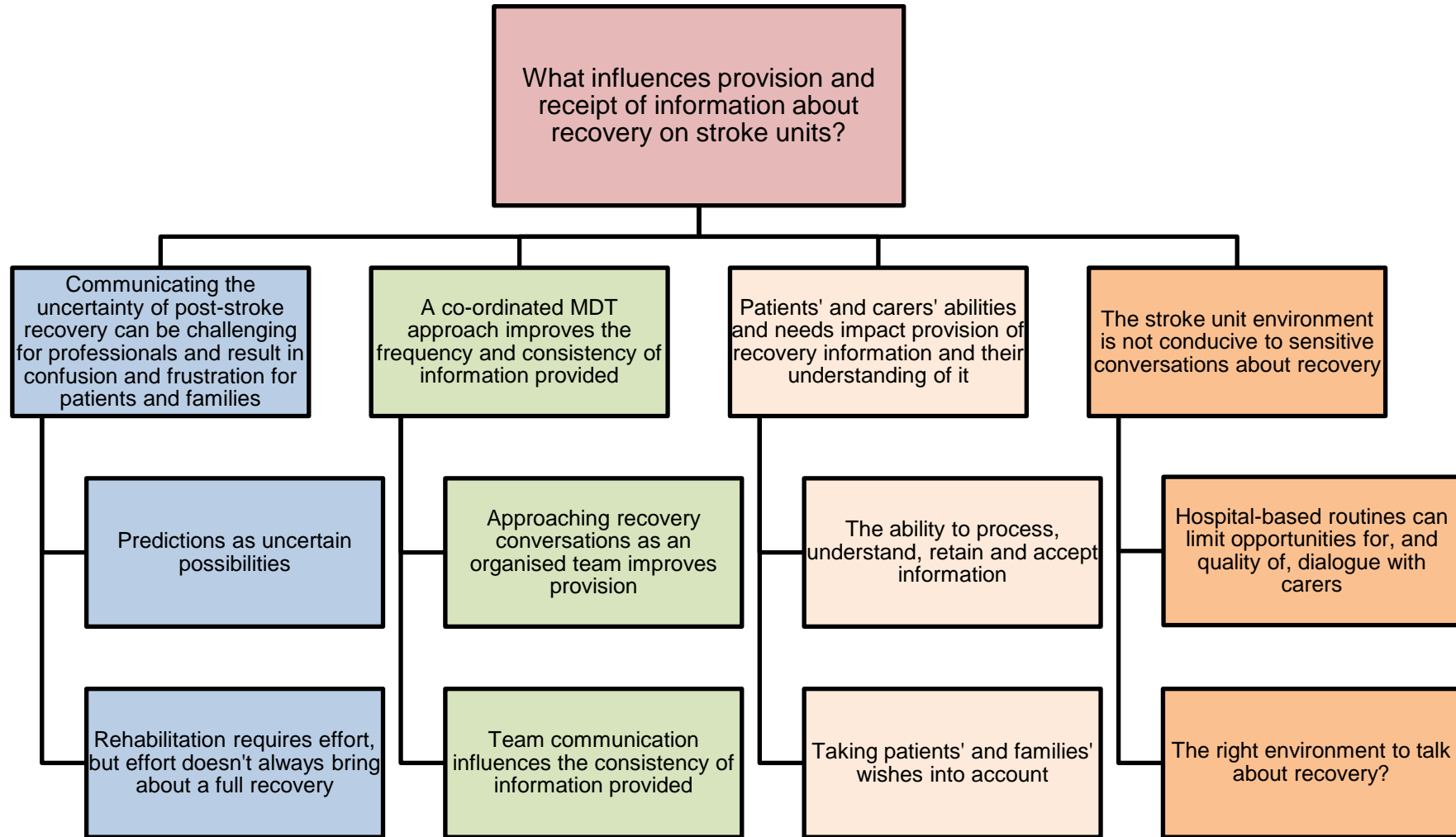


Figure 4.1 Themes

4.2.1 Communicating the uncertainty of post-stroke recovery can be challenging for professionals and result in confusion and frustration for patients and families

The context of an uncertain stroke trajectory meant that predicting recovery, and sharing these predictions with patients and families presented challenges for professionals. This uncertainty made definitive individual predictions challenging to make, and where such predictions were shared with patients and families, they were presented as uncertain possibilities. Despite this uncertainty, all professionals believed that the degree of recovery could be maximised through rehabilitation, and communicated the importance of engagement and effort in therapy to patients and families. However, they struggled with the challenge of motivating their patients to continue participating in therapy whilst managing their expectations that this participation may not lead to a complete or quick recovery. In an effort to protect patients' and families' hope (and thus engagement), they frequently focused information provision on generic and vague statements, e.g., about the long-term nature of post-stroke recovery. Where more specific predictions about individual recovery were not provided alongside this, this lack of clarity left some patients and families feeling frustrated and disappointed when their efforts did not result in the recovery they anticipated.

4.2.1.1 Predictions as uncertain possibilities

A common mantra, heard in both sites (but also in stroke units more generally) was that *'every stroke is different.'* Professionals discussed how stroke could vary in its aetiology (ischaemic or haemorrhagic), could occur in different locations of the brain, and could cause lesions varying in their sizes and effects. Stroke survivors also varied in their pre-morbid characteristics and the way in which they initially responded following the stroke; this resulted in a wide range of interacting factors that could impact a single individual's recovery. Collecting information about these factors, and predicting how they might interact to provide patient-specific information was required before it could be provided to patients and families.

"I think everyone is so different and yeah, everyone just does so differently, even somebody who's had exactly the same stroke, they might be the same age, their recovery will be so different, I think it depends on so many factors." Junior Occupational Therapist (OT), Summerfield

Although professionals varied in the degree to which they believed post-stroke recovery could be predicted, all generally agreed on the factors that they considered

when formulating opinions about the potential extent and timing of individual recovery. Initially medical factors, such as the size, type and location of the stroke informed predictions about the types of impairments and deficits that would result. History-taking and early clinical assessments then determined premorbid levels of function and co-morbidities (e.g., pre-existing dementia or decreased mobility) and revealed the extent (severity and pattern) of the patient's initial deficits respectively, which could influence both how they might respond to therapy and the types of goals that might be achievable. Predictions were adapted following assessment of early spontaneous recovery, and response to treatment or other medical events, e.g., further bleeding in the brain. Most therapists thus described how they often became more certain of, or confident in, their predictions over time. They therefore delayed providing personalised information about the potential timing and extent of recovery with patients and families, typically waiting around two weeks into the patient's admission. This may have contributed to the differences in provision of information between sites; at Summerfield, the shorter length of stay likely resulted in fewer opportunities for conversations at times when professionals felt sufficiently confident in their predictions to share them.

“As you go further along you can [...] become a little bit more certain, you never are 100% but a little bit more certain about the level of recovery you think they're going to make.” Experienced Physiotherapist (PT), Brownside

Professionals were quick to point out that, although they used these factors as indicators of the likely timing and extent of recovery, the uncertain trajectory meant there would always be patients with negative indicators, who recovered better than they first anticipated, and vice versa. In their interviews, professionals discussed the importance of sharing this uncertainty with patients and their families, wishing to avoid providing inaccurate predictions (such concerns are further described in 5.2.3.1). Whilst believing that patients and families would want a *'definite answer'* (experienced PT, Summerfield) about their recovery prospects, many described that admitting this wasn't possible (particularly at the beginning of rehabilitation) represented a more *'honest'* approach (senior OT, Brownside).

“You always have to temper it with that uncertainty.” Stroke consultant, Summerfield

Professionals conveyed this uncertainty both directly and more subtly within the language they used when discussing recovery with patients and families. During therapy sessions at both sites, it was rare to hear individualised predictions about recovery; the few observed were provided through relatively subtle 'hints' or mitigated with conditional language such as *'likely'*, *'might'* or *'we think'*. Although explicit

conversations about individual recovery were more frequently observed during the consultants' ward rounds at Summerfield, and during family meetings at both sites, attempts were made to emphasise that these predictions were not absolute.

"The PT said that when she was home, they could sort out some equipment for her to make it easier to have a bath [..]. This appeared a hint that she thought Janet would still have some level of disability when she went home, though she wasn't explicit about this and Janet didn't ask." Fieldnotes from Summerfield therapy session (Janet), 18.06.19

"The Speech & Language Therapist (SLT) told Adil that he was likely to have some continued problems with his speech upon discharge and that it might take months for this to get better." Fieldnotes, family meeting (Adil), Brownside, 10.09.19

Some professionals felt presenting uncertainty could provide hope for patients and families; they reported conveying the message that they would *"never say never"* (experienced OT, Brownside) in relation to a patient recovering function or achieving their goals. This uncertainty was accepted by patients and carers, and supported by their own experiences and observations of others around them (further discussed in 6.2.1.2).

4.2.1.2 Rehabilitation requires effort, but effort doesn't always bring about a full recovery

In the absence of early individual predictions about recovery, professionals typically provided generic information, e.g., that recovery was uncertain, and required time, rest, and effort. As such, the idea that engagement with therapy was important to achieve post-stroke recovery was prominent in communication between professionals, patients, and families. It featured in the written information provided to some patients at Summerfield, and underpinned much of the dialogue between professionals, patients, and families across sites. This included hints that increased engagement and motivation could result in better or faster recovery, although this was infrequently directly articulated.

"Medications prescribed by the medical team help to reduce the risk of further strokes but there are no medications to assist in the stroke recovery. Recovery is gained through participation in therapy- including physiotherapy, occupational therapy and speech/language therapy." Documentary evidence, Summerfield Rehabilitation File

"I think it's important to give general information, in terms of what the process is, the fact that recovery has to be active, we can't do it to them [..] to make sure they're aware that neuroplasticity only takes place if it's an active process and they're engaged in the therapy, and to educate them on what therapy entails." Senior PT, Summerfield

During therapy sessions (in which patients were required to effortfully participate), therapists' communication reinforced this message, praising patients' efforts and highlighting progress towards their short-term goals, often through comparing their current performance with their previous performance on specific tasks. This likely indicated to the patient that recovery was occurring as a result of their efforts and encouraged them it would continue if their endeavours were maintained.

"The OT said that last time they had been in the kitchen to make a hot drink, Marie hadn't been able to stand but now she was." Fieldnotes from Summerfield therapy session (Marie), 08.04.19

"The OT told Bill not to forget his right side, particularly when he was washing. She said he was much better at that now than when she had first seen him." Fieldnotes from Brownside therapy session (Bill), 02.09.19

Professionals' emphasis on the importance of therapy in achieving functional recovery likely motivated patients to continue to apply themselves, with the expectation that such efforts would result in recovery (patients' views are reported in 6.2.2.1). Aware of the possibility that patients and carers could therefore assume a full recovery was anticipated, professionals simultaneously sought to manage their expectations about the likely timing and extent of recovery. This was felt essential to prevent the maintenance of false hope, where beliefs that the patient would be returned to their pre-stroke state were upheld, even where they were experiencing significant functional disability. Where false hope was maintained and the expected recovery was not achieved, professionals worried that the patient and family would experience negative psychological effects, including disappointment, sadness, and distress. However they simultaneously feared that information about recovery outlook, particularly where it was negative, could impact patients' motivation, potentially causing them to disengage with therapy and further lessening their chances of achieving the best outcomes. As a result, their attempts to manage expectations primarily relied on provision of generic prognostic information, including description of the long-term and uncertain nature of stroke recovery. They encouraged patients and families to focus on short-term goals, discouraging looking to the future. This information was however often vague and lacking in detail, e.g., about exactly how 'long-term' the process would be, and the mechanisms through which improvements occurred.

"I think we need to, people need to stay motivated and as positive as they can be, but I wouldn't ever want people to have unrealistic expectations as well." Experienced OT, Brownside

"Peter appeared tearful and the PT said that recovery from a stroke was a 'hard slog.' She described that compared with a few weeks ago, he was doing much better, as he previously hadn't had sitting balance and now his sitting balance and strength were, 'so much better.' [...] She said that he

was 'working so hard towards what he was going to be able to do'. The OT reiterated that he was 'getting there'." Fieldnotes, therapy session (Peter), Summerfield, 21.03.19

Perhaps as a result of therapists' concerns (particularly in relation to demotivation), provision of individualised recovery predictions was rarely observed during therapy sessions; information focused on progress to date, alongside some general information. However, in family meetings (particularly at Brownside), professionals' attempts to convey the potential realities of recovery after stroke were more evident, and where the outlook was negative, they sought to bring patients and families to the realisation that the recovery they achieved might not be the one they hoped for. Such information included their likelihood of recovering specific functions, e.g., walking, and their potential levels of functioning at specific time-points (e.g., at discharge or in six months' time). Despite professionals' described concerns, in these cases (whether the outlook was positive or negative), there generally appeared little impact on patients' subsequent therapeutic engagement. However, clear strategies were used to deliver this information, including promoting focus on short-term, achievable goals and highlighting functions amenable to change through rehabilitation, which allowed patients and families to maintain hope.

"I think it's just reiterating and trying to almost say, 'well why don't we try and get you as good as we can', and almost trying to look at the benefits a bit and focus on the stuff they can do and, rather than focus on the stuff what they might not be able to do." Experienced Physiotherapist, Summerfield

"The consultant looked at Marion and described how recovery from stroke was a long-term process; he summarised her prospects for recovery, stating that even in six months' time, she probably wouldn't have made a full recovery. He stressed that they would work with her to give her the 'maximum possibility' of recovery." Fieldnotes from family meeting (Marion), Brownside, 03.09.19

Where individualised predictions weren't provided, patients' and carers' understanding of post-stroke recovery focused on time, the provision of therapy, and the effort they expended. Some of those who had not achieved their expected recovery (and their carers) felt disappointed and frustrated, believing that they had not received enough therapy in hospital and/ or tried hard enough. They continued to believe that further recovery would transpire with continued therapy, and the effort they applied. These views and their impact are further described in 6.2.2.

"I think [recovery] might've been a little bit quicker with having the support from the nurses and the physios to make it a bit more faster." Janet, patient, Summerfield

4.2.2 A co-ordinated MDT approach improves the frequency and consistency of information provided

At both units, rehabilitation was delivered by a MDT of doctors, nurses, and therapists. Involvement of numerous professionals within the care of individual patients was both beneficial to, and created challenges for, provision of information about recovery. The team's agreed approach to information provision, including shared plans for how and when recovery should be discussed, impacted whether, when, and how information was delivered. Additionally, whilst members of each discipline brought with them expertise in both predicting recovery and conveying these predictions to patients and families, the uncertainty of stroke recovery invited potential for differing opinions, and thus potential inconsistencies in the messages provided to patients. The way that the teams worked together to share these predictions and the task of discussing recovery therefore impacted the consistency of the messages provided to patients and families.

4.2.2.1 Approaching recovery conversations as an organised team improves provision

Although the uncertain trajectory and the need to maintain continued engagement with rehabilitation were viewed as challenges for professionals across sites, each team differed in their approach to communicating recovery information to patients and families. The extent to which the team organised and proactively offered this information resulted in varied experiences for patients and families.

At Brownside, the team adopted a shared and co-ordinated approach to the provision of recovery information, led by the stroke consultant. This involved a structured process, through which professionals worked together to understand and manage the expectations of patients and families, invite and respond to their questions and proactively deliver information in an attempt to meet their needs (primarily through family meetings). An important feature of the approach was early and proactive provision of information. The team aimed to meet with patients and families in the first fortnight of admission to manage their expectations, to ensure that false hopes were not formed and promote the beginning of adjustment to life with a potentially life-changing disability. Professionals endeavoured to hold subsequent meetings every two to three weeks, with procedures in place to ensure that they were organised, including visible reminders in MDT meeting paperwork and on a whiteboard, and designated responsibility for liaising with patients' families to arrange a convenient time. The team's work was organised to facilitate this, with one afternoon per week allocated to conducting family meetings. This structured process meant that patients

and families knew when they could expect to receive information, and had regular access to discussions with the whole team. Almost three quarters of patient participants had met with their treating team at least once (most attended two meetings); the remainder had length of stay of less than ten days.

In contrast, at Summerfield, each discipline worked independently to provide information about recovery to their individual patients with limited co-ordination (except OT and PT, who frequently undertook joint working). Leadership of the approach across the MDT was relatively absent, although there appeared an implicit understanding that the medical team would provide information about physical recovery and would direct questions about functional recovery to therapists, and vice versa.

Although professionals at Summerfield reported that collaborative delivery of information through family meetings was important and useful, the absence of leadership and co-ordination meant that meetings were not routinely offered to all patients. As a result, they were held infrequently and reactively, typically in response to the need for decision-making, e.g., around medical care, termination of therapy or discharge plans. Only three of the ten patient participants had experienced one, and others were unaware of their availability. Delivery of recovery information by the MDT was therefore relatively rare, and as a result, professionals described that this information was most frequently delivered one-to-one, during therapy sessions or ward rounds. Observations revealed this primarily constituted generic information about the process of post-stroke recovery or information about progress to date, with a relative absence of individually tailored predictions about likely future outcomes. Few therapists described proactively discussing recovery with patients or their families, and others reported more reactive approaches, e.g., waiting until the patient or family approached them with questions. The lack of an organised approach meant that information about recovery was not routinely provided and provision outside of family meetings was somewhat “*chaotic*” (Stroke consultant, Summerfield).

Where family meetings were held, ownership of this process was lacking, and organisation primarily occurred through informal conversation between professionals, with dates communicated verbally or via electronic patient records. The relatively haphazard way in which meetings were organised resulted in negative experiences for some patients and families, who reported attending a pre-arranged meeting only to find that the required professionals were not available.

“This multidisciplinary meeting [...] should have been organised two or three times and [...] we’d come in and it turns out it hadn’t been organised and the doctor [...] or sister hadn’t been told or didn’t know it was happening, wasn’t in the diary.” Stacey, carer, Summerfield

The aims of family meetings at both sites (proactive management of patient and family expectations vs reactive response to problems) were reflected in the content of the discussions. At Brownside, each therapist’s update usually included information about the patient’s potential for recovery; at the patient’s first meeting, this frequently involved the expression of uncertainty, with clearer predictions emerging throughout the course of subsequent meetings. This aspect was typically absent from discussions at Summerfield, with updates limited to current functioning and progress in therapy. Occasionally, questions and comments from patients and families elicited further information, including personalised predictions, but this frequently focused on the impact of potential progress on discharge planning. As a result, Summerfield professionals felt many patients did not receive enough information about recovery. In addition, the organisation of meetings only in response to challenges led patients and carers who had experienced one to report that the aims were unclear; those who were not offered one perceived that professionals were not proactive enough in providing information. Carers of the only patients who recalled family meetings at Summerfield (Jean and Karen) described them as negative experiences, feeling that the aims were to expedite discharge, rather than to discuss recovery or progress. For both, this was a worrying prospect, as their relatives had significant disability and they felt unprepared to cope.

“They probably needed to be a bit more clearer as to why that review was happening, rather, ‘this isn’t a review to chuck you out, this is a review of his care’ [...] because I were in fear of that, when I went into the meeting, that, how am I going to manage with him, being hoisted.” Jean, carer, Summerfield

4.2.2.2 Team communication influences the consistency of information provided

In the context of team working, maintaining consistency in the prognostic messages provided by different professionals could be challenging. Some professionals described how there was potential for contradictory messages to be delivered to patients and families, depending on the individual opinions of the professional providing them. Differences in opinion could result from the uncertainty of post-stroke recovery, and/ or the experience and skills of the professional making predictions. These contradictions were felt to be confusing and a primary source of complaints. As such, professionals were keen to avoid them by sharing information about their predictions

and conversations they had had about recovery across the team, to maintain a consistent message.

“You can have it where there’s someone who is less experienced in stroke will come along and say, [...] ‘you’ll be fine, you know, you’ll be walking within four weeks’, and it’s like, ‘well they’re hoisted and really dense upper limb, they’ve got no sensory feedback at all in that side’ [...] different people tell people different things.” Senior OT, Summerfield

“They do get inconsistent messages, [...] I think being in hospital sometimes everything’s still quite verbal handovers and then it becomes a bit Chinese whispers. [...] I find if there’s lots of people tend to be involved in something, it gets more confusing.” Senior OT, Brownside

At Brownside, this took place through the daily board round and weekly MDT meetings, which facilitated sharing of predictions about recovery and how these were communicated to patients and families to manage their expectations. These issues were seen as central to discharge planning and therefore discussed predominantly during board rounds. There appeared a recognition that (1) the sharing of recovery predictions could support effective collaborative decision-making (e.g., therapy goals and discharge plans) across the team, and; (2) that managing patient and family expectations about the extent of recovery in the in-patient setting could lead to a smoother discharge, promoting acceptance and encouraging collaboration between professionals, patients, and families. Discussing predictions as a team could promote consistency in prognostic messaging, which was felt helpful in avoiding potential complaints due to receipt of contradictory information. Discussions about how information had been provided and received could inform decision-making and planning of further communication.

“[The patient] was described as ‘heavy’ and a family meeting was to take place tomorrow. The consultant asked for a long-term prognosis from an OT/PT perspective. The ward sister said her cognition was fluctuating and the PT described her as ‘heavy.’ The consultant said it was ‘not a good stroke.’ [...] The consultant said they needed to set realistic expectations about her outcome.” Fieldnotes, Brownside board round, 02.09.19

“Normally we have a board meeting and [...] if we’ve had a bit of a difficult conversation with a family member because they’re not necessarily recognising what we’re recognising, say ‘heads up guys, I had a conversation with so-and-so’s wife or daughter and they don’t really understand what’s happened’, or ‘the patient’s told them this so they think this, we need to sort things out really’.” Junior PT, Brownside

Conversely, at Summerfield, opportunities for sharing this information were more limited. Board round and MDT meetings allowed for only brief discussion of each patient, were medically-led and primarily structured around updates from each discipline (current treatment and functioning), with a focus on discharge planning. As a

result, predictions about recovery and how these had been received by patients/families were only communicated when they significantly impacted discharge planning.

“There was very little in the way of discussion about what patients’ might achieve, excepting one patient who was described as not engaging and the consultant suggested that a nursing home might be suitable, and a second patient who was not engaging and the consultant commented that ‘we’re not going to get anywhere with him; we need to think about discharge planning.’ Discussion was focused on discharge plans.” Fieldnotes, Summerfield board round, 12.03.19

Some discussion of these issues was however evident at the weekly therapy planning meeting, at which more time was afforded for OTs and PTs to discuss the current treatment, progress, and discharge plans of individual patients. The team leader (a senior PT) facilitated problem-solving in cases where the treating therapists reported difficulties, teasing out clinical reasoning and prompting them to make predictions about recovery potential; this informed discharge planning. However, dissemination to the wider team appeared rare, as did the sharing of such information with patients and families.

“The next patient was described as having come into hospital from residential care; it was ‘early days’. The junior OT said she thought it looked like discharge would be to 24-hour care, as he was very fatigued. The team leader asked what the family thought and the OT said she didn’t know. The team leader suggested a family meeting to discuss, saying they might be looking at a nursing home placement.” Fieldnotes, Summerfield therapy planning meeting, 10.04.19

Where opportunities for verbal information sharing between disciplines were limited, professionals described how documenting predictions and conversations about recovery in the patient’s electronic record could function to communicate with their colleagues. Although most described they would document these instances, many suspected that their colleagues would not do the same or provide the same level of detail. Some felt that there was a tendency to document only objective details of care and therapy provision, which precluded these conversations; this was generally supported by documentary data. Some therapists also described potential fear of documenting predictions, due to the uncertainty of the stroke trajectory and concerns about the consequences if their predictions proved inaccurate. Such uncertainty could be conveyed through wording or the use of standard phrases, but this limited the use of records for communicating information between professionals, as information required decoding before it could inform their clinical care.

“Your documentation needs to be accurate and [...] people worry about where they stand legally if they say, ‘right, oh yeah, well by next week you’re going to be back doing the London Marathon,’ when actually they

might be walking, but they're going to have quite an impaired gait, they're not going to be back to running." Senior OT, Summerfield

"I think it's the way you word things as well, isn't it, like I'd never say that 'this patient is never going to make any more progress', I'd word it differently to that because yeah, you have always got that thought."
Experienced SLT, Brownside

Use of written documentation to communicate recovery predictions and delivered information was also reliant on professionals reading each other's notes. At Brownside, professionals were frequently observed reading through patients' records in preparation for contact with them; this appeared less frequent at Summerfield. Nursing staff in particular were generally perceived as less likely to read other professionals' documentation, due to a lack of time and limited access to computers. Additionally, social workers at both sites could not access the electronic system, which meant that occasionally team members felt that they and the patient's social worker were not providing consistent messages about the patient's potential for further recovery around the time of discharge (specifically around informing decisions about how on-going care needs might be met and the environmental adaptations required).

"The nurses necessarily don't know what's going on from a therapy point of view, so we've heard patients in the past being given information that is wrong from the nurses [...] Our little struggle at the minute is around kind of communication from what happens in our team and discharge plans and therapy plans, we document it all on [the electronic patient record] and it's making sure the nurses [...] read it." Senior PT, Summerfield

"There's one consultant who reads all of our notes to the letter so he knows exactly what that person is working towards but others don't and obviously it's difficult because doctors work at different times and so they're not always there and sometimes they're like locum doctors and things so mixed messages definitely happen." Junior OT, Summerfield

Failures in communicating predictions (either verbally or through written documentation) could have consequences for the consistency of information provided to patients and families. One such example was documented at Summerfield:

"The junior doctor introduced the next patient, saying they had 'no long-term plan' and that the patient was 'unlikely to survive the admission', required critical care and that the family were aware of this. The OT said her colleague had already ordered equipment to go in at home, which was due to be delivered today. The discharge nurse started to make some calls to try to halt this process, but it transpired that the equipment had already been delivered. The team agreed there had been 'crossed wires'."
Fieldnotes, Summerfield MDT meeting, 21.03.19

Other examples related to family meetings, where professionals felt it imperative that the team communicated beforehand to ensure that consistent prognostic messages

would be provided. Where this did not occur and colleagues subsequently spontaneously delivered information that was in contradiction to their own views, therapists felt discomfort and worried about confusion for patients and families.

“I find that incredibly frustrating [..]. Unless we get a few minutes with the doctor before the review meeting we’re relying on the fact that the doctors have read our notes and are on the same page, and there has been situations where the doctors have given a different viewpoint to what we were going to give [..]. So it’s either kind of trampling over what’s already been said, or kind of going along and [..] that’s very difficult from a patient and family perspective to hear two different views.” Senior PT, Summerfield

Such a situation was observed at Brownside: The ward-based stroke consultant was unavailable and a different consultant presided over Bill’s family meeting, having not discussed his case with the team. He began the meeting with positive and motivational messages about recovery potential, which clashed somewhat with the later information delivered by the treating therapists, who believed such potential was limited. This situation likely contributed to later difficulties, when (despite professionals’ attempts to manage their expectations), Bill’s family attempted to delay his discharge, stating that he had not made the recovery they expected and they were unable to manage his care at home. This suggests that positive messages can resonate with patients and families, and impact adjustment.

Further, the failure to communicate whether information about recovery had been provided and plan who should provide it likely contributed to patients’ and carers’ perceptions of a lack of proactivity in information provision at Summerfield.

4.2.3 Patients’ and carers’ abilities and needs impact provision of recovery information and their understanding of it

Their endeavours to provide patient-centred care impacted professionals’ clinical reasoning about whether, when, and how to provide information about recovery to individual patients and families. Judgements were informed by patients’ stroke-related impairments, and patients’ and families’ emotional reactions to the acute event, which could impact their understanding and retention of information. Professionals attempted to adapt information, or limit provision to meet patients’ and families’ needs, however at times competing demands, such as impending discharge, meant that they were required to more directly impart understanding to enable patients and families to engage in decision-making. Further, few directly asked patients and families about the

information they desired, and a reliance on patients' ability to question them may have resulted in their information needs remaining unmet.

4.2.3.1 The ability to process, understand, retain and accept information

An important initial consideration described by professionals when making judgements about providing recovery information to individual patients was whether they could effectively attend to, process, understand, and retain the information. For patients, cognitive changes, including a lack of insight, as well as communication difficulties, could impact their ability to receive information. Informed by objective assessments and their clinical observations, professionals made judgements about how much information to provide and when, and how to deliver it to the patient and/ or their family. These issues were reflected in some patients' and carers' comments; they accepted that the stroke had resulted in cognitive changes, which made receiving information more challenging.

"I think sometimes you just can't deliver discussions around prognosis or recovery to patients when they've got profound communication deficits, so that's really difficult." Experienced SLT, Brownside

"I don't think me head were right clever either, [...] it weren't taking it in." Marie, patient, Summerfield

In addition to stroke-related difficulties, the shock and distress patients and carers experienced as a result of the overwhelming nature of the stroke diagnosis and its impact on functioning could impact their ability to process and retain information; this required careful consideration by professionals. Some patients and carers also reported that their initial response to the shock of stroke meant that survival, rather than information about functional recovery, was their immediate concern. Professionals also recognised that family meetings had the potential to overwhelm patients and carers, due to the number of people present as well as the amount of information provided and its emotional significance; this could impact retention (patients' views on these issues are further discussed in 6.2.3.3).

"It was such a shock to start with that I really didn't think about anything, all I was thinking about was getting back home." Bob, patient, Summerfield

"Even when you speak to the family they're in a stressed state because their loved one is in hospital and so they can't take it all in." Senior PT, Summerfield

"I think there's some challenges to [family meetings] in the fact it's very overwhelming and I don't necessarily think that families take everybody's information from what they say because it's quite a big thing coming into a room and having a representation from each of the MDT speaking at them." Junior PT, Brownside

In most cases, where professionals deemed a person unlikely to understand or retain information about recovery, they considered how to adapt or individualise the information to meet their needs. Strategies to do this included repeating information over time, providing information to relatives rather than patients, or limiting the amount of information provided or the number of people present so as not to overwhelm the recipient. Some professionals described giving simple information to the patient about what they were doing in therapy and their progress, rather than engaging them in more complex discussions about what might happen in the future and conveying the associated uncertainty. Despite acknowledgement of the potential benefits, provision of written information was not a regular occurrence.

“So if somebody has got a significant cognitive impairment and can’t understand what I’m saying, I’d keep any education or advice quite limited and I’d maybe then discuss it with the family, next of kin, either on the phone if appropriate or face-to-face.” Senior PT, Summerfield

“Cognition’s often affected after a stroke so people can’t take in a lot of information. So you always have to back it up with discussion with relatives and reiterating what you’ve told them on ward rounds.” Consultant, Summerfield

Finally, denial was also considered as a barrier to families’ acceptance of information, causing them to maintain hope for a full recovery, even in the face of contradictory evidence and professionals’ attempts to manage expectations. This was sometimes understood as part of the process of grieving for the lost abilities of the stroke survivor and the ensuing life changes, and meant that professionals spent more time explaining, and repeating, information about the effects of stroke, process of recovery and potential outcomes, particularly where enhanced understanding was required to facilitate shared decision-making.

“Their family were adamant they were going to be walking before they went home. We said that’s probably not realistic and families are still, I think it’s sort of a grieving for what the patient once was but they just, it’s really difficult for them to take that information on board.” Junior PT, Brownside

4.2.3.2 Taking patients’ and families’ wishes into account

Alongside patients’ abilities, professionals also made judgements based on their perceptions of how much the patient and family wanted to know about their recovery outlook. While some assumed that patients and families both required and desired this information, particularly to effectively engage in the discharge planning process, there was a recognition that this did not apply to all, and as a result, they described careful decision-making about how much information to provide.

“Again it’s down to the patient what they’re wanting, because some people don’t want any information at all [...] and some other people they want everything, every little bit of information that they could possibly find.”
Senior OT, Summerfield

“There’s some people that just want to know hard and fast rules, facts, figures about that patient. There’s some people who say, ‘I’m never going to give up hope,’ and you have to be more careful around delivery and how much you deliver to them.” Experienced SLT, Brownside

Some professionals discussed that their reasoning was informed by patients’ and families’ responses to general conversations about stroke and recovery, including their body language and eye contact. Others described how it was important to develop relationships with patients and their families, to assess how much information they might want, and how to deliver it. Unlike clinical judgements made about patients’ cognition, which could be supported by objective assessments, decisions based on how much information a professional perceived the patient and family wanted about recovery appeared more subjective.

“If it looks like they’re kind of not engaging, so looking for those social cues, like if everybody’s avoiding eye contact with you, if everybody’s kind of turned away from you, you know, it’s not the right time because they’re not open to that kind of conversation.” Experienced SLT, Brownside

“I suppose some people, especially if they’re like a proud person who was doing x, y and z before and then this has happened, they almost want to like be ignorant to it and be happily oblivious to the fact that they might actually not get to a certain level.” Experienced PT, Summerfield

The extent to which patients and relatives asked questions was also an important consideration in professionals’ clinical reasoning about how much information to provide, giving an indicator that was potentially easier to interpret. Professionals’ reliance on waiting for questions at Summerfield however likely contributed to patients’ and carers’ perceptions that recovery information was not proactively provided.

“It often starts with the relatives, they ask a lot of questions and I think it just opens up a conversation that you can then gauge these patients. They want a lot of information, they’re really anxious or they really want to step back from this, they can’t handle a lot and you can gauge it like that.”
Experienced SLT, Brownside

Given the potentially subjective nature of making judgements based on their perceptions of how much information about recovery they believed a patient or family might want, interviewees were questioned about whether they might directly ask them: Only three of the 19 interviewed said that they would (Brownside senior OT and consultant; Summerfield junior PT). In most cases, this question was met with

surprise, but on reflection, professionals felt this was important. One SLT at Brownside felt that patients and families might find it challenging to answer this question, due to difficulties in quantification. This may reflect an awareness that patients and their families are unsure of the amount or type of information that could be provided, and are therefore dependent on the guidance of professionals.

"I don't know if I ever have, or if [pause], that's a very good question, I like that." Experienced SLT, Brownside

"I think it needs to be guided by what people would want to know, I think sometimes my personal approach is that you ask them how much do you want to know, how detailed. [...] what do you feel is important for rehab may not be what the family wants to know." Consultant, Brownside

A minority of professionals (a consultant and experienced OT at Summerfield and an experienced OT at Brownside) discussed how they would not proactively provide information about the recovery of specific functions, unless a patient or relative directly asked these questions. However, this reactive approach relies on patients and families being able to ask these questions, i.e., having the required communication and cognitive abilities, the opportunity to approach professionals, and the confidence to do so. An experienced OT at Summerfield, who used this approach admitted that questions were not always forthcoming. In general, therapists described how they would offer the opportunity to ask questions at the end of a therapy session, with the expectation that concerns would be raised then.

"Consultant: I think you do tend to avoid it unless they ask specifically. So you wouldn't say, "I don't think you're going to walk again," unless they ask that question specifically. I don't think you would.

Interviewer: Why?

Consultant: Well, I think if it's important to the patient, I suppose it's almost like you're saying 'would I be able to get back to playing squash again' or 'would I be able to go on holiday again'. If they didn't ask those questions, you wouldn't necessarily answer it for them." Consultant, Summerfield

"So if your patient, on day one is asking you lots of questions about returning to work, and you're saying, "Actually it's really unrealistic at this point, to think about work. We need to be focusing on this, this and this", and then we might review where we're at and then look at work. But then actually some patients don't ask those questions, so I wouldn't routinely go up to them, and go, "Oh, talking about work, actually, you're not going to be going back for at least six months"." Experienced OT, Brownside

From a patient and carer perspective, all but one of those interviewed described that they wanted information about recovery outlook, describing this information as important for them to plan and make decisions. The exception was Marie, who

described preferring to maintain hope for her recovery, which she did not want to be dashed through negative information. None reported being asked how much information they wished to receive.

“I want to know what there is but I don’t want to know too much if you know what I mean, because it’s no good telling you something if you, I mean I’ve still got hope for me leg so, you know, so I’m going to keep hoping and trying.” Marie, patient, Summerfield

4.2.4 The stroke unit environment is not conducive to sensitive conversations about recovery

The focus of this study was the hospital-based stroke unit, as the starting point of a patient’s post-stroke journey when conversations about recovery begin. Professionals were required to work within a context of factors largely outside of their control, including hospital-based routines, such as staff working hours and visiting times, which could limit access to patients’ families; and the physical environment of the stroke unit, which was frequently inconducive to the routine provision of sensitive and confidential information.

4.2.4.1 Hospital-based routines can limit opportunities for, and quality of, dialogue with carers

Professionals described how they endeavoured to discuss recovery with patients and families when they had contact with them. The opportunities for such interactions were however limited by hospital-based routines, particularly at Summerfield. The stroke unit at Brownside employed an open visiting policy, which meant that patients’ families were able to visit at any time, facilitating their engagement in the rehabilitation process. As a result, patients’ families were frequently observed on the ward and therefore able to opportunistically approach professionals, attend when patients were invited to therapy sessions, and observe ward rounds. They were therefore privy to information provided to patients about their progress and recovery. Daytime visiting at Summerfield however was restricted to a two-hour period in the afternoon; as a result, relatives were unable to be present during ward rounds, which took place in the morning, and had fewer opportunities to approach professionals and join therapy sessions. They were therefore reliant on direct invitations from the treating therapist to arrange sessions, and on the patient to relay information provided by professionals in their absence. Due to the potential for cognitive and communication problems after stroke, this was not always possible.

“At visiting time, I went back to see a patient and his family to whom I had provided information about the study the day before. The patient’s son (who I had not previously met) responded that they didn’t know if the patient had suffered a stroke, as they had first been told he had a [urinary tract infection] but they hadn’t yet spoken to a doctor and were waiting to do so. Having observed this morning’s ward round, I was aware that the doctor had given the patient information about his stroke, however his cognitive impairment meant that he was unlikely to have retained this information to pass on to his family.” Fieldnote, Summerfield, 01.04.19

“When a stroke victim’s had a brain injury, he can’t always relay what a doctor’s said. So, really, it might have been an idea to have more consultations with us present.” Jean, carer, Summerfield

Opportunities for families to receive information about recovery from professionals were also limited by their working hours. Whilst visiting at Summerfield was also permitted for an hour in the evenings, most members of the MDT had left the ward by this time. Therapists typically worked weekdays from 8.30-16.30, with no rehabilitation provided at weekends at either site. As such, family members who visited only in the evenings and weekends, e.g., those who also worked standard hours, had little opportunity to discuss their relatives’ recovery, except with nursing staff, and attended only when invited to pre-arranged therapy sessions or formal meetings. Particular challenges arose for SLTs at Summerfield, whose working patterns enabled their presence on the stroke unit only in the mornings (due to holding caseloads across the hospital for the rest of the day), thus restricting access to patients’ families.

“I suppose it’s kind of a reflection of how the speech and language therapy team work on the stroke ward is we don’t often see families because we tend to be up there for like the morning and then it’s just the way that our caseload goes is that we tend to do our other wards in an afternoon, so we’re not there for visiting.” Experienced SLT, Summerfield

The relative absence of opportunities for professionals and families to directly converse about recovery had an impact on both those providing and receiving information. Therapists in particular described the importance of building rapport with patients and families, which they felt was important in determining how much information about recovery to provide, and also in preparing families for more formal family meetings, particularly where a patient was progressing slowly. Where opportunities were lacking, therapists at Summerfield admitted that patients’ families were not provided with the information about recovery that they needed.

“Sometimes if you can’t meet the patient’s relatives before or you can’t see them before, [giving bad news] does come as quite a shock and I’d like to think as a team we manage that quite well but it’s still very challenging.”
Junior PT, Brownside

“If I don’t have contact with them, then I probably don’t give them an update, as much as I probably should. I think just from the time point of view you don’t have time to ring.” Experienced SLT, Summerfield

For carers, particularly at Summerfield, the impact of these organisational factors was that their day-to-day interactions with professionals were limited in duration and to nursing staff, who were most readily available. Some carers described that nurses provided little information about recovery, often simply reading from the patient’s electronic records or agreeing to pass on a message to an MDT colleague, which often did not prove fruitful. They spoke about their struggles to access the most appropriate person from whom to gain information about their relative’s recovery and were frustrated about the lack of available opportunities to discuss it.

“A lot of them are healthcare assistants and they don’t know, and by the time a message gets to that person, and a message gets to that person, and a message gets to that, it gets lost. And it’s quite frustrating, is that.” Jean, carer, Summerfield

“I did, one day I didn’t get upset about it or angry, I just thought, right they’re busy, I wanted to talk to one of the nurses or one of the doctors about Mother’s progress at the time, and they never got back to me. And I says, “Well, you know, visiting time’s over, I have got to go”, you know what I mean?” Adam, carer, Summerfield

Therapists described how a re-organisation of their working hours, to cover evenings and weekends, would facilitate provision of information about recovery. However, organisation of working hours was deemed to be outside of their control, and whilst feeling that such an extension would be beneficial for their patients, a minority expressed that they would be reluctant to participate if these changes were made.

4.2.4.2 The right environment to talk about recovery?

The observed stroke units were situated in busy NHS hospitals. Although both provided rehabilitation, neither appeared specifically built for this purpose, and Summerfield appeared primarily focused on acute care. Professionals at both sites spoke about the stroke unit as a finite space, describing how increasing demand for beds outstripped capacity, such that therapy rooms were being re-purposed and not replaced. As a result, they discussed how their physical environment presented a barrier in providing information about recovery to patients and their families. Outside of formal family meetings, which were held in confidential spaces, quiet and private areas to discuss recovery were limited. Where conversations during therapy sessions occurred, this was typically at the bedside (usually within an open bay area with privacy

afforded only by curtains) or within an open gym space (where multiple patients were frequently treated simultaneously, again separated only by curtains). Therapy kitchens, meeting rooms, and day rooms (Brownside only) provided opportunities for more privacy to discuss recovery, however they were few, and there was frequently competition to gain access. The absence of such areas occasionally resulted in information about recovery being provided in suboptimal environments and may have contributed to the relative absence of recovery predictions provided during therapy sessions.

Providing information about the potential for future recovery in a quiet and private space was deemed important by professionals for three reasons. Firstly, they acknowledged that the nature of the information they were delivering was of great importance to the patient and family and potentially life-changing; as such it could provoke an emotional response, particularly when they were delivering bad news. The continued availability of private space after bad news delivery, providing an opportunity for recipients to digest the information, was also seen as important.

“I think it's really a shame that we don't have anywhere for people to go [when receiving bad news], especially when people are very upset. Like you will see [...] whole families that are just stood out in the corridor crying and everyone else is just walking past going about their day, and it's just really uncomfortable [...] and I think it must be hard to be so upset just on the corridor for everyone to see.” Junior SLT, Brownside

Secondly, the information they were delivering was deemed confidential, and as such, it was inappropriate to provide it where there was potential for them to be overheard, e.g., in open bay areas. One PT believed this could also inhibit questions from patients and families.

“Sometimes you're mindful that you're in the middle of a bay and you really don't want to deliver information around prognosis or recovery to them when there's ears everywhere, listening in.” Experienced SLT, Brownside

Thirdly, professionals described how a noisy environment with distractions, caused by, e.g., the radio/ television or other conversations in bay areas and open gyms, could further impact on patients' and families' ability to process the information they were providing.

“If you're on the ward there's too much going on and I don't think they'll take in what's happening anyway, what you're saying because there's so much other noise.” Experienced OT, Summerfield

It is perhaps noteworthy that patients and carers did not offer the physical environment of the stroke unit as a barrier to receiving information about recovery (though they were

not specifically asked about it). This could be due to an acceptance of the limitations of the hospital environment, or the fact that information was most often provided in the quiet and private environment of the family meetings and so, although concerns about privacy and noise levels bothered professionals, this issue did not arise for them.

4.3 Discussion

4.3.1 Summary of main findings

This research has identified the factors influencing how, when, and why information about recovery is provided to patients and carers on stroke units, including those which facilitate and limit provision.

The uncertainty of the stroke trajectory can make prognostication challenging for professionals, which may limit the amount of information about recovery provided to patients and carers, particularly early after stroke. These challenges, alongside professionals' desire to promote therapeutic engagement and maintain patients' motivation, contribute to the delivery of information in the form of generic and ambiguous statements about the long-term nature of recovery and requirement for therapeutic effort. Such a focus can result in patients' and carers' beliefs that a full recovery is to be expected should they work hard enough, which can lead to disappointment and self-blame where this is not achieved. More specific tailored predictions are provided in the context of formal meetings between patients, carers, and professionals, however their organisation can prove challenging and where they are not offered, patients and carers may not receive the information they require and perceive professionals to lack proactivity.

The assessment of individual differences in patients' and carers' abilities can also present challenges for professionals, requiring enhanced clinical reasoning to make decisions about when, whether, and how information is provided. The ability to receive information can be affected by stroke-related impairments, e.g., in cognition and communication, and the shock of the diagnosis, and requires careful consideration for information delivery. These findings reveal that patients and carers are rarely asked about their information needs, which could result in them remaining unmet.

Finally, this study has demonstrated how the multidisciplinary nature of stroke care requires team collaboration to formulate and share information about recovery with patients and families. However, the physical environment of the stroke unit, specifically

the relative absence of quiet and private spaces can prohibit information sharing about this sensitive subject, particularly during day-to-day practice. Hospital routines, including professionals' working hours and visiting times can reduce the opportunities for dialogue between professionals and carers, rendering them reliant on reports from stroke survivors for information, which can be distorted due to cognitive and communication difficulties.

These findings will be put into the context of, and compared with, existing research in the main discussion chapter (Chapter 10), where their implications for clinical practice will also be discussed.

4.3.2 Strengths and limitations

A strength of this study is the triangulation of professionals', patients', and carers' experiences of providing and receiving information about recovery, which have not previously been contemporaneously explored in in-patient stroke care using observation, interview, and documentary methods. The exploration of the problem from different perspectives and particularly the use of observation has facilitated the development of rich, in-depth understanding and highlighted aspects of practice of which participants may have been unaware. For example, it was evident from their interviews that professionals spent much time considering provision of recovery information to patients and carers, however this translated into their actions in only a limited way. These concerns would not have been evident without the use of interview methods, whilst, without the use of concurrent observations, the impact on professionals' practice would not have been identified. Additionally, analysis of documentary evidence facilitated exploration of the extent to which written information was provided to patients and families, and the value placed on recording provision of information in their patients' records.

The study of only two stroke unit contexts could be considered a weakness. However, the use of purposive sampling enabled the selection of sites, which differed significantly in their approach to provision of recovery information. These sites were felt generally representative of UK-based stroke units providing rehabilitation, and the professional participants generally reflected those making up a typical stroke unit MDT. The relatively smaller numbers of participating nurses is however a limitation, and the day-to-day interactions between nurses and patients, e.g., during personal care, may have been missed, due to the focus of observations on therapy sessions and family

meetings. As such, it is difficult to draw firm conclusions about nurses' roles in providing recovery information and the challenges they face.

Chapter 5 Findings: How do professionals experience providing information about recovery after stroke and what do they perceive as the key challenges?

5.1 Background

In Chapter 4, I argued that provision and receipt of information about post-stroke recovery is complex, and impacted by a range of factors, which could affect the amount and timing of information provided to patients and families. In this chapter, I will pay specific attention to the experiences and views of professionals involved in providing information about recovery to patients and their families, to address the following objective:

- To develop an understanding of the perspectives of healthcare professionals, including their perceived ability to make predictions about stroke recovery, how they feel about sharing this information with patients, carers, and other members of the multidisciplinary team (MDT), and whether and how training to deliver such information is provided.

I will argue that stroke unit professionals consider that providing information about recovery is an important clinical task resulting in benefits to patients and families, however they experience a range of challenges to doing so, including a lack of training and concerns about negative consequences. I will also discuss the strategies employed to address these challenges. Although I will draw primarily on interviews with professionals, I will also look to corroborate their accounts with instances from observational and documentary data, and to explore whether their experiences and views are also evident in patients' and carers' accounts.

5.2 Analysis

Three themes and seven sub-themes were constructed (see Figure 5.1), which highlight professionals' experiences of providing information about post-stroke recovery.

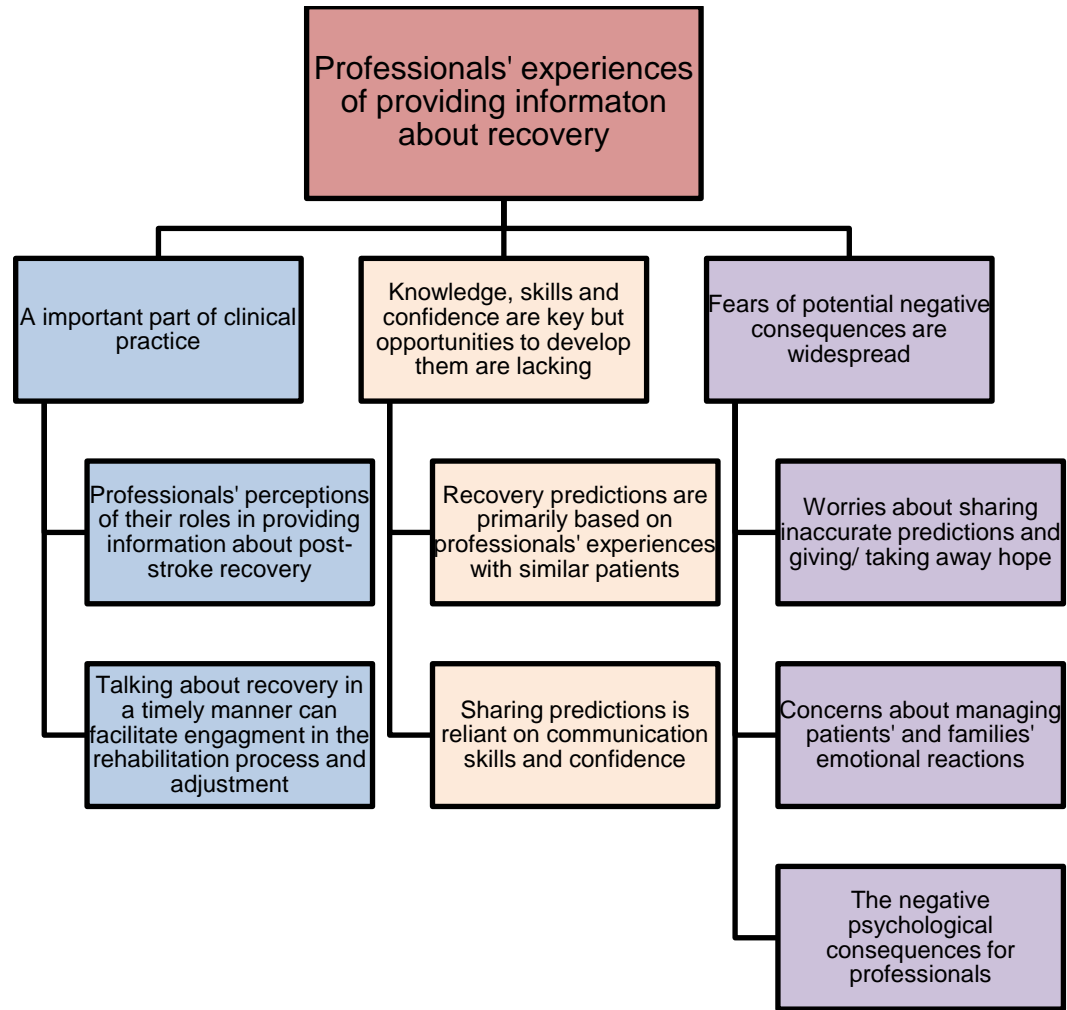


Figure 5.1 Themes

5.2.1 An important part of clinical practice

Despite differences in the organisation of recovery information provision across sites, most professionals perceived that providing such information was an important part of their clinical role. They identified benefits in promoting patients' and families' acceptance to life with a potentially long-term disability, and in supporting their engagement in planning and decision-making, particularly around discharge. As such, they attempted to prioritise this task even where their time was limited, e.g., due to low staffing levels.

5.2.1.1 Professionals' perceptions of their roles in providing information about post-stroke recovery

All therapists and doctors reported that discussing recovery was an important part of their role. Their responsibilities included providing information within their area of expertise and according to their knowledge and experience levels, both individually and as part of the MDT. In general, professionals felt that information about medical recovery should be delivered by a doctor, whilst therapists were best placed to provide information about functional recovery and participation; although at Brownside, professionals jointly contributed to information delivery in family meetings. Providing predictions about future recovery was seen as part of the role of qualified members of the MDT, whilst more junior members could provide general information or comment on progress to date.

"I wouldn't mind the healthcare saying, "Oh, you've stood for that re-turn really well", you know, that's still an indicator of your recovery, isn't it. Like, "Oh, you were on a hoist last week when I came in, and now you're re-turning", [...] It's like to the level of the profession, really." Experienced OT, Brownside

"It's so important to work as an MDT but I think [...] delivering news about recovery [...] needs to be from the person who's like the therapist in that area, so whether that's the mobility with the physios, the cognition and our language and swallowing." Experienced SLT, Summerfield

Despite informal attempts to define the roles of different MDT members in delivering recovery information at both sites, professionals reported an absence of established guidelines identifying who should provide it. Additionally, most professionals agreed that patients and families were more accepting of information when it was provided by a consultant, perceiving them to have a greater degree of expertise, which could be frustrating for therapists. This was reflected in patients' and carers' comments, most of whom expected information about recovery to be provided by a consultant. Some

therapists and the consultants at both sites however noted that information about recovery could come best from therapists, who regularly worked closely with patients and developed trusting relationships with them. Those ascribing to this view felt that patients and families understood the expertise of therapists in stroke rehabilitation. At both sites, the consultant led and chaired family meetings, encouraged introductions and provided a summary of key messages to conclude the meeting. This perhaps provided a way of supporting, and giving credence to, the information provided by therapists.

“They will take it better from the consultant because I think they recognise them as a figure of authority, so I think they respect their opinion more. And a lot of challenges I’d say that therapy get is that we don’t always give the patients [...] or families the answers that they want, which then I think ends up a lot of patient’s relatives saying, ‘well I don’t believe you, I think they’re still going to get better’.” Junior PT, Brownside

“I think we do spend a lot of time with them and they kind of open up to us quite a lot I think so we do kind of use that time to talk about recovery because they feel comfortable enough to ask.” Experienced PT, Summerfield

The role of nurses in providing recovery information was described as an unknown by many professional participants. While some therapists felt that nurses had busy workloads and more important priorities, some felt that the round-the-clock nature of their work and therefore opportunities to develop close relationships with patients and their families meant that they were well-placed. However, other professionals generally expressed concern about the messages about recovery delivered by nurses, with worries about their knowledge and confidence in providing individualised predictions, which could affect consistency of information provided from across the MDT. This was particularly the case at Summerfield, where staffing problems meant that nurses were frequently provided by an agency rather than being permanent staff members, and therefore were thought to lack stroke-specific knowledge and skills.

“I mean in some way they’re a bit of a loose cannon, aren’t they? The discussion with nurses or healthcare assistants who mean well but I think they feel sometimes like they have to give information, even if it’s not the right sort of information. [...] There’s nothing worse than patients or relatives getting multiple information which is different from different specialties.” Consultant, Summerfield

“I think some nurses try and be a bit more involved than others, but I think, again sometimes they might misinterpret information and often provide different information to what we have, so I think sometimes it can be conflicting.” Experienced PT, Summerfield

Only one nurse was interviewed (Brownside), who reported that talking to patients and families about future recovery was not part of the nursing role. He described how nurses provided support and reassurance to patients and families, however he would defer to his multidisciplinary colleagues when questioned about medical or functional recovery, even when related to aspects of nursing care. I rarely observed nurses providing information about recovery and uncovered few documented instances in patients' records. At family meetings, their contributions tended to focus on the level of day-to-day help required on the ward, occasionally including progress (decreasing care needs) over time. However nurses featured heavily in patients' and carers' accounts, which tended to reflect the view of the interviewed nurse; that nurses expressed generic principles about the need for effort and patience to gain recovery, but did not provide tailored information.

“So it’s difficult but if the relatives or the patient wants to know more and I feel I can’t answer it, I’ll either arrange like a meeting with the doctors or the therapists. The therapists are fantastic, they will know the progress more than I will, you know, and be able to give them more of an update and, but we try and keep the patient positive and [...] try and encourage [them].”
Junior Nurse, Brownside

5.2.1.2 Talking about recovery in a timely manner can facilitate engagement in the rehabilitation process and adjustment

Professionals described several benefits to managing patients' and families' expectations about recovery and thus saw it as an important part of their clinical practice. Many described that helping patients to develop an understanding of what they might achieve through rehabilitation could help them to adapt and adjust to their post-stroke life. Whilst professionals described how some could make a good recovery, they perceived that most (particularly those undergoing in-patient rehabilitation) would be left with at least a degree of residual disability. They felt that the sudden and life-changing nature of the stroke event, sometimes with an overnight transition from independence to dependence, could be shocking and therefore difficult for patients and families to process psychologically. This led to what some referred to as a grieving process, both for the functions patients had lost and the subsequent impact this could have on their ability to participate in previously enjoyed activities and roles. As a result, therapists described how their role in providing information about the long-term nature of stroke recovery, the role of rehabilitation and how much recovery might be possible for an individual could promote acceptance, both for patients and relatives.

“The problem with stroke is that it’s people can be fully independent and mobile and a stroke just happens like that [...] that’s obviously going to take

time for them to come to terms with that and then like I say, if all they're doing is hanging on to the hope of well I can get through this because I know I'm going to walk again but they're not, somebody needs to say that to them." Experienced PT, Brownside

Smaller numbers of professionals across sites spoke about the benefits of providing information about recovery to help patients and families to feel informed, reducing their anxiety and increasing their sense of control over the uncertain situation in which they found themselves. Somewhat surprisingly, only a minority of professionals reported that benefits included supporting engagement with decision-making and planning for the future. For patients with on-going disability, this could include providing information about an individual's likely functional abilities and care needs upon discharge, facilitating discussions about how care and support could be sourced, and the potential for changes in the roles of relatives, who may themselves provide this. Discussions about whether further improvements were likely to occur could also inform decisions about the suitability of the patient's previous home environment and the need for environmental adaptations.

"And for family as well, being able to see how much help they're going to need [...] because their role might change so their partner or husband they might then end up being the main carer or doing a role that they weren't doing before." Junior PT, Summerfield

"It can help them again like manage expectations of what they might be at the other end of it [...] and what support the family might be needing [...] to think about, and things like discharge destination, they might not end up going home to the family, that's a big thing to come to terms with."
Experienced PT, Summerfield

One SLT at Brownside described how providing information about how much recovery an individual might make with rehabilitation could inform patients' decisions about whether they wanted to engage in therapy at all, or what aspects of rehabilitation they wished to focus their energies upon.

"If you give them the information [...] in some patients it makes them realise, "Well, actually, I'm going to make some decisions about my rehab and what I want it to look like." [...] I think there's some times where it helps because it puts things into perspective for them, helps them plan and guide us to guide their rehab." Experienced SLT, Brownside

5.2.2 Knowledge, skills and confidence are key but opportunities to develop them are lacking

Professionals described how making predictions about recovery and sharing them with patients and families required knowledge and skills. However, they described limited access to formal training to help them undertake this challenging part of their job. They

discussed how their skills were primarily learned through experience and support was provided informally by their colleagues, resulting in them becoming more confident in their own predictions and ability to share them with patients and families over time.

5.2.2.1 Recovery predictions are primarily based on professionals' experiences with similar patients

Although most professionals described considering broadly the same factors when attempting to predict the likely timing and extent of an individual patient's recovery, the evidence informing this knowledge was primarily accrued through clinical experience. Although most described how research evidence informed their basic knowledge about stroke recovery, junior staff (who had been more recently in formal education) described a greater enthusiasm for, and reliance upon, research evidence. As therapists became more senior, they described how their increased clinical experience could cause them to doubt the application of research evidence to individual patients and to view the evidence base more critically. For example, although it was possible to make some generalisations about recovery potential based on patient-related factors, the uncertainty of the trajectory and the wide range of factors impacting an individual's recovery made it difficult to be exact, and they had experienced anomalies, where a patient's recovery was not as they had expected. This led to a greater reliance on their own clinical experience of the recovery patterns of similar patients, which in turn impacted the information they shared with patients and families. Professionals described how their confidence in their own predictive abilities increased over time, as they worked with more patients. The influence of experience and its effect on confidence meant that patients treated by junior therapists could potentially receive differing amounts of, or variable, information than those treated by more senior professionals. However, professionals described how this impact was diminished through the multidisciplinary nature of stroke care, which enabled junior therapists to access the knowledge and experience of more senior colleagues, through formal supervision, informal discussion, or joint sessions with a patient.

"I think sometimes the evidence is a bit conflicting and I think we initially thought, like the first six weeks is how you make the most recovery, but people are making so much more recovery after that now." Experienced PT, Summerfield

"I find it very challenging really, because part as a physician, you know you rely on evidence, or you try to back up as much as possible on evidence to give accurate information, but you know, no two patients are the same and the variability is so significant that using research to guide people I find that very challenging." Consultant, Brownside

"I'm quite keen on literature, but I think speaking to other colleagues, especially senior members of staff that have been here a long time, they'll

have seen these patients come through and they know what kind of progression they're going to have.” Junior OT, Brownside

The reliance on clinical experience was however problematic when it came to predicting long-term outcomes. Most professionals rarely saw their patients after hospital discharge, rendering them unable to observe how their acute deficits and treatment translated into long-term outcomes. Some highlighted the idea that patients' performance might change in their home environment, but whether this improved with familiarity or deteriorated due to an absence of routine could be difficult to predict. A minority of SLTs at Brownside had however spent time working in the community, treating patients across the stroke pathway and other professionals reported that past patients might visit the stroke unit to express their gratitude; both provided opportunities to assess longer-term progress. Professionals thus worked on the assumption that the greatest changes would happen during the patient's hospital admission, and subsequent improvements would be smaller; although some reported anecdotal evidence that gains could be made long after the initial stroke.

“Some of our therapists on the unit, they don't see what [patients] do outside of here. And there's some patients who you think will do really well and do really terribly once they're home. Or vice versa, some people just need their environment back. So I think that experience [in the community] was invaluable, I don't think you can get an insight into what's next until you're out there and you've seen it. And I think that helped me predict better the people in here.” Experienced SLT, Brownside

5.2.2.2 Sharing predictions is reliant on communication skills and confidence

Therapists discussed how they were expected to discuss recovery with, and break bad news to, patients and families, even as a junior team member. This could cause anxiety, and professionals described lacking confidence. Such potentially challenging conversations required communication skills to impart information sensitively and empathetically, particularly where they involved breaking bad news, e.g., if limited on-going recovery was anticipated. However, despite the perceived importance of providing information about recovery, no training in this area was provided and therapists described how the generic communication skills training included in their degree courses did little to prepare them for the real world of clinical practice in stroke care and the questions they faced from patients and families. Instead, learning was described as experiential, with therapists describing how their skills and confidence in talking about recovery were developed through observing their peers and their own involvement in conversations. This process was supported by preparatory discussions with their peers and seniors and subsequent reflection (either individual or collective)

following an experience in which they were required to discuss recovery. This method of trial-and-error learning meant that junior therapists, or those who had recently rotated on to the stroke unit, could find early experiences challenging, although they might bring with them some skills developed in earlier placements.

"[Recovery is] definitely something that families always ask [about] and especially the less experienced you are the harder it is to answer [...] When you first come on to stroke and you're quite inexperienced, [it] can make you feel quite nervous [...] or anxious to answer because you're just never quite sure." Experienced PT, Brownside

"We don't get any training actually. Again, I just think it comes from experience which, on the job, which I suppose when you're coming into it and you're new it's quite difficult. But watch, again watching seniors and things like that, seeing how they kind of do it." Junior PT, Summerfield

"I've never had any formal training on how to break bad news [...] I suppose I've just kind of learnt it over the years through probably getting it wrong a hundred times [...] you should always be reflecting anyway on how you've done stuff and [...] there are times when you think "Oh, Jesus, I shouldn't have done it like that, that was terrible". And then sometimes you kind of think, "Yeah, you know what, that went really well"." Senior OT, Brownside

Doctors did not describe these challenges, perhaps because breaking bad news training now forms part of standard medical education. Additionally, despite not seeing discussing recovery as part of his role, the interviewed nurse described how his training would not have adequately prepared him to break bad news.

"As a student [...] to get signed off on the competencies we had to break some bad news, but it could've been like a lower level of like 'I'm sorry Mr Smith you can't go home today, you're going to have to go home tomorrow because your medication's not ready' but not really breaking bad news about, not like the doctors have to do." Junior Nurse, Brownside

As a result of this experiential route to skill development, professionals described variation in individual skill levels in discussing recovery. Whilst some assumed that greater experience meant enhanced skills, not everyone agreed. In addition, learning from senior professionals required that those acting as 'models' had themselves developed skills to talk about recovery and break bad news effectively. This led to concerns being expressed by some professionals if this were not the case, and past mistakes were repeated.

"You're just expected to almost pick stuff up along the way, so I think as kind of giving information and advice to patients it's almost on your own clinical judgement, so my clinical judgement's probably going to be different from a Band 5 [junior] than it is to a Band 7 [senior], so we're probably going to clinically think a little bit differently." Experienced PT, Summerfield

"I think there is an unmet gap in education for people who step into the stroke service, you know you're learning on the fly [...] but learning on the fly

it has its own problems, because you know, you may end up doing the same thing people have done before, which hasn't worked." Consultant, Brownside

Most professionals felt that formal training would benefit their professional development and practice. They suggested that learning strategies to discuss recovery and break bad news would be helpful, as well as learning about how to manage recovery expectations and respond to questions in the uncertain context in which they operated. Senior therapists at both units described how optional breaking bad news training was offered by their organisations, however there was a perception that this was aimed primarily at medical and palliative care professionals, and none of the interviewed therapists had accessed it. They were also unsure how widely such training was advertised and how frequently it took place; more junior staff appeared unaware of it. Therapists at Brownside had however proactively organised some informal training from the hospital's palliative care team to fill this gap, which they found helpful.

"The Trust do do a course on how to, I don't know how often they do it, though, I've not actually done it myself, on delivering bad news [..]. I don't know if it's that widely advertised and how often they do it, but it's not like mandatory training [..]. And then I think a lot of it probably just comes from [..] experience." Senior OT, Brownside

"There's breaking bad news training as part of the staff, it's not a mandatory one, it's one that you can book to go on separately, and it's more like when you start to take a management role that they send you on those." Senior PT, Summerfield

5.2.3 Fears of potential negative consequences of providing information about recovery are widespread

Despite recognition of the benefits of providing information about post-stroke recovery to patients and families, professionals described an assortment of worries relating to the consequences of doing so. The uncertainty of the stroke trajectory discussed in 4.2.1 resulted in concerns about the potential for sharing predictions which would later prove inaccurate, which they were aware could result in complaints. Professionals worried about prolonging false hope in the face of predicted on-going disability, but were equally concerned about taking hope away by providing bad news, and the potential consequences this could have on patients' mood and motivation. Where they were required to engage in difficult conversations, e.g., those involving breaking bad news about the potential for sub-optimal recovery, professionals felt anxious about their own skills in delivering this information and in managing patients' and families' negative reactions, including sadness and anger. Each of these concerns represented an emotional cost to the task.

5.2.3.1 Worries about sharing inaccurate predictions and giving/ taking away hope

As a result of the uncertain post-stroke trajectory, many professionals described anxiety about sharing individualised recovery predictions with patients and families, fearing they could later prove inaccurate. They worried about receiving complaints should the patient achieve a lesser degree of recovery than they had suggested. Some also described a loss of trust in the therapeutic relationship following presentation of imprecise predictions, even where a patient achieved greater recovery than was anticipated. As a result, many described a reticence to share specific predictions with patients and families, at least until they were very confident in their accuracy.

“What you don’t want is somebody to come back and say, “He’s walking now and you said he never would.” But equally they say, “They’re not walking now and you said he would.” And that’s what you want to avoid. So I think as long as you get that uncertainty message across, then you can make sort of predictions, I suppose.” Consultant, Summerfield

“It’s difficult to predict and then if I say the wrong answer and say [...] “oh yes, it’s definitely going to improve,” however, if that’s not the case and the patient comes back and says to me in three months’ time or sends a letter in, and says ‘actually, [S28] staff nurse, said, you know, continence was going to improve for my partner but now it’s just the same, why have you lied to me?’ you know, it’s a tricky one. So it’s erring on the side of caution.” Junior Nurse, Brownside

Alongside worries about the accuracy of their predictions, professionals also discussed how they walked a fine line between giving and taking away hope for recovery. Whilst they felt it necessary to prepare patients and families for potential ongoing disability, they worried that such information could result in them losing hope, which could affect their mood and motivation to participate in therapy; this reduced participation could then further limit their potential for recovery. Equally, they were anxious to ensure that patients and families did not maintain high hopes of recovery that they did not expect to be realised, which had the potential to result in disappointment should their expected recovery not be achieved. Many described how these issues required careful wording when discussing recovery with patients and families, and they worried about the consequences.

“Don’t want to raise anybody’s hopes but then don’t want to say, “actually you’re not going to...” “this isn’t you know, possible.” You know, you have to be really, yeah careful.” Experienced OT, Summerfield

“For some people it could have a real negative effect and they feel like giving up and they don’t engage in therapy and they’ve still got potential to improve, but because they know they’re not going to get walking they just feel like giving up and then they don’t engage with therapy and it becomes

a negative thing, so you have to be very careful." Experienced PT, Brownside

Due to their knowledge about post-stroke recovery, there was a sense that professionals found themselves in the powerful position of the 'expert' and were aware of the responsibility that came with this. There was a degree of paternalism in their comments, with several suggesting a tendency to err on the side of caution when sharing their predictions, particularly when they were positive. Professionals described that the motivation behind this was to avoid giving false hope to patients and families; it was preferable to 'under-promise and over-deliver' to avoid potential disappointment. This viewpoint appeared more common at Summerfield than at Brownside, where the team's approach meant professionals placed greater value on sharing their honest views about the potential for recovery, whether positive or negative. None of the interviewed professionals however discussed how being selective with the information shared with patients and families about their potential for recovery could reduce the benefits of sharing such information, e.g., in terms of engagement with decision-making.

"You don't really want to get their hopes up and then for them to not get where you expected, so I hold back certain information on what I think with families, I think it's appropriate." Experienced physiotherapist, Summerfield

"I think people are often, I don't know, maybe a bit negative about outcomes, just for fear of not wanting to [...] disappoint people." Consultant, Summerfield

"Try and be honest, and then if they outdo your expectations that's fantastic, but you've not given family that false hope." Junior SLT, Brownside

Professionals described a range of strategies they used to manage this challenging aspect of communication, to allow patients and families to maintain hope for their recovery. Firstly, they described the importance of conveying the uncertainty of the stroke trajectory to patients and families, and being honest in saying that they were unable to make accurate predictions early after stroke. Some felt this uncertainty could provide hope for patients and families. Secondly, a minority also discussed how they tried to present information about the potential for a negative outcome in ways that could help the patient and family to maintain hope. These included presenting 'bad news' about functions affected by the stroke alongside 'good news' about the functions that had been preserved, and encouraging a focus on what was amenable to change through therapy, e.g., through goal setting.

"I think if somebody told me I was never going to walk again, I'd be like, 'well what's the point' [...] but I think it's just reiterating and trying to almost

say, 'well why don't we try and get you as good as we can', [...] and focus on the stuff they can do and, rather than focus on the stuff what they might not be able to do." Experienced Physiotherapist, Summerfield

"I would never say you're never going to walk again but I would say it's looking like you might not get back up on your feet and be walking independently. But everything we're doing is about trying to improve your quality of life as best you can. [...] And when you think about sort of speech, swallow, transfers, continence, mobility, cognition, you can usually say there's four or five things that are improving a little bit. And you can sort of distract them a little bit from the fact that they may not actually be walking again in due course." Consultant, Summerfield

5.2.3.2 Concerns about managing patients' and families' emotional reactions

It was accepted that discussing recovery, particularly where the outcome was likely to be sub-optimal, was not only challenging for professionals, but could also be distressing for patients and families. Therapists in particular worried about facing and managing patients' and families' emotional responses to the provision of negative information, which could include sadness that their recovery may not be as they hoped, and anger that this was due to the care they had received.

"It can be quite upsetting. I think it can be hard to manage the emotional side of it after you've delivered some information, if it's not going to be a positive recovery." Experienced SLT, Brownside

"I think the only negatives is when it's not what people want to hear, it can be perhaps quite confrontational. Erm, it's hard sometimes to balance being really honest versus thinking about somebody's feelings as well, how they feel about that. Erm, and I think sometimes if you get it wrong or something like that, then your families might get cross about it." Junior SLT, Brownside

The professionals at Brownside specifically worried about the emotional reactions of patients who were already low in mood or anxious. Conscious that these difficulties were common post-stroke, some expressed concerns that sharing negative predictions could cause these mood difficulties to worsen, further impacting on the patient's motivation to engage in therapy and their subsequent outcomes. One OT expressed concerns that time spent alone in hospital after receiving bad news about their potential for recovery could give patients space to ruminate, potentially exacerbating their distress. Referrals for psychological support could be made at Brownside, which provided an opportunity for two recruited patients to discuss these feelings and supported adjustment; limited support was available for others, and there was no provision at Summerfield.

"I think you get to [...] understand how they respond to information like that in terms of if you feel that it's not appropriate because it's really going to affect their mood, for some people it could have a real negative effect and

they feel like giving up and they don't engage in therapy and they've still got potential to improve [...] so you have to be very careful, yeah." Experienced PT, Brownside

"[Marion] is struggling to tolerate the uncertainty and sadness surrounding her situation. [...] She thinks she is grieving for the life she had and aware this is a process one has to go through to adjust to her reality." Clinical record, psychological therapist, Brownside, 16.09.19

Professionals responded to patients' and families' emotional reactions to the information they provided in several ways. They described 'checking in' with a patient/family member following delivery of bad news, and listening to their concerns. Where the emotional response, particularly anger, impacted the relationship between the patient/family and a therapist, they described that they could make changes in which member of the team treated the patient, and/ or approach future conversations about recovery with a senior team member.

"Sometimes we might take them out the room, or sometimes after the family meeting I might go back [...] and just say, "How are you feeling?", and, "We're really sorry we had to tell you that"." Experienced OT, Brownside

Although professionals accepted that emotional responses were not always avoidable given the sensitive and potentially life-changing nature of the required discussions, they described how distress might be limited through early management of patients' and families' expectations. Therapists described how they would 'drip-feed' information in day-to-day sessions before confronting the topic directly in family meetings. Given the observed absence of personalised predictions provided in therapy sessions, it is possible that the subtlety and vagueness of professionals' attempts may not however have been detected by patients and families. Professionals at Brownside also discussed providing information in a team setting, to demonstrate how, whilst some aspects of functioning were unlikely to recover, others were amenable to change. Some suggested that it would be beneficial to receive advice from a psychologist to guide them in delivering information in ways sensitive and empathetic ways.

"I think [a psychologist] might be helpful in just, I suppose helping us work out how best to deliver it but at what level it needs to be at. And I suppose, supporting them after they've had this information." Experienced SLT, Brownside

Some professionals described a temptation to be more positive about a patient's potential for recovery than they really felt, to provide encouragement, support, and hope. However, most perceived that instilling realistic expectations was more important, and discussed the importance of careful wording, feeling that patients and

families could focus on the more positive aspects of the information they were conveying.

“Sometimes you have to be really careful what you say. [...] You really want to tell someone they’re getting better, you want to tell them it’s all going to be alright but actually you have to be really realistic and if we’re not seeing that they’re making potential we need to be really honest with them and the family because if not it just makes the conversation that we’re going to have in a couple of weeks or in a month’s time even harder.” Junior PT, Brownside

Where low mood or anxiety was a consideration, some therapists described how they might avoid or delay conversations about recovery until the patient’s mood had improved or the stress of the situation was less acute. There were however again hints of paternalism in therapists’ comments; it appeared they were trying to limit patients’ emotional reactions in their best interests, but at times this could potentially mean withholding specific information about recovery or delaying providing it, which could potentially limit the benefits.

“Definitely when I first started, I avoided it [talking about recovery with a patient low in mood] like the plague, [...] it’s something I’ve kind of picked up as you go, no formal training, but I think where when I first started I definitely avoided it, 100%.” Experienced SLT, Brownside

5.2.3.3 The negative psychological consequences for professionals

Although they endeavoured to manage patients’ and families’ emotional reactions to information about recovery, most therapists described how doing so represented an emotional cost for them. Described emotions ranged from feeling “*uncomfortable*” to “*drained*”, with therapists experiencing anxiety, stress, and sadness around these conversations. They worried about their own abilities to impart information sensitively and to manage the subsequent emotional reactions of patients and families. However, most discussed the importance of conveying this information, however uncomfortable or upset they might feel. A particular situation described by some therapists was when they felt blamed by families for not providing enough therapy, or giving up on a patient, particularly in situations when discharge was being considered and the patient had not regained their pre-stroke levels of function. However, some were accepting and understanding of these responses, and empathised with their grief.

“People do worry about their reaction, I think, or they’ll worry that they’re going to say the wrong thing, [...] that they’re going to say something that’s going to make the situation worse, [...] because nobody likes giving bad news do they, let’s face it.” Senior OT, Brownside

“We’ve all had meetings where we’ve come out and it’s not necessarily that the family were nasty, it’s not necessarily that they were angry, it was just

that it's really sad [...] I can think of family meetings where I've been in and it's just been horrific, horrible for everybody because it's been so sad."

Experienced SLT, Brownside

"It's really draining. You do go home and wonder if you're doing a good job. I had a bit of a nightmare family who the son sat next to me in the family meeting and just kept telling me that I was giving up on his mother. [...] and I can't get upset because I can see why because they're angry, because they're angry that this horrible thing has happened." Junior PT, Brownside

The extent to which professionals were affected by these feelings varied. In response to an emotional reaction from patients' families, one junior PT at Brownside described questioning her own ability, whilst an OT at Summerfield discussed having considered leaving her job. In contrast, others were more matter of fact about these conversations, putting this down to their personality type or emotional resilience. Three therapists described how the extent to which they were bothered by difficult conversations had decreased with experience, suggesting they became more emotionally resilient over time. Other factors impacting how emotionally affected professionals were by individual cases were the length of time spent in the therapeutic relationship and the strength of the relationship formed.

"Sometimes you almost have to take yourself out of the situation almost, and it's difficult because you almost have an attachment with that patient, because they're yours, you spend a lot of time with them, but almost put yourself in kind of their shoes a little bit and kind of take the flack."

Experienced PT, Summerfield

"I think I've become [...] sort of hardened to other people's emotions, and it's very much like life goes on [...] I think I just deal with it quite well, and just accept that it's [...] part of the job and unfortunately some horrible things happen to lovely people, but there's not always much we can do about it."

Junior SLT, Brownside

Professionals however reported a lack of formal support, e.g., counselling, in managing their emotions, with some describing how this would need to be proactively sought and that they would be unlikely to do so. Instead, therapists described how positive and trusting team relationships enabled them to discuss their emotions with their peers and supervisors, particularly within their own disciplines, and access informal personal support. Debriefing often followed a family meeting where negative predictions were provided, allowing professionals to express their emotions with support from their colleagues, as well as reflecting on what had gone well or could be improved. Access to shared private spaces for staff facilitated this. Personal reflection on their experiences, individually or with more senior staff, was also felt helpful in managing emotions and providing reassurance about professionals' handling of difficult situations.

However, some felt that promoting and increasing the availability of formal support services could be beneficial.

“In stroke, I think they are quite good at, if something’s kind of, getting a bit much for you, or you feel like you can’t handle something, then I think they will very much give you that support and either, give you guidance on it, or them take over kind of their care if they feel that’s necessary. But I think most of the time you probably have to seek for it if you want it, rather than it just kind of being there.” Experienced PT, Summerfield

“A lot of time even just after the family have left the room after a meeting all sitting together and going “well that was awful” or “you know what, that was good” or “I think they might have taken that” or “you know what, I don’t think they took that, let’s think about this going forward”, that can also help as well.” Junior PT, Brownside

“I feel lucky that I work in a big team and there’s always a Band 7 [senior] around. If I am feeling that it’s getting to me, psychologically, I’d just go and speak to one of them, I think. But, yeah, sometimes you get a bit of a tear in your eye, well, quite often [laughs]. You’ve got to try and hide it.” Experienced OT, Brownside

Discussion of the emotional cost to breaking bad news and required levels of support were largely limited to therapists. Consultants described that they did not access support from the MDT and felt that therapists managed this separately from the rest of the team.

“I don’t really know about peer support. We don’t, from a medical point of view but the therapists may.” Consultant, Summerfield

“You often are kind of blinded to what others are thinking, others are feeling [..] I don’t hear about the vast majority of day-to-day lack of confidence or you know, “hold on I’m not comfortable with this what do I do” kind of questions.” Consultant, Brownside

5.3 Discussion

5.3.1 Summary of main findings

Findings from this study suggest there was a relative absence of training and guidance for therapists and nurses engaging in conversations about recovery. This could result in perceived variability in information delivery and decreased confidence, particularly when breaking bad news, and a range of psychological effects, including worry and sadness that could accompany such conversations. Underlying these concerns were the uncertain trajectory of stroke recovery and concerns for the emotions and engagement of patients, whom professionals feared could be negatively affected by the receipt of information that may not match their expectations for recovery and/ or may not transpire.

These findings, and their clinical implications, will be discussed in the context of existing literature in Chapter 10.

5.3.2 Strengths and limitations

The strengths and limitations presented in 4.3.2 apply equally here. Specific to this chapter, the use of the Framework approach to analysis supported between-case analysis, and particularly the identification of deviant views (88). Interviewing only one member of nursing staff however limits the applicability of findings to their profession; the experiences of nurses in providing information about recovery therefore warrants further investigation.

Chapter 6 Findings: How do patients and carers experience receiving information about recovery after stroke and what information do they want to receive?

6.1 Background

This is the third and final chapter in which findings from my qualitative study will be discussed. In this chapter, I will explore the experiences and views of patients and carers on the stroke units, including those who received information about recovery and those who have not received (sufficient) information, and the potential impacts, to address the following objectives:

- To identify the information patients and carers want and need about recovery after stroke;
- To explore how patients and carers feel about the prognostic information they receive.

Although I will draw primarily on interviews with patients and carers, due to the impact of the COVID-19 pandemic, the views of patients and carers from Brownside are underrepresented in this dataset. However, my analysis of these interviews has been supplemented with data collected through informal conversations with stroke survivors and carers at this site (documented in my fieldnotes), as well as their responses and reactions to information when provided, in an attempt to understand their experiences and draw comparisons with those at Summerfield. Additionally, when questioned during formal interviews around one month post-discharge, recollections of information provided in hospitals varied. Therefore I also sought to corroborate the accounts of all patients and carers with instances from observational and documentary data, and to explore whether their experiences and views are evident in professionals' accounts.

Stroke can be experienced as a "*biographical disruption*" pp. 167 (196), causing a disturbance not only to a survivor's physical functioning but also to their sense of identity. Survivors seek to make sense of and give meaning to the disruption to their on-going lives through integrating the stroke's residual effects into re-formulations of their identities (197). Their interpretation of stroke as a disruption may impact their views of recovery and how information provided by professionals contributes to their post-stroke identity; the concept of biographical disruption thus presents a theoretical lens through which the data presented here could be explained. Although the data were not analysed specifically through this lens, this explanation is one I will return to in the Discussion (Chapter 10). In this chapter, I will argue that patients and carers want information about recovery to be provided proactively, sensitively, and in ways which

help them to maintain hope. There was a general acceptance of the lack of specific predictions about individual recovery, based on beliefs about the heterogenous nature and effects of stroke. I will also explore in more detail how insufficient understanding of the process of post-stroke recovery could impact patients' views about discharge and withdrawal of therapy, which could result in disappointment.

6.2 Analysis

Four core themes were constructed (see Figure 6.1).

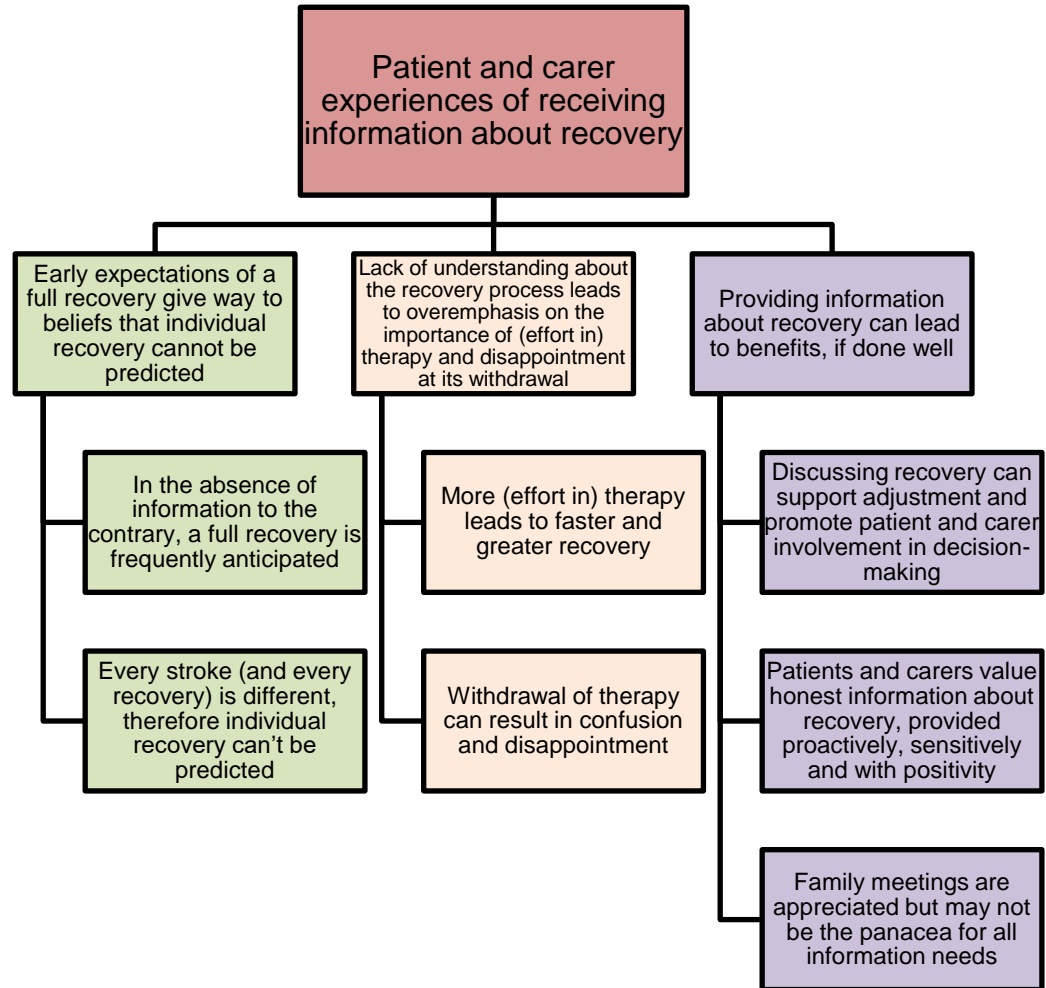


Figure 6.1 Themes

6.2.1 Early expectations of a full recovery give way to beliefs that individual recovery cannot be predicted

Despite (for most) early expectations of a full recovery, patients and carers began to gather information about their likely progress and recovery, both from professionals and other sources, including observing those on the ward around them. Through this process, they learned of the heterogenous nature and effects of stroke, which led to strongly-held beliefs that their individual recovery could not be predicted. This gave rise to acceptance that specific information could not be provided, which generated hope.

6.2.1.1 In the absence of information to the contrary, a full recovery is frequently anticipated

Once their medical condition stabilised, most patients underwent initial assessments and were informed about the stroke's effects. Whilst the importance of engaging in rehabilitation was communicated to them, at this stage they did not describe receiving specific information about this process or how their recovery might progress. This was not considered troubling; they were simply grateful to have survived, and that something was being done to help. However, in the absence of information, they formed their own expectations of what recovery might entail.

"The consultant told me what had happened, and I've no reason to believe that his interpretation of the scans he saw were anything but professional. The physios were talking mainly about what could be done to alleviate the position." David, patient, Summerfield

"As I keep saying I'm very, very lucky, very lucky." Bob, patient, Summerfield

The most important factor impacting expectations at this stage appeared to be patients' and carers' previous knowledge and experience of stroke. The majority had not encountered stroke before and thus expected a return to their pre-stroke life, including their previous physical function, and the activities and roles they had enjoyed. For others, who had previously met other stroke survivors, there appeared an awareness that recovery may not be complete. Carers of patients of advancing age also considered the stroke in the context of wider health problems, which impacted their expectations, resulting in greater concern for their loved one's quality of life rather than their functional recovery.

"I'm so fed up, I just want it over, I just want to get it back, I want to be like I was." Lynn, patient, Brownside

“My first thought was she’s not going to recover, she’s probably never going to live independently ever again, which is true, so I didn’t really have a particularly high expectation of anything really happening.” Stacey, carer, Summerfield

Where patients anticipated a full recovery would be quickly achieved, their early questions directed at professionals often related to upcoming events, e.g., their attendance at a football match or impending travel. Although typically told such plans were unlikely and that a period of rehabilitation was required, in the absence of concrete information about their likely outcomes, their expectations that a return to their previous function was simply a question of time persisted. Some continued to question when they would return to valued activities, such as walking and driving, and in response, were encouraged to think about recovery as ‘*baby steps*’ rather than focussing on long-term outcomes (*Janet, patient, Summerfield*). Such ‘*gentle management of expectations*’ (*Junior PT, Brownside*) by professionals, typically involving information about the uncertain nature of recovery, thus allowed them to maintain hope for and belief in complete recovery in the early weeks post-stroke. Professionals’ own beliefs that the potential outcome of in-patient rehabilitation was the optimisation of function and quality of life within the context of residual disability, rather than a return to pre-stroke life, were infrequently shared.

6.2.1.2 Every stroke (and every recovery) is different, therefore individual recovery can’t be predicted

In the absence of early information from professionals, patients and carers gathered information about stroke recovery from a range of sources, which began to impact their expectations about their own likely recovery. They compared their experiences of the stroke’s effects and the speed of their early recovery with those of other stroke survivors, including their peers, finding comfort where they deemed themselves less profoundly affected or improving more quickly. Some sought to comprehend why others had not achieved a full recovery; this was typically attributed to insufficient therapy, or effort (see 6.2.2.1). Carers sought information from external sources, including the internet, stroke charities, and health professional acquaintances, though they at times struggled to relate this information to the individual circumstances of their loved one, e.g., due to a lack of knowledge about locally available services. However, through these sources, both patients and carers came to the understanding that stroke, its effects and therefore recovery, were individual to each patient, and affected by a wide variety of factors, such that there were few commonalities between individuals. Only Albert had previous personal experience of stroke, and he highlighted the

difference between the mild effects of his previous stroke, which had resulted in a short hospital stay, and the more severe and wide-ranging effects he was currently experiencing, confirming his beliefs about stroke's heterogenous nature.

"My mother, she had a stroke when she was 47, she had her first one and then she had a second one. [...] But they didn't know as much as what they do now to help you." Lynn, patient, Brownside

"There were one chappie, his left hand, he couldn't use his left arm. But he were having to learn to read and write again. But, I mean, I wasn't that bad, I mean, at least I could understand people and speak to them and read things. But, same as I say, everybody's different aren't they, it affects different people different ways." Albert, patient, Brownside

Professionals reinforced this understanding through their provision of typically vague answers to patients' questions about recovery, and reports that such answers were not available due to the uncertain trajectory, reiterating the message that every stroke was different. When tailored predictions about the likely extent and timing of their own recovery were eventually provided by professionals (typically ~two weeks into their admission at Brownside, and later, if at all, at Summerfield), patients noted these were tainted with uncertainty. Those who did not receive such predictions were thus accepting of, and resigned to, the idea that they could not be provided, and thus typically denied any unanswered questions. However, their beliefs about the uncertain nature of recovery likely prohibited further questions on the subject, which were infrequently observed. Despite these beliefs, most patients reported they would have wanted further tailored information about recovery, should it have been available, e.g., through basic statistics about the likely long-term outcomes of those with a similar stroke type.

"It were all, 'no two strokes are the same', so they don't know, do they?"
Peter, patient, Summerfield

"Just how long will it take, that's all I kept asking, how long will I be like this? But they just say, it's just time, just time. And rest. And that's it really."
Janet, patient, Summerfield

"So like with strokes, I think they're just totally independent to people. I don't think you can say a stroke's going to last this long, it's going to last that long." Adam, carer, Summerfield

"[If they had said] 'from experience we've seen that people who've had a stroke like yours often recover blah, blah, blah', rather than not saying anything, it would've been a bit better." Diana, patient, Brownside

These beliefs impacted patients' and carers' views about the way information about recovery could be delivered. Although some highlighted that written information would have been beneficial to overcome obstacles such as difficulties in processing and

recall, and to promote sharing of information amongst families, others felt that individual differences in recovery meant that this couldn't feasibly be provided.

"I don't know how they'd do it, I don't know how they'd get a personalised thick pack for you [...] unless it could be tailored for the various different types of strokes that you can get." Diana, patient, Brownside

"How can you write something that's sort of, how can I say? Is to him, because they are all different. You know, you can't write something for one, and write something for another." Jean, carer, Summerfield

Despite these perceived challenges, patients and carers described benefits in the uncertainty in recovery presented to them by professionals, namely that it allowed them to maintain hope. Although most patients and carers reported a desire for tailored information about recovery if available, Marie preferred not to receive information about her potential long-term outcome in advance, discussing how the uncertainty allowed her to maintain hope for further recovery. Where information was provided, the uncertainty conveyed by professionals about the possibility of a negative outcome left room for patients and carers to continue to see a future where they achieved the recovery they desired. They thus focused on this uncertainty, e.g., despite being told that it would be very unlikely that Peter would be able to walk in the weeks to months ahead, Jean continued to maintain hope for such an outcome in the future.

6.2.2 Lack of understanding about the process of post-stroke recovery leads to overemphasis on the importance of therapy and disappointment at its withdrawal

Faced with (for most) the novel situation of having been hospitalised with a stroke, patients and carers placed their trust wholeheartedly in the treatment and information provided by professionals. Perceiving professionals as knowledgeable experts, they described the importance of doing as they were told, believing that this would result in the recovery they hoped for, regardless of whether they understood the reasoning behind it and the fact that this was never explicitly stated. This implicit trust meant that they rarely questioned *how* therapeutic intervention would benefit them; and in the relative absence of information provided, learned little about the process through which stroke recovery occurred.

"They had me [...] laying on me bed kicking me legs in the air and juggling with Oxo cubes. If you put that on Twitter, it'd sound hilarious, wouldn't it? But, as I say, I took the view that the physios are professionals, they've met a lot of other people that have had the same problem, if they say do something, you damn well do it." David, patient, Summerfield

6.2.2.1 More (effort in) therapy leads to faster and greater recovery

Most patients were able to describe the effects of their stroke, including demonstrating understanding that the result of a clot or haemorrhage was (in most cases) physical weakness on the contralateral side of the body, alongside a range of other symptoms. However, only a small minority expressed (during observations or interviews) understanding of the concept of neuroplasticity, i.e., that repetitive practice of activities stimulates the brain to build new neural connections. Fewer still described understanding of the likely trajectory of post-stroke recovery, typically involving initial rapid improvement, followed by increasingly slower and smaller changes, and the wide range of factors that could impact it. Information from professionals about the process of recovery was typically limited to a series of standardised and relatively simplistic messages, which were understood as important by patients and carers. These messages included the idea that recovery required participation and effort in therapy, time (although the specific time-frame was usually vague, e.g., weeks, not days), and, to a lesser extent, rest. Patients were informed by professionals there was no 'quick fix' or medication that could recover their physical function, and as such, they were frequently encouraged to focus their efforts on therapy, which they did, expecting these efforts to result in recovery. As a result, they placed much emphasis on the amount of therapy provided (leading to complaints where they believed not enough was received resulting in delays to recovery) and their own motivation during sessions.

"The OT described that, although there wasn't really any evidence for this, when someone was motivated, their progression was quicker." Therapy session fieldnotes, Diana, Brownside, 02.09.19

"It's just your own will wanting to get yourself better. Do stuff for yourself." Janet, patient, Summerfield

Patients and carers often related these messages to the experiences of other stroke survivors, comparing their own perceived motivation levels and the extent and speed of their recovery with those of others on the ward or in their personal lives, typically believing that increased determination would result in enhanced or expedited progress. Gradual improvements in therapy sessions (no matter how small), alongside reassurance and encouragement from professionals, reinforced the belief that these efforts were effective and promoted hope. Where patients were less able to engage with therapy, due to drowsiness or severe aphasia, carers related this to the lack of observed functional improvement.

"They turned round and said, "Well, you're definitely, definitely trying and, you know, you're not sitting back and saying, "I can't do this, I can't do that," you know what I mean? Apparently you get folk like that." Lynn, patient, Brownside

“Everybody on the ward [was] absolutely impressed that she were coming back so rapidly, going from nil by mouth to having full food within a week, I think they felt that were brilliant. Because she’s a battler, she’s a fighter, she’s a little Welsh dragon, aren’t you, Mum?” Adam, carer, Summerfield

Although the belief that the extent and timing of post-stroke recovery was related to their own efforts likely provided some stroke survivors with a sense of control, it also had some negative consequences. For those who perceived they were not recovering as quickly as hoped, there was a tendency for self-blame, which could lead to low mood. Peter in particular described feelings of loneliness in the knowledge that his recovery was down to his sole efforts. This was particularly frustrating for those who had dependants, and those who took pride in their independent lifestyle. Some carers also believed that recovery was dependent on patient effort, expressing pride in their progress, or disappointment and frustration with the lack thereof. Reassurance was typically provided by therapists, supported by generic information about the long-term and challenging nature of stroke recovery. Whilst some patients and carers at Brownside were able to access help with these feelings in the form of psychological support, helping them process their emotions and begin to adjust to continuing disability, such services were not available at Summerfield.

“Brian explained that he felt a 'burden' to his wife on Thursday. He described feeling 'powerless' and 'useless'. Reassurance was provided; Therapists expressed the difficulty within stroke recovery and assured patient that he is making slow and steady progress.” Documentary analysis (Brian), Experienced OT, Brownside

*“Peter: [They said] you can get there if you push yourself and do what you have to do, yeah.
Int: Okay, and how did you feel about being told that?
Peter: There were times when you get lonely and you’re down, when I’m sat here on my own I got really down a few times, and I got down in the hospital a lot, especially on the night, it’s not nice.”*

Peter, patient, Summerfield

6.2.2.2 Withdrawal of therapy can result in confusion and disappointment

In the absence of information about the typical trajectory of post-stroke recovery (and occasionally encouraged by professionals), some patients believed that improvements (as a result of therapy) occurred in a linear fashion, with the tacit understanding that it would continue at the same rate until they were able to return to life as they knew it. As a result, the thought of discharge from hospital, which they equated with the withdrawal of therapy, appeared alarming for some patients and carers who had yet to achieve the recovery they anticipated, particularly at Summerfield. Whilst those at Brownside were

typically informed of their likely length of stay and potential level of functioning upon discharge at their first family meeting, this information was not frequently provided to patients and carers at Summerfield. This rendered them largely unaware of their potential length of stay on the stroke unit and meant discussions about discharge could begin unexpectedly. Those who believed recovery would be largely complete upon discharge expressed surprise and disappointment that this was not the case.

“I thought that I’d carry on when I come home and within a couple of week I’d be fine. [...] But it didn’t happen like that.” Marie, patient, Summerfield

“Diana appeared unwilling to commit to accepting reablement services, reflecting on the potential uncertainty of her recovery. The PT reassured her, telling her that her walking was much better today, “if you continue that same progression..” “We’ll do two flights of stairs tomorrow!” finished the OT.” Fieldnotes, family meeting (Diana), 03.09.19

Even where they were prepared for their likely length of stay, discharge was met with trepidation by some patients and carers. Due to the emphasis placed on therapy and effort, patients frequently viewed intensive hospital-based treatment as their best chance of recovery, and were confused and disappointed when notified this was to end. Some carers attempted to use the uncertainty presented by professionals to delay discharge, questioning how they could know that further in-patient therapy would not result in further recovery. Some of these fears were allayed following information about the long-term nature of post-stroke recovery, which they were informed was likely to continue with on-going community-based therapy (although recovery rate or extent was typically not discussed). However at both sites significant concerns were expressed following information about waiting lists for ongoing community-based therapy (representing gaps in therapy of up to a year in some cases), and its decreased frequency and intensity in comparison with the in-patient setting. Patients and carers worried that this would result in stagnation or regression of the progress made in hospital and reduce their potential for on-going recovery. These concerns occasionally prompted discussion about the need to take advantage of the ‘critical window’ of heightened neuroplasticity by provision of intensive therapy early after stroke, which was deemed inessential in the chronic phase, during which recovery would slow. Such information provision was however rare, vague, and typically reactive, following concerns expressed by patients and families.

“Adil’s brother described that he was looking to access the same amount of speech therapy for Adil in the community as he was receiving in hospital, saying that based on the progress he had achieved to date, using a simple linear model, he would likely be able to converse in the next month or two.” Family meeting fieldnotes (Adil), Brownside, 10.09.19

“Bill’s son asked how often he would have therapy at home, as he didn’t think it would be as much as he was getting here. The PT described that

the daily treatment he was getting in hospital wasn't needed at home; that didn't mean that recovery stopped but it would slow down and so it was less important that he had therapy every day.” Therapy session fieldnotes (Bill), Brownside, 23.09.19

In two cases (Anne and Ethel), therapy was withdrawn during the in-patient stay, having been deemed by professionals to be no longer beneficial due to a lack of progress. Based on their observations of the absence of improvements, in both cases family members were unsurprised and accepting that therapy had ceased. However, both reported that this information was not readily provided to them, and reported having to ask for it (due to cognitive and communication problems, neither Anne nor Ethel were able to relay this information themselves). Stacey reported frustration at having been informed by nurses that therapy had occurred, when she later learned that it had not.

“So I think we actually had to ask [...] is that it, no more rehab and they said yeah, we don't think we can really do much but we had to kind of push to get that answer.” Stacey, carer, Summerfield

When interviewed after discharge, those still in receipt of therapy typically still lacked information about its overall duration, and generally perceived that it would continue until recovery was, as they defined it, complete. Two employed private therapists to continue therapy to bridge the gap between services caused by waiting lists. As such, they maintained their efforts, and hopes, that recovery would come.

“I don't know [how long physio will continue], they don't say, do they. I mean, it's till you get going properly, I should imagine. But we'll have to see, just keep hoping, that's all.” Albert, patient, Brownside

“I'm hoping it's just going to be ongoing until Mum is, stays where they can say, "Right your arm's working, just keep up with your normal own self-therapy". [...] But, from the therapy side, nobody's communicated with us how long that's going to go on for.” Adam, carer, Summerfield

6.2.3 Providing information about recovery can lead to benefits, if done well and in a timely manner

Despite the identified challenges, receiving information about recovery brought some clear benefits to patients and families. These benefits were related to enabling patients and carers to be involved in decision-making about the patient's care and future, and in supporting adjustment to life after stroke. However, for these benefits to be realised, and for information about recovery to be accepted, it was important for patients and carers to receive information from professionals in a timely manner. They valued professionals' efforts to provide information proactively, sensitively and with positivity,

to enable them to maintain hope. Opportunities to meet with the MDT were valued, however the variability with which they were conducted impacted the extent to which they met the needs of patients and their families.

6.2.3.1 Discussing recovery can support adjustment and promote patient and carer involvement in decision-making

Most patients discussed the emotional challenges that stroke could bring. They described their stroke as a sudden, unexpected, and shocking event in their lives, relaying how their initial shock was followed by relief that they had survived, and (following observation of their fellow patients) that they were not more significantly affected. However, most described their pre-stroke lives as active and independent, and, for those who experienced ongoing disability, the overnight transition to dependence was challenging, requiring a process of adjustment. This applied equally for carers, who saw their loved one suddenly change, with often significant impacts on the lives of their whole family. Emotions observed and described by patients and carers during this process included grief and sadness at the loss of their independence and ability to enjoy previous activities; denial, including refusal to accept that the difficulties they were experiencing were unlikely to resolve quickly; and frustration and anger at the slow speed of recovery and, for some, the insufficient amounts of therapy that they perceived were limiting it. Over time, patients and carers began to show signs of acceptance that life as they knew it had changed and would never be the same. For some, this occurred in hospital; for others, it was evident at the time of their interviews.

"It's like having locked-in syndrome, you are locked into a state of how you have to be now. And adapt, that way. It's affected us, a great deal. [...] We can't do what we used to do, we have to think about where we go, preparation, weather, we have to think about everything. We've recently become grandparents, and we're not kind of fulfilling that duty or experience, because we can't visit, because they've all got stairs [...]. It's just affecting us in every way. Obviously, Peter more than me, but me as well, it's not just happening to Peter, it's happening to me, as well, as a carer." Jean, carer, Summerfield

It appeared that receiving information about recovery, particularly around its long-term nature and potential incompleteness could help to speed up the start of the adjustment process, allowing patients to address their potential for on-going disability and experience some of these emotions within the supportive environment of the hospital. For example at Brownside, following information that their difficulties were likely to be long-term, Marion and Brian were both able to begin their journey to acceptance with support from the multidisciplinary team (MDT), including input from psychology

services, where they were given space to process their emotions and adjust to their new realities.

"We discussed that living with the uncertainty of the stroke and not fully knowing how [pt]'s recovery will go was hard. We also discussed how stroke has many different effects- some psychological and 'unseen', unlike the physical effects. The couple seemed to value this discussion and engaged well with it." Documentary analysis (Brian), clinical psychologist, 07.11.19

"[Marion] is aware she will need to tolerate the uncertainty and sadness surrounding her situation. She has good understanding that she is grieving for the life she had and is adjusting to the massive change to her situation, is not sure what her new life would look like but is willing to live it the best she can and adjust to her reality." Documentary analysis (Marion), Mental Health Liaison Team, 23.09.19.

Failure to receive timely information could delay this process; at Summerfield, individualised predictions were typically provided later in the admission, allowing less time for patients and families to digest and come to terms with them before discharge. Jean described her shock at hearing that Peter may not fully recover only mid-way through his admission. Her anger and frustration at the NHS system, including her belief that not enough therapy had been provided to facilitate his recovery, were evident during observed interactions with professionals, including at a family meeting, and documented in complaints in Peter's records. At the time of her interview however she was able to reflect on the experience, having gained some acceptance of their new situation. In contrast, Janet was still struggling with her mood at the time of her interview. In the absence of information about the process of recovery, she had believed that her efforts were all that was required for a full recovery, and was still struggling to accept the potentially long-term loss of her independence. She described how her mother had forced her to seek help by taking her to her GP, who had prescribed antidepressants, but otherwise her support was limited to the visits of the community OTs. She was unhappy that she had not received information about the emotional effects of stroke during her in-patient stay.

"Nobody actually said, "do you know, strokes can leave them like this", you know? "This is life-changing for you". Because it is. It is life-changing."
Jean, carer, Summerfield

Janet: I thought I'd be a bit, with meself a bit more faster, but that's me own independence thing, but your body tells you what to do and what you can't do and that but...

Int: It's harder to accept when you're independent?

Janet: Yeah. That's been the hardest bit [emotional].

Janet, patient, Summerfield

At the other end of the scale, a subset of patients with milder disabilities recovered sufficiently quickly that they were deemed safe to continue home-based rehabilitation with ESD services. Despite their short length of stay, those who received care at Brownside had typically received some tailored predictions about their long-term recovery potential. This occurred infrequently at Summerfield; likely being deemed unnecessary due to the uncomplicated nature of decision-making around their discharge. These patients were however satisfied with their progress and therefore denied unmet needs for information; having made swift progress in hospital, they typically believed their recovery would continue as it had begun. Nevertheless, some were later disappointed by their continuing difficulties. They typically sought out information from community-based professionals, including their GP, and described surprise at hearing they potentially might never regain their previous abilities. This delay in receiving such information likely meant their adaptation to on-going disability began only in the community, where there was less available support.

"I'm very, very, very lucky and very, very fortunate that I didn't have a serious one, if I'd have had a serious stroke then maybe I would have needed more information." Ajay, patient, Summerfield

"They didn't say owt about, nobody said owt about, because I'm really shocked that this leg don't work properly, you know, seen as everything else is, well it ain't back to normal because I'm so tired." Marie, patient, Summerfield

There were also suggestions that receiving information about the potential for long-term disability could help patients and families to be involved in decision-making about how their future care needs might be met. For example, after experiencing a severe stroke, Marion was told from an early stage in her admission that she was likely to stay in hospital for around three months and upon discharge, would continue to have significant disability. Aware that her progress in therapy was slow and armed with the information that her recovery was likely to take time, as well as understanding that her home environment was unlikely to be suitable for her on-going needs or large enough to facilitate continued therapy, she felt able to appraise her post-discharge options. At her second family meeting she proactively suggested that, following her discharge from hospital, she wished to enter a residential care facility for a fixed period of time, to continue her rehabilitation and recovery in a supportive and suitable environment and develop a better understanding of her long-term care needs, before making a decision about whether she could return to her home environment and make the necessary adaptations. She was able to discuss this idea with the MDT, including a social worker, who provided information about the benefits and disadvantages. Possession of information about her potential for long-term recovery thus enabled Marion to fully engage in the decision-making process, and allowed her to take control of the

challenging situation in which she found herself. As previously described, with support from a psychologist, she was able to begin the process of adjustment to her potential long-term difficulties, whilst maintaining hope that her recovery would continue in the long-term.

In contrast with this example, Peter and Jean were not provided with predictions about Peter's potential for recovery until he was nearing discharge. As a result, when discharge planning was raised in a family meeting, they both appeared shocked and ill-equipped to engage with decision-making around how Peter would be cared for when he returned home. In particular, Peter argued that more in-patient therapy was required to enhance his recovery and enable them to manage; Jean expressed significant concerns about her own ability to provide care for Peter and facilitate his quality of life whilst maintaining her own employment and interests. She appeared angry and frustrated, and there was a sense of discharge being forced upon them, rather than agreed through a process of shared decision-making.

Patients' understanding about the uncertain nature of their recovery (discussed in 6.2.1.2) could however hamper their involvement in decision-making, particularly around how their care needs would be met post-discharge. Both Diana and Marie experienced challenges in identifying how much help they would require, due to uncertainties about their likely future progress.

“The PT asked what had happened with the social worker [..]. Marie said she was asking about how she managed at home, but Marie said she hadn't really been able to answer as she didn't know. She said she didn't know what she would be like when she went home, and whether she would be walking or not, as from last week to this week, she had made progress.” Therapy session, 09.04.19, Marie (patient), Summerfield

6.2.3.2 Patients and carers value honest information about recovery, provided proactively, sensitively and with positivity

In their interviews, patients and carers described their experiences of receiving information about recovery, in the context of the care and other information with which they were provided by professionals. Those who had good experiences described benefits in being given the time to talk through and understand the information provided, as well as feeling able to ask questions and have those questions answered. Patients and carers valued honesty and openness in conversations about their potential for recovery. They appeared more likely to accept information about

recovery, and thus be able to utilise it to make decisions where it was provided in this way (e.g., in Marion's example, 6.2.3.1).

“Up to that point nobody had really talked me through it, but this [consultant] did, and he says to me, this is where it is, that's why you're doing that, that there is why you're doing, your eye [...] and he were brilliant, absolutely amazing, I could've spoke to him all afternoon.” Diana, patient, Brownside

“I think his terms were that people do recover, but at this stage we can't guarantee how far. Erm... I think he was honest in this sense, because it would be wrong to tell somebody you might make a full recovery and you're not.” David, patient, Summerfield

Patients and carers expressed a preference for information to be provided with positivity and sensitivity. Whilst most wanted professionals' honest appraisal of their (or their relative's) recovery potential, they wanted this information to be provided in ways that could allow them to maintain hope, and was sensitive to their needs. Several patients and carers at Brownside described a preference for information provided by a specific consultant, who they deemed more positive about recovery potential, whilst another consultant was felt to provide information too directly.

“[Bill's wife] described finding the consultant too negative. She reported that he had said that he had told them 'bluntly' that some people with stroke fully recover, but that her husband would not be one of them. [...] She said that she couldn't understand how they could say these things after only two weeks after the stroke.” Informal conversation (therapy session), Bill, Brownside, 19.08.19

Many carers had worries about the long-term effects of the stroke on their loved ones, and how their potentially increased care needs might be met; they wanted these issues to be dealt with sensitively. Some described additional stressors within their own lives which impacted the extent to which they felt able to engage with conversations about their relative's recovery and to use this information to make decisions, e.g., about on-going care. These needs were family-related, e.g., other relatives with serious illnesses or disabilities who required their care and attention, and work-related, such as continuing to run their business. They affected both when they could attend the ward to receive information and how easily they felt they could engage with sensitive conversations about recovery and decision-making. For example, Karen described how her sister was in receipt of palliative care at the time of her mother's hospital admission; she described dissatisfaction with the lack of sensitivity of professionals, who she perceived did not provide the family with time to engage with conversations about recovery and subsequent decision-making.

Patients and carers wanted information to be provided proactively. At Summerfield, family meetings were not held routinely and most patients and carers were therefore not invited to speak with the MDT about their progress and recovery potential; as a result they complained that information was not available *'unless you ask'* (Jean (carer), Summerfield). Carers felt frustrated that, due to the restricted visiting times, they were often unable to locate the right member of the MDT to approach with their questions. They particularly felt that stroke consultants, their preferred source of information about recovery, were not accessible.

"I think it were us asking, I think it came from the family, all of us, myself, my wife, my siblings, just asking relevant questions, that they thought were relevant, anyway, to just try to get feedback." Adam, carer, Summerfield

"All they got were the nurses and healthcare assistant. They didn't get somebody in authority, like my consultant. They [...] tried to make an appointment, but they couldn't, or he said he would come on to the ward during visiting time, he never arrived." Janet, patient, Summerfield

The additive effects of a lack of proactivity and challenges in locating the right person to whom their questions could be directed left some patients and carers feeling frustrated. Some felt that information was being withheld or even that inaccurate information was being provided, suggesting a degradation of the trust they had in professionals. None however reported specific contradictions in the information provided to them about their likely outcomes.

"We kept asking is she still having treatment and we were told, "yes", complete and utter lie by the nurse that told us that. And then it turns out she didn't get any more treatment and we weren't really involved in that discussion." Stacey, carer, Summerfield

David specifically described that he felt that information was withheld because it was felt by professionals that patients would not be able to understand it. He felt his own intelligence was underestimated.

"I suppose one of the problems tends to be that you don't maybe always get told as much as you could be, because they feel that you wouldn't understand it. I think there's one or two occasions when you nearly felt as though you're being treated as a child." David, patient, Summerfield

Some participants worried that professionals' lack of proactivity in providing information could disproportionately impact those who were unable to ask for it. For Stacey, this came down to confidence, having experienced herself being *"fobbed off"* by staff when asking for information. She worried for those who did not have families to advocate for information for them, or whose families were more passive and waited for information to be provided to them. David agreed, expressing concern for those with cognitive

impairment, and those who might feel too intimidated to ask questions. Both perceived themselves as confident and educated and felt this had an impact on their ability to ask questions.

“I think we were in quite a lucky position in that we were relatively knowledgeable, we were confident enough to seek out people. If we hadn’t been that confident, I think it would have been a whole different experience.” Stacey, carer, Summerfield

“I think if you asked questions, you got a straight answer, but I think if anybody didn’t bother to ask much, might not have found out all they ought to have known. [...] The people I might feel concerned for are possibly some of the more confused older people, who could be a bit in awe of people in positions of importance.” David, patient, Summerfield

Despite these concerns, overall, patients and carers described that they were generally satisfied with the patient’s care and grateful for professionals’ help in their recovery; they acknowledged that professionals were working within the context of limited resources and were understanding of the demands on their time.

6.2.3.3 Family meetings are appreciated but may not be the panacea for all information needs

Family meetings were seen by professionals as the primary arena for delivery of information about recovery. Patients and carers generally appreciated the opportunity to meet with the treating team to discuss their recovery, and to facilitate their involvement in decision-making, particularly around discharge. However experiences of receiving information about recovery during family meetings were variable across sites. It is worthy of note that interview data on the topic of family meetings are limited; as such there is a reliance on observations and informal conversations in the hospital). Only one of the three interviewed participants at Brownside had attended a family meeting (Albert declined to attend his, and Lynn did not stay on the ward long enough for one to be deemed necessary). At Summerfield, only five interviewed participants (two patients, three carers) had experienced family meetings (and only one patient and two carers recalled this experience when interviewed).

At Brownside, where family meetings were regularly held for nearly all patients, meetings were generally viewed positively, and understood as a key part of the stroke unit experience. In contrast, those who experienced family meetings at Summerfield had more mixed experiences. Most were not offered a meeting, but would have appreciated the opportunity to discuss their care and recovery with professionals, had they been invited. The reactive planning of meetings by professionals (typically as a

result of the need for family involvement in decisions about discharge and care) did not go undetected by patients and carers. When invited to attend a meeting, some carers feared that their relative's eviction from the stroke unit, which they worried meant that (with a subsequent lack of therapy), recovery would cease and they would be faced with managing the patient's long-term care needs themselves. For Jean, it became clear during the meeting that this was not the case, whilst for Karen, the discussions reinforced their understanding that the primary purpose of the meeting was discharge-related, rather than for sharing of information.

"They probably needed to be a bit more clearer as to why that review was happening [...] They need to be more explicit that it was for his care, not, 'this is a discharge nurse and we're going to chuck you out', because I were in fear of that, when I went into the meeting, that, how am I going to manage with him, being hoisted and this and that." Jean, carer, Summerfield

"Basically after that meeting we, me and me brother [...] felt that they wanted to just get rid of me mum personally." Karen, carer, Summerfield

For others, problems with organisation of meetings impacted their experiences. Stacey in particular described multiple attempts to arrange meetings with professionals at Summerfield, only to find the required individuals were unavailable on arrival. She found these experiences frustrating. Some issues were also experienced at Brownside, largely due to the timing of meetings, which were organised to take place back-to-back in half-hour timeslots. The consultant felt it was challenging to fully involve patients with communication and cognitive difficulties in this short space of time, and this was observed to lead to meetings over-running and delays for subsequent patients and families. Diana perceived her meeting felt hurried, whilst Marion became uncomfortable having been sitting for too long in her wheelchair when her meeting was delayed.

"We were having this multidisciplinary meeting which was organised two or three times. Well, I say organised, should have been organised two or three times and we'd been told it's this time, this day and we'd come in and it turns out it hadn't been organised and the doctor [...] or sister hadn't been told or didn't know it was happening, wasn't in the diary." Stacey, carer, Summerfield

"Me daughter said afterwards, she says, don't you think though that it were a bit cut short, really quickly, they didn't quite give you time to formulate any questions that you might've had. [...] That were a bit rushed I felt, towards the end." Diana, patient, Brownside

At both sites, patients and carers described challenges in receiving information at family meetings. The volume of information provided could be vast and overwhelming, and the number of professionals present could feel intimidating. Some patients and

carers described how this could impact their processing and recall of information provided, particularly due to the emotional nature of some of the discussions. When later asked to recall these discussions, some patients and carers were unable to; others reported general summaries of their understanding which were at times in conflict with observational data. For patients with communication difficulties, involvement could be challenging. At some meetings, efforts were made to facilitate this involvement, e.g., an SLT supported Adil's understanding with written communication of key words, as well as helping him to verbalise his questions. However discussions were too rapid to enable complete involvement and in practice much of the communication took place between professionals and families.

“Sandra described that this was their second family meeting and she had found their first one ‘hard to take’. She described feeling overwhelmed by all of the ‘white coats talking at’ their family.” Informal conversation (therapy session), Bill, 19.08.19

“My sister came with me, so I'd get an understanding, because you can't always hear what's happening, can you? Initially.” Jean, carer, Summerfield

6.3 Discussion

6.3.1 Summary of main findings

The findings of this study highlight patients' and carers' often high expectations of recovery after stroke, and demonstrate the need for professionals to gradually intervene with information to ensure they are realistic. Where patients' and carers' needs for information about recovery were met, these findings suggest that such conversations could hasten the process of adjustment to on-going disability and support contributions to shared decision-making. However, few demonstrated understanding of the process of recovery and the impact of the often vague and ambiguous way that information was conveyed, alongside professionals' attempts to motivate them, caused patients and carers to place significant emphasis on the role of effort and therapy for recovery. This could result in feelings of disappointment when therapy was subsequently withdrawn, and guilt and blame where their expectations were not realised. Although patients' and carers' understanding of the uncertainty of recovery, based on both information from professionals as well as their own observations and research, enabled them to maintain hope for further recovery, it could also prevent them from reaping the benefits of receiving information, including facilitating adjustment and engagement in decision-making.

Where personalised predictions about outcomes were not provided, patients' and carers' acceptance of uncertainty and of the heterogeneous nature of stroke and

recovery meant that they generally did not report a lack of information; they displayed greater concerns about the timing and delivery of information. These findings suggest patients and carers wish for information to be provided honestly, sensitively, proactively, and with positivity; these needs were not always met. Although some appreciated the opportunity to meet with the MDT to discuss their progress and recovery, these opportunities were not available to all, and problems with their organisation, including a dearth of information about the aims, marred their experiences.

These findings are explored in the context of the existing literature in Chapter 10, where their clinical implications are also discussed.

6.3.2 Strengths and limitations

Strengths and limitations are largely similar to those previously reported (see 4.3.2 and 5.3.2). Of particular additional relevance in this chapter is a strength in the range of stroke survivors, who participated in the study, including those with various impairments, stroke severities, and lengths of stay. This facilitated comparison between their views and experiences. Participants also included those with communication and cognitive difficulties, allowing the experiences of those who may struggle to request or receive information about recovery to be explored. However, the views of patients and carers from Brownside are under-represented; only three patients and no carers who experienced rehabilitation at this site took part in interviews. Although this limited my ability to directly explore their views, I was able to gather some information through informal conversations and observations, which contributed to my analysis.

6.4 Qualitative findings indicate the need for novel intervention development

Through my qualitative work, I have developed in-depth understanding of the wide range of factors impacting the provision and receipt of information about recovery in stroke units, including those relating to:

- Professionals (including the availability of training and understanding of each other's roles);
- Patients (e.g., the communication and cognitive deficits that can arise from stroke);

- Stroke unit organisation (including professionals' working hours and how MDTs work together to develop and provide information);
- Environmental factors (the availability of appropriate spaces to deliver information).

Exploration of professionals' experiences and views revealed their perceptions of the importance of, and benefits to, providing information about recovery, despite the challenges they experienced in making predictions and the emotional cost of sharing them with patients and families and managing their responses. Investigation of patients' and carers' experiences confirmed their dissatisfaction with information provided and revealed particular issues relating to a lack of proactivity from professionals, provision of unclear information, and varying clinical practice (with some patients receiving more opportunities to discuss their recovery potential than others).

These findings indicate the need for improvements in the ways in information about recovery is provided to patients and their families on the stroke unit. Such improvements have the potential to improve patients' and carers' satisfaction with information (and care more widely), improve engagement in shared decision-making and support adjustment to life after stroke. Options for achieving these improvements could include attempting to empower patients and families to communicate their information needs and question professionals more assertively or the development of accessible generic information materials. However, these options would not address a key problem identified in my qualitative work about the ways in which information is provided; patients and carers described how information should be provided with empathy and compassion and in ways which support them to maintain hope. Training for professionals is likely to be necessary to help them develop the confidence and communication skills needed to achieve this and provide clear and individualised information.

In the final section of this thesis, I describe application of guidance in developing complex interventions to begin the development of a novel intervention. Firstly, I outline my attempt to identify existing interventions which could be used to improve the provision of information about recovery, through systematically reviewing the literature in stroke and other neurological conditions (Chapter 7). Although searches revealed no existing interventions with this focus that had been tested for their effectiveness in improving patients' and carers' outcomes, synthesis of data from four studies provided important insights into considerations for the development of a novel intervention.

Improvements in the delivery of healthcare often take the form of behaviour change interventions. In Chapter 8, I use the findings from the qualitative work reported in this section alongside behaviour change theory, to develop a theoretical understanding of how an intervention might drive behaviour change and the expected changes that might arise. This work highlighted a wide range of strategies that could be used to change professionals' behaviour (influenced by their capability, opportunity and motivation) to improve the provision of information about recovery and I subsequently sought their views of these strategies through an online survey, to further inform intervention development (Chapter 9).

Section 3: Complex intervention development

A systematic review of the literature (Chapter 1) and collection and analysis of primary qualitative data (Chapters 2-6) have identified, and informed understanding of, the challenges in providing and receiving information about recovery in stroke units. Approaches and strategies to address these problems would be helpful. This section details the early stages of development of an intervention, designed to improve provision of information about recovery on stroke units. The available guidance relating to intervention development will first be discussed, and then applied to this context.

Guidance on developing and evaluating complex interventions

Interventions with multiple, interacting components are common in healthcare, however when traditionally evaluated using randomised controlled trials (RCTs), trials of their effectiveness have often produced surprisingly null results, e.g., Bowen et al., (198). Where this is the case, it can be challenging to determine why an intervention appears to lack the anticipated benefits; e.g., whether the intervention is simply ineffective, for example, due to problems in its design, was not delivered as intended, or there was some fault with the study design (199). Understanding the development of such interventions, including the mechanisms and processes through which an intervention is proposed to work, has therefore received increasing attention over recent decades (200). The first Medical Research Council (MRC) framework was published in 2000, out of concerns about the increased challenges in evaluating interventions that were more complex, i.e., involved several interacting components, when compared to single component interventions, e.g., drugs (201). This guidance recommended RCTs to examine the effectiveness of such interventions, to determine whether those provided in healthcare represent value for money, progressing along similar stages to those commonly used in drug trials (201).

Although this framework was widely used (202), a series of limitations were identified, not least the parallels with the stages of drug development and testing, but also the inadequate attention to intervention development and piloting, and the limited consideration of the contexts in which interventions are delivered and their implementation (199, 203). The guidance was subsequently updated in 2008, with the resulting framework recommending a more dynamic approach to intervention development and a reduced reliance on the use of randomised trials for evaluation

(203). This updated guidance provided further definition of what makes an intervention complex and highlighted the importance of a solid theoretical underpinning for interventions, to identify how change occurs, recommending the use of process evaluation alongside RCTs to further understand why interventions are (in)effective and how they could be improved (203). Greater emphasis was also placed upon the context in which the intervention is implemented, and how this might impact effectiveness (203).

The 2008 framework was again influential but lacked specific detail about the phase of intervention development (204); the concepts, theory and methodology have also undergone significant development over the last 15 years (205). Further guidance on specific aspects of the development and evaluation process has been published, e.g., O’Cathain and colleagues put forward a series of non-linear actions to address within the development phase, following a process of qualitative interviews and consensus-gaining (204). These actions include planning the development process, involving stakeholders, establishing a team, identifying and reviewing published evidence and theory, articulating programme theory, collecting primary data, considering implementation and designing and refining the intervention (204). The latest iteration of the MRC framework, published in 2021 (see Figure 6.2) places similar weight on the meaningful involvement of stakeholders to make decisions about development, and use of programme theory to understand how an intervention is expected to deliver its effects (205). Additionally, it emphasises economic considerations to support real-world implementation, and recommends consideration of context, which can affect an intervention’s implementation or effects (205). The guidance also makes further recommendations for intervention evaluation using the most appropriate study designs (rather than a reliance on RCTs) (205).

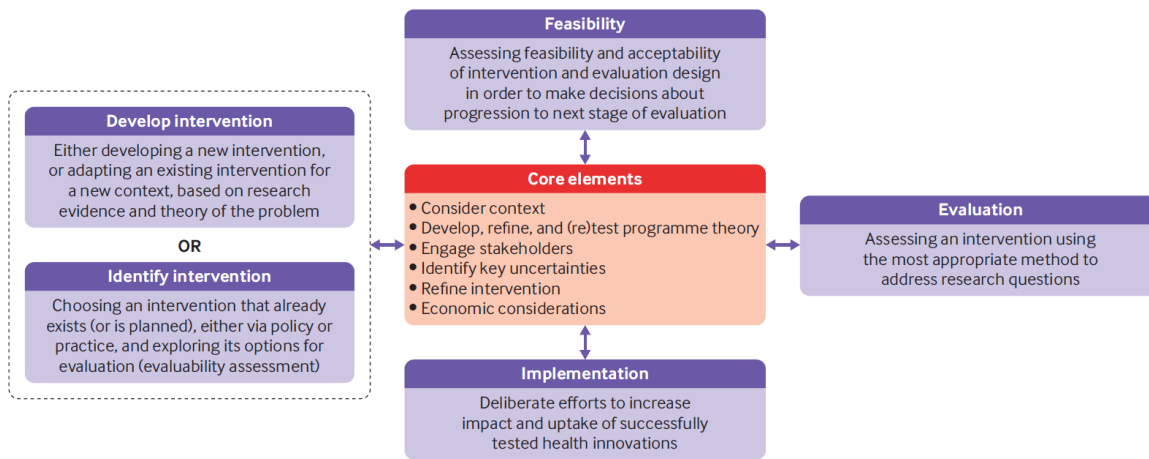


Figure 6.2 Updated MRC framework for developing and evaluating complex interventions, reproduced from Skivington et al., 2021, pp. 4 (205)

Applying the guidance to develop an intervention to improve provision of information about recovery on stroke units

According to the MRC framework (205), the intervention required to improve provision of information about recovery on stroke units was defined as complex. A range of behaviours were likely to be targeted, potentially those exhibited by professionals, patients, and carers. Flexibility was required because of the differences in the way stroke unit care was organised, and the recognition that components might therefore be delivered variably across services. The inherent complexity of the intervention meant that a range of outcomes would require consideration during evaluation at the organisational (e.g., feasibility of delivery), professional (e.g., confidence), and patient and carer levels (e.g., satisfaction with information/ care provided, mood, quality of life), likely requiring a number of interacting components.

In the process of developing an intervention to improve conversations about recovery in stroke units, the key actions identified by O’Cathain et al. (204) and features of the MRC Framework (205) were considered. The development process was planned, with consideration of the time and resources it might take. The problem was identified through review of published evidence (Chapter 1) and primary data collection undertaken, including qualitative inquiry to understand the stroke unit context (Chapters 3-6).

This section details further intervention development work, including review of published evidence to identify any existing candidate interventions, and to understand

their potentially effective components (Chapter 7). As no existing intervention was identified, subsequent work involved identification of theory (the Behaviour Change Wheel (206)) to inform development of a new intervention. This theory was applied, defining the problem of providing and receiving information about recovery in stroke units in behavioural terms, using earlier qualitative and review work, and processing to develop understanding of how an intervention might work to change behaviour and the specific strategies to use (Chapter 8). Use of theory was important to develop an understanding of how intervention components and strategies might cause their effects. Finally, stakeholders (professionals) were involved in considering whether addressing the identified barriers was important in other stroke unit contexts; and whether the suggested BCTs would be useful and feasible to implement in clinical practice, using an online survey study (Chapter 9). Involvement of stakeholders at this stage functioned as early consideration of factors that might affect implementation. The work culminated in the identification of intervention components. Further design and refinement of the intervention is not a feature of this programme of work but will include further engagement with stakeholders (professionals, patients, and carers) to ensure the final intervention is acceptable to them and meets their needs, before progressing to phases of feasibility testing and evaluation.

Chapter 7 Systematic Review: Effectiveness of existing interventions

7.1 Background

Before beginning development of a new complex intervention to improve provision of information about recovery in stroke units, as recommended in guidance on developing complex interventions (203, 204), I took steps to review evidence to identify existing knowledge; such a review is the focus of this chapter.

To begin, it was important to identify any existing interventions, their effectiveness, and to develop an understanding of how and why they might be effective. As already identified, stroke, like other neurological conditions, presents particular challenges to provision of information about recovery, including the uncertainty of the disease trajectory and the associated communication and cognitive deficits that may result. This makes providing information to patients and their families somewhat different to those with other conditions, e.g., cancer. Whilst strategies to discuss recovery and prognosis within cancer settings have been extensively reviewed (119, 207), no review could be identified which considered the effectiveness of strategies designed to improve the communication of recovery/ prognosis information to those with neurological conditions. Given the degree of dissatisfaction with information about recovery reported by patients and carers (56), and the requirement for an intervention to address these needs, this review focuses on assessing the effects of interventions on patient and carer (rather than professional) outcomes.

7.2 Development of the research question

The research question was formed using the PICO (Population, Intervention, Comparison, Outcome) criteria (208).

7.2.1 Population

The population of interest was adults with a diagnosed neurological condition and/ or their adult carers. I was interested in patients with neurological conditions because, as in stroke, these conditions often have an uncertain trajectory in terms of the timing and extent of recovery that might be possible, and because any damage to the brain can result in a wide variety of impairments, including cognitive and communication problems, which may impact patients' ability to receive information. Carers are also

important stakeholders, who require prognostic information to support patients with their recovery and manage the repercussions of patients' potentially increased care needs on their own lives (60).

7.2.2 Intervention and comparators

As I wished to identify a broad range of interventions and develop a comprehensive review of the evidence, the experimental interventions of interest were strategies, guidelines or protocols that were designed to improve the ways that healthcare professionals deliver information relating to recovery or prognosis (including wider interventions of which this constituted a substantial part). I was unaware of any existing 'gold standard' comparator or existing strategies to which any identified interventions might be compared.

7.2.3 Outcomes

I considered previous literature to identify appropriate and meaningful outcomes for this review (209). When measuring the impact of stroke rehabilitation interventions, patients' and carers' subjective evaluations, such as quality of life and satisfaction with overall care, have long been recommended (210). As such, I felt it likely that these outcomes would be reported by research investigating the effectiveness of information provision interventions. Studies have shown that communication between healthcare professionals and patients, and specifically communication of the outcomes of care, is a contributing predictor of satisfaction with care (211). Thus, I felt satisfaction with care was likely to be impacted by communication of information about recovery and was important to evaluate. Patient and carer satisfaction with the information provided also appeared to be relevant outcomes following receipt of information about recovery, and have been included in similar reviews of the effectiveness of information provision interventions (49, 212). However, whilst similar reviews have also included knowledge about the condition as a primary outcome, I decided that this was less relevant to information about individual recovery and prognosis and therefore it did not form part of the inclusion criteria.

The sudden diagnosis of a neurological, and potentially chronic, condition can be shocking and worrying to patients and carers, particularly in light of their future hopes and plans. Receiving information about the likely timing and extent of recovery is likely to be emotionally challenging, even in the face of a positive prognosis, and has the potential to result in psychological distress. The way that this topic is addressed and how information is communicated may impact patients' and carers' experiences and as

such, strategies to provide recovery information (positive or negative) may therefore result in increased or improved anxiety or depression. Likewise, the absence, or sub-optimal nature, of information provision also has the potential to result in distress (56). To assess the impact of strategies used to provide recovery information on experience of these symptoms, anxiety and depression appeared important to consider as outcomes for this review. The potential impact of receiving information about recovery on adjustment to life with a neurological condition was identified in my qualitative work (Chapter 6) and thus psychological adjustment was also felt to be a relevant outcome.

Following identification of the key components of the review, the FINER criteria (Feasible, Interesting, Novel, Ethical and Relevant) were considered to ensure the review question was well-formulated (213). To be *feasible*, it must be possible to conduct a review within the resources available. In this study, an Information Specialist assisted to identify search terms related to the proposed research question and run practice searches, to ensure the number of results returned would be manageable for screening. I also decided to include only studies reported in English; although it is possible that this could have excluded relevant studies in other languages, no budget was available for translation. I felt the review topic was *interesting* and therefore worthy of spending the significant time required to undertake. To ensure that the review was *novel* and did not represent duplication of existing work, searches were run in major databases and the PROSPERO database, which identified that no similar reviews had been undertaken or were in progress. Care was taken to ensure the review question was framed *ethically*. Finally, the review was deemed *relevant* to ensure that strategies previously proven effective in improving patient/ carer outcomes could be considered during intervention development.

The final research question was:

- How do interventions used to provide information about recovery to patients with neurological conditions and their families affect patient and carer outcomes, including: satisfaction with information provided; overall satisfaction with care; quality of life; adjustment to life with their condition; anxiety and depression?

7.3 Methods

This systematic review was prospectively registered with PROSPERO (CRD42018082277).

7.3.1 Eligibility criteria

The study designs, population, interventions, comparators, outcomes, setting and language were further specified, according to guidance from the Cochrane handbook (73). The eligibility criteria for inclusion in the review are outlined in Table 7.1.

Table 7.1 Inclusion criteria

| | |
|----------------|--|
| Study designs: | Quantitative studies presenting empirical data, including randomised controlled trials, non-randomised controlled trials, controlled cohort and case-controlled studies. |
| Participants: | Human adults (≥ 18 years), where $\geq 50\%$ participants had a diagnosis of, or were caring for someone with a diagnosis of acquired or progressive neurological condition, including stroke, traumatic brain injury, spinal cord injury or peripheral nerve lesions, Multiple Sclerosis, Motor Neurone Disease, dementia or Parkinson's Disease. No restrictions according to time post-diagnosis. |
| Interventions: | Strategies, guidelines, or protocols designed to improve the delivery of information about recovery or prognosis, including breaking bad news, by healthcare professionals to patients with neurological conditions and/or their carers. Studies of interventions including general information provision/ education about a condition, of which recovery/ prognosis did not form a substantial part, were excluded. |
| Comparators: | Any type of control (no use of prescribed strategies, alternative prescribed strategies). |
| Outcomes: | One or more of the following outcomes: patient and/or carer satisfaction with the information provided, patient satisfaction with care, patient quality of life, adjustment to life with the condition, anxiety, or depression. Studies with outcomes relating only to implementation of interventions on healthcare professionals' performance or confidence in delivering information were excluded. |
| Setting: | No restrictions according to setting (e.g., in-patient, community, outpatient, or primary care). |
| Language: | English language. |

7.3.2 Search strategy

As previously discussed, and in line with recommendations (73), an Information Specialist was involved from an early stage in developing search strategies, advising on filters and selecting databases. It was decided that the same search strategy (detailed in Appendix A) would be used to conduct both this review, and the qualitative systematic review detailed in Chapter 1, as they considered the same subject matter, therefore whilst study design is often recommended for inclusion in search terms (73), no keywords or filters related to design were included. Searches were limited to English language and human adults.

Seven databases likely to include relevant studies (Medline, EMBASE, AMED, CINAHL, PsycINFO, Web of Science and the Cochrane library) were from their inception to 17th July 2019; the search strategy was adapted to the MeSH terms and syntax requirements of each database. Searches were subsequently updated to 31st July 2022. To combat previously discussed challenges in variations in language within keyword searching and to ensure comprehensiveness (see 1.3.2), I employed backwards (through manual searching of reference lists) and forwards (using Google Scholar) citation searching of included articles and searched the reference lists of relevant systematic reviews for applicable titles.

7.3.3 Data management and study selection

Search results from each database were imported into separate EndNote files, which were combined, and duplicates removed. Initial title and abstract screening were conducted using EndNote, and full-text articles were assessed using a decision tree, with results recorded in a Microsoft Access database, including reasons for exclusion.

Records of report titles and abstracts were initially screened for eligibility. The first 10% of records were screened independently by a second reviewer (a supervisor). Independent reviewers are recommended during systematic reviews to ensure studies are not mistakenly discarded (214), however dual review is deemed less important at this early stage (73). Levels of agreement between reviewers were deemed satisfactory, and I subsequently continued screening independently, retaining records deemed to meet inclusion criteria and where there was uncertainty. Full-text reports were subsequently obtained for each remaining record and all were assessed by both myself and a second independent reviewer (a research colleague with expertise in systematic review), before final eligibility decisions were made. Uncertainty or discrepancy was discussed and referred to a third reviewer (another supervisor) for consensus. Reasons for exclusion were recorded.

7.3.4 Data extraction

Data from all papers were extracted independently by both myself and a second reviewer (a research colleague) using a standardised form, and were subsequently compared to check agreement levels. Extracted data included research design, aims, recruitment methods, sample size, participant demographic information (age, gender, medical diagnosis), country, study setting, methodology (data collection and analysis), content of the intervention and control condition, and outcomes.

7.3.5 Critical appraisal of included studies

Review findings are dependent on the validity of the included studies, therefore failure to consider the potential for bias in the included studies could yield misleading conclusions (215). Assessment of risk of bias involves identification of aspects of the design, conduct, or analysis of the individual included studies, and evaluation of the extent to which they may have produced misleading findings (215).

Tools for the critical appraisal of studies have evolved over time (215). Quality scales, which involve rating different aspects of quality against established criteria, and subsequently computing a score for each study, were previously used to label studies as 'high' or 'low' in quality (215). Higgins et al. warn against the use of these traditional scales, as problems in interpretation can arise due to the unknown weighting of individual quality aspects and their contribution to overall ratings (216). More recently, recommendations have focused on the use of risk assessment tools, which look to determine the possibility that bias may be present (215). The appropriateness of any given tool largely depends on the designs of the studies in which risk of bias is being evaluated. In this study, risk of bias was assessed using the Cochrane Effective Practice and Organisation of Care risk of bias criteria (217). This tool is widely used and was selected for this study because it permits assessment of studies with multiple types of design, including RCTs, non-randomised controlled trials and controlled before-after studies (217). Nine standard criteria are scored individually as 'low risk,' 'high risk' or 'unclear risk' (217) (see 7.4.3). To determine the scores, both I, and second reviewer, independently rated each included study according to the checklist; I then compared the scores and discussed areas of disagreement with the second reviewer to gain consensus. In this study, risk of bias assessment was not used for the purpose of exclusion, but to reveal possible limitations to the included studies, and thus inform results and interpretation.

7.3.6 Data synthesis

I initially intended to use meta-analysis to pool results and summarise effectiveness. This technique enables the combination of study results to determine an overall effect size; but is not appropriate for all reviews, e.g., due to heterogeneity (218). In this review, clinical diversity in interventions indicated that meta-analysis was inappropriate and unfeasible. In such cases, narrative synthesis, referring broadly to the use of text rather than statistics to summarise and develop an explanation of findings, can be alternatively employed (219). In this study, synthesis was underpinned by broad guidance from Popay et al., who suggest that four processes should be undertaken: developing a theory of how and why the intervention works; developing a preliminary synthesis of study findings; exploring relationships within and between studies; and assessing the robustness of the synthesis, though not necessarily in this order (219). The Template for Intervention Description and Replication (TIDieR) checklist was also used to compare interventions (220).

7.4 Results

7.4.1 Study selection

Searches yielded 14,977 results, with eight additional papers identified from citation searching. This was reduced to 10,746 following removal of duplicates. Full-text screening took place for 105 reports, of which four studies (six reports) met inclusion criteria (see Figure 7.1). Although some studies initially appeared to meet inclusion criteria, upon full-text review the interventions undergoing evaluation did not include a significant component relating to delivery of recovery/ prognostic information, or the intervention lacked sufficient description for this to be ascertained. For example, in Jin et al.'s 2022 trial comparing systemic rehabilitation nursing, publicity and education with routine nursing, it was thought possible that the education element could involve conveying information about recovery (221). However, on closer inspection, only transfer of knowledge about health behaviours, stress and daily functional training were mentioned. Such studies were therefore excluded.

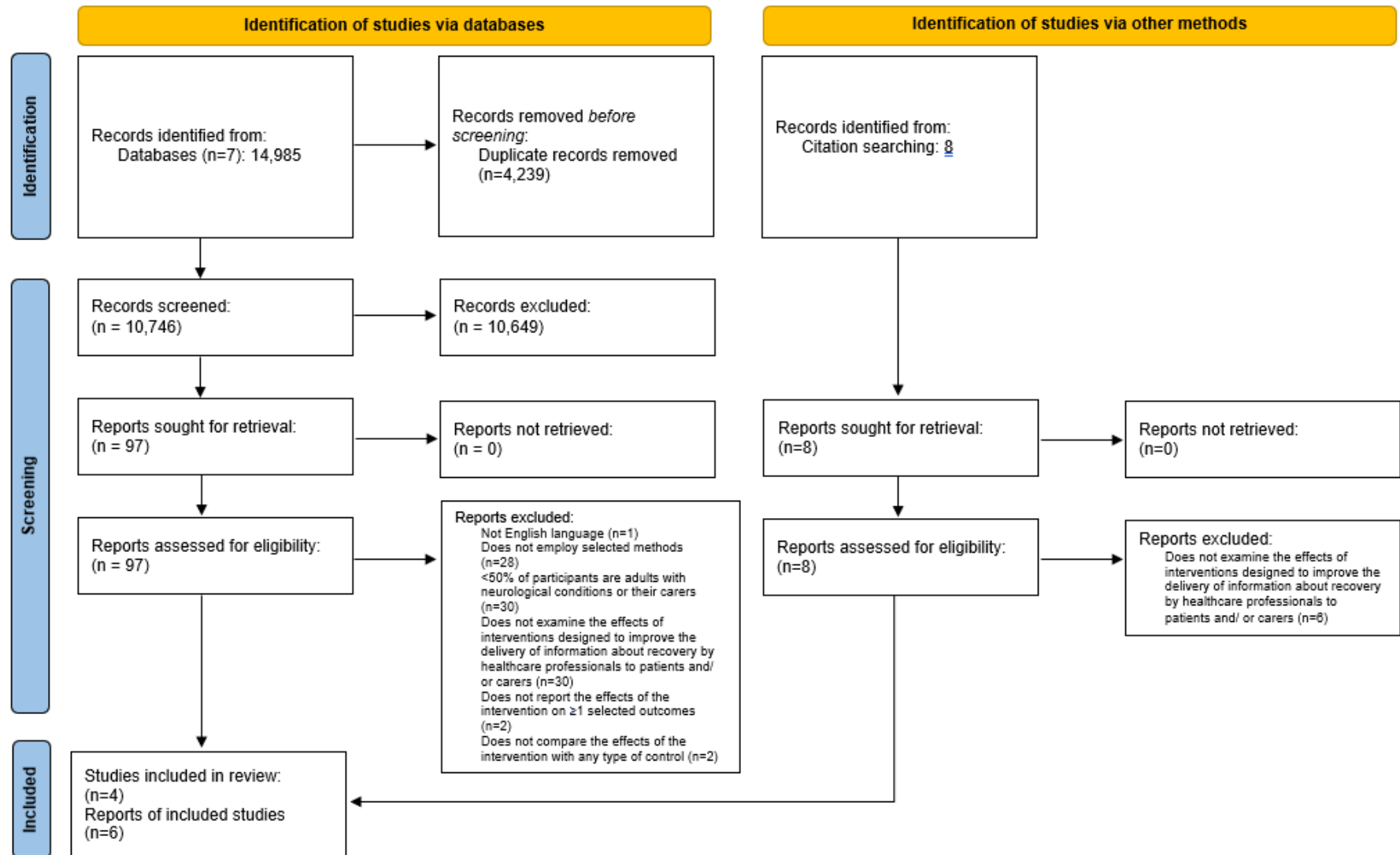


Figure 7.1 PRISMA diagram of included studies

7.4.2 Study characteristics

Four studies were included in the review. Two were conducted in the USA (222-224), and two in Germany (225-227). All four were RCTs, employed a two-arm parallel group design, and randomised individual patients to either the intervention or control condition (222-227). Two were pilot studies, with the primary aim of assessing intervention feasibility and trial procedures (223, 224, 226, 227).

7.4.2.1 PICO of included studies

7.4.2.1.1 Population

Overall, 334 patients with a neurological condition and 66 'proxies' (next-of-kin of patient) participated in the four included studies (see Table 7.2). Individual study sample sizes ranged from 28 (222) to 192 (225). Two studies included community-based patients with Multiple Sclerosis (MS) (225-227), one included rehabilitation in-patients with Traumatic Brain Injuries (TBI) (222) and one included critically-ill in-patients with TBI, stroke or intracerebral haemorrhage (223, 224).

7.4.2.1.2 Interventions and comparators

Interventions are compared using the TIDieR checklist (220) in Table 7.3. The experimental interventions employed across the studies varied significantly, though all involved some form of information provision supported by written materials (sometimes delivered online) and face-to-face discussion, with the aim of improving patient/ proxy participation in decision-making or involvement in care. Köpke et al.'s experimental condition aimed to promote informed decision-making, particularly in relation to the use of Disease Modifying Drugs (DMDs) and involved provision of a detailed educational booklet to patients with MS and a subsequent four-hour group session, during which evidence-based information (including prognostic information) was delivered through presentations, with opportunities for group discussion and reflection (225). The comparator intervention involved a short booklet based on information from a charity's website and a group stress management programme of similar length.

Two other studies also aimed to promote shared decision-making, but interventions were delivered at the individual level (223, 224, 226, 227). Rahn et al.'s experimental condition was a decision-coaching intervention, comprising a series of coaching sessions delivered by an MS specialist nurse, supported by a patient workbook and online educational resource (226, 227). The decision in question again related to uptake of DMDs and information included the potential impact of

medications on prognosis, and encouragement to consider risks and benefits of importance to the individual. Participants in the control group received access to the online resource only. A paper-based goals-of-care decision aid was provided to proxies of TBI patients in the experimental condition in Muehlschlegel et al.'s study, which comprised explanation of treatment options (comfort care vs continuation of survival care), an icon array detailing predicted outcome for the individual and a proxy-completed worksheet exploring the critically-ill patient's perceived values and proxy readiness to make a treatment decision (223, 224). This was employed at a family meeting with the treating team to support a tailored discussion about prognosis and treatment. The control intervention was usual care, comprising an unstructured family meeting.

Pegg et al.'s study differed in that it did not aim to address involvement in a specific decision, but perceived control and involvement in care more generally (222). The experimental intervention comprised three meetings between the patient and intervention deliverer, provided across a period of TBI rehabilitation, during which personalised information (including assessment results, progress, and prognosis) was provided alongside generic information. The control condition involved individual presentation of generic information using videos.

7.4.2.1.3 Outcomes

A variety of outcomes were measured across studies. In the two pilot studies, primary outcomes related to the feasibility of recruitment procedures and participant retention, as well as acceptability and usefulness of the intervention; all other outcomes as described below were exploratory (223, 224, 226, 227). In terms of the outcomes of interest for this review, one study measured patient satisfaction with information provided, and overall care (222), two measured quality of life (225-227) and three measured anxiety and depression (223-227). No studies measured patient adjustment.

Follow-up periods also varied with one study ceasing data collection at the patients' discharge (222), and single studies following participants up to three months (223, 224), six months (226, 227) and one year (225).

Table 7.2 Included studies: Trial design and participant characteristics¹

| Authors | Condition | Country | Design and unit of allocation | Inclusion criteria | Sample size | Mean age (sd) | % Female | Mean time post-diagnosis (sd) |
|---|--|---------|--|---|---|---|---|---|
| Köpke et al., 2014 (225) | MS | Germany | Design: 2 arm parallel group Unit: Individual randomisation | Patients from six university-based MS centres with a diagnosis of clinical isolated syndrome or definite relapsing-remitting MS within the last 2 years, aged 18-60 years. Excluded: Patients with major cognitive deficits | 192 I: n=93 C: n=99 | I: 36.5 (10.3) C: 36.7 (10.3) | I: 74% C: 75% | I: 1.4 (0.9) years C: 1.2 (0.8) years |
| Muehlschlegel et al 2020, 2022 (223, 224) | TBI, stroke, intracerebral haemorrhage | USA | Design: 2 arm parallel group Unit: Individual randomisation | Critically-ill patients from two neurological ICUs ≥3 days since hospital admission with acute ischemic stroke, primary intracerebral haemorrhage or non-penetrating TBI and their proxies (documented as next-of-kin) Excluded: Patient near-death or anticipated to be soon extubated and swallowing, proxy non-English-speaking or illiterate | Proxies: 66 I: n=33 C: n=33 Patients: 41 I: n=20 C: n=21 | Proxies: I: 51 (17) C: 57 (15) Patients: I: 58 (19) C: 64 (21) | Proxies: I: 82% C: 67% Patients: I: 45% C: 29% | - |
| Pegg et al., 2005 (222) | TBI | USA | Design: 2 arm parallel group Unit: Individual randomisation | Patients admitted to one TBI unit with moderate or severe TBI, intact receptive language. Excluded: Patients deemed to have limited potential to benefit from rehab, poor receptive comprehension, displayed agitation or drowsiness | 28 I: n=14 C: n=14 | 30.25 (10.57) years | 11% | Mean days in intensive care prior to TBI unit admission: 29.14 (sd=15.34), range=7-75 |

¹MS=Multiple Sclerosis; TBI=Traumatic Brain Injury; ICU=Intensive Care Unit; I=Intervention group; C=Control group

| | | | | | | | | |
|--|----|---------|---|---|----------------------------------|---------------------------------------|----------------------|---|
| Rahn et al., 2015, 2018 (226, 227) | MS | Germany | Design: 2 arm parallel group Unit: Individual randomisation | Patients from two MS centres with a diagnosis of suspected or relapse- remitting MS, facing a decision about starting or switching a first-line treatment. Aged ≥18 years. Excluded: Patients with secondary progressive or other suspected nervous system disorder, facing a decision on escalation immunotreatment, on symptomatic treatment, severe cognitive deficit or major psychiatric disorder affecting information uptake, no internet access. | 73 I: n=38 C: n=35 | I: 38.3 years C: 36.2 years | I: 68% C: 80% | - |
|--|----|---------|---|---|----------------------------------|---------------------------------------|----------------------|---|

Table 7.3 Details of study interventions, structured according to TIDieR checklist

| | Köpke et al., 2014 (225) | Pegg et al., 2005 (222) | Rahn et al., 2015, 2018 (226, 227) | Muehlschlegel et al., 2020, 2022 (223, 224) |
|---|--|---|--|---|
| Name of intervention | Interactive evidence-based educational programme | Personalised information provision | Decision-coaching intervention | Goals-of-care decision aid |
| Why: Rationale, theory, or goal for the intervention (how it is expected to work) | Providing education facilitates greater involvement in treatment decisions and increases patient autonomy. Sessions aimed to address attitudes, normative beliefs, and behavioural control as per the Theory of Planned Behaviour (228). Aim to promote informed choice, not specific behaviour. | Provision of patient-specific, tailored information increases patients' sense of control and produces better health outcomes (effort in rehabilitation, rehabilitation progress and treatment satisfaction), particularly for patients who have high desire for information. | Decision coaching facilitates more active participation in treatment decision-making and improves efficiency of physician consultations. Development of the training package for nurses was guided by the Theory of Planned Behaviour (228). | Shared decision-making tools improve quality of life and limit communication breakdown between physicians and patients' families. Decision aid based on Ottawa Decision Support Framework (229) and conceptual framework for decisional conflict (230). Decisional needs affect decision quality, which then affects behaviour, outcomes, and emotions. Shared decision-making targets decisional needs and decisional conflict through provision of information and support. |
| What (materials): Materials used within intervention | 57-page educational booklet including recent evidence on diagnosis/ prognosis/ early therapies. Structured presentation materials and moderation cards. | No written materials provided to participants Discussions structured around personalised information from participants' records, assessments and treatment plans/ reports and scripted generic information at each session: <ul style="list-style-type: none"> Personalised: Participant's injury and complicating conditions, results of neuropsychological assessment, treatment plan, how the treatment plan would contribute to desirable outcomes. Generic: the brain and TBI. Personalised: progress in cognitive/ physical functioning, detailed review of progress in ≥ 2 therapies. Generic: similarities and differences between | Patient workbooks (one for first-line treatment and one for those considering treatment change). DECIMS-Wiki: Online resources providing evidence-based information on topics relevant to MS, focussing on treatment options and their potential effects (risk reduction). | Paper-based decision aid (booklet) containing: <ul style="list-style-type: none"> Explanation of goals-of-care decision and treatment options (descriptions and photos), including tracheostomy, PEG, post-ICU discharge locations and comfort-based care. Icon array detailing estimated survival and 6- or 12-month outcome depending on condition based on validated prediction models, and information about uncertainty. Worksheet prompting consideration of patient values/ preferences and decision-readiness (1-page) |

| | | | | |
|--|--|---|--|---|
| | | <p>patients, anticipated behavioural/ cognitive/ psychological changes post-TBI, brief explanation of rehabilitation modalities</p> <ul style="list-style-type: none"> Personalised: progress update in 2 therapies, discussion of residual deficits and potential effects, information about discharge plans and results of discharge neuropsychological assessments. Generic: life after TBI, guidelines for enhancement of functional domains, cognitive remediation, advice for seeking medical information. | | |
| What (procedures): Procedures, activities, and processes | <p>Receipt of educational booklet</p> <p>Participation in interactive educational programme, including Power-point presentations of best available evidence about diagnostic testing, prognosis, and early therapies; opportunities for questions; guided group discussion; individual work; and reflection.</p> | <p>Personalised and generic information provided via scripted, structured discussion. Participants encouraged to ask seek information of specific interest to them.</p> | <p>Decision coaching sessions following six steps of shared decision-making: review problem, primary message, pros and cons of treatment options, patient expectations, decision, arrangements. Sessions supported by materials above.</p> | <p>Proxy provided with decision aid with standardised information about its use.</p> <p>Goals-of-care meeting between physician (provided with individualised icon array for each patient) and family, including review of proxy-completed worksheet.</p> |
| Who provided: Expertise, training given (how/ in what setting) | <p>Non-medical persons from MS centre (no further detail of background or training provided)</p> | <p>Clinical psychology doctoral researcher (no training details)</p> | <p>MS Specialist Nurses, who completed a 16-hour training based on train-the-trainer principle. Aimed to convey knowledge on evidence-based information and shared decision-making. Included role plays with case examples and simulated patients.</p> | <p>Trained research assistants provided decision aid.</p> <p>Goals-of-care meeting delivered by treating clinical team. Physician provided with initial education about research processes and the use of the worksheet to facilitate a detailed, personalised discussion about decision.</p> |
| How: Mode of delivery (including individual/ group) | <p>Individual receipt of educational booklet</p> <p>Group-based programme with some individual work with decision trees</p> | <p>Individual sessions</p> | <p>Individual, face-to-face sessions</p> | <p>Individual, face-to-face</p> |

| | | | | |
|--|---|--|---|--|
| Where: Locations where intervention was delivered | No details about location University-based MS out-patient clinic? | TBI unit | MS centres? | Neurological ICUs in two hospitals |
| When and how much: Timing and intensity (including number of sessions, schedule, duration) | 1 x 4-hour session Receipt of 1 educational booklet 4 weeks prior to session | 3 x 60-minute sessions Sessions held: <ul style="list-style-type: none"> • Following initial assessments (7-14 days after admission) • At mid-point of rehabilitation (7-10 days after first session) • Pre-discharge (3-7 days prior to discharge) (Length of intervention varies dependent on individual length of stay) | Up to three coaching sessions, up to two physician consultations (no detail on schedule or session duration) | Decision aid provided following recruitment (>3 days post-admission) and goals-of-care meeting held within 2 weeks of patients' admission (timing dependent on patient) Brief re-education if needed every 3-6 months. |
| Tailoring: Planned personalisation of the intervention | None reported | Information at each session was tailored according to participants' assessment results and treatment plans, gained through the medical record | Tailored sessions to individual patients, selection of workbook (first-line treatment vs change of treatment) | Icon array (outcome prediction) tailored to individual patient Personalised review of worksheet at goals-of-care meeting |
| Modifications (to the study) | None reported | None reported | None reported | Added fidelity plan for clinician-family meetings, specifying at least one meeting per patient, sharing of the decision aid to physician, integration of the worksheet into family meeting and avoidance of other prognostic discussions |
| How well (planned): If/ how fidelity was assessed | Not reported | Not reported | Coaching sessions video-taped and rated by observer for six steps of decision coaching on a scale of 1 (low) to 4. Logins to DECIMS-Wiki were tracked (some participants) | Not reported |
| How well (actual): Extent to which intervention was delivered as planned | Not reported | Not reported. Comment that timings of sessions was generally well-adhered to | Videos from only 1 of 2 centres available. Scored mean 2.4/ 4 (sd=0.6). | Not reported |

7.4.3 Risk of bias in included studies

Risk of bias assessment results are detailed in Table 7.4. In one study, the method of participant randomisation procedures and allocation concealment were considered to present high risk of bias (226, 227). Insufficient information was provided to make a clear judgement about the effectiveness of participant randomisation procedures in a further study (222) and in three studies it was unclear whether participant allocation was adequately concealed (222-224). Baseline characteristics and outcome measures appeared similar between the two groups in three studies (222-225), whilst inadequate reporting meant this could not be assessed in the fourth (226, 227). Levels of missing outcome data were disparate between intervention groups in three studies (223-227), such that it was deemed at high risk of impacting study conclusions in one (226, 227). In the fourth study, no data about attrition was provided, therefore assessment was not possible (222). This study also did not fully report all listed outcomes; no selective outcome reporting was observed in the other three studies.

There was a high or unclear risk of contamination between groups in all four studies (222-227), resulting from individual patients being randomised to different groups within a single centre (therefore increasing the likelihood that participants received the unallotted intervention), or patients receiving treatment from the same professionals who delivered both the experimental and control intervention. There was therefore a high risk of outcome assessors gaining knowledge of the participants' allocated conditions in two studies (222-224). In the other two studies, outcomes were assessed by blinded assessors, either by telephone, post or online (225-227).

Finally, in one study other bias may have resulted from some of the outcome measures used (e.g., Treatment Satisfaction Questionnaire (231), Rehabilitation Intensity of Therapy Scale (232)) being developed by the authors, with no available validity or reliability data outside of this sample, or detail of analysis reported (222). Internal consistency of these measures, as reported in this study, was mixed, with some Cronbach's alpha results falling below the 0.7 usually indicated for acceptability (233). As only descriptive statements of the results or analysis of variance are reported, it is also unclear how the data were analysed and interpreted.

Table 7.4 Risk of bias assessment

| | Köpke et al., 2014 (225) | Muehlschlegel et al., 2020, 2022 (223, 224) | Pegg et al., 2005 (222) | Rahn et al., 2015, 2018 (226, 227) |
|--|---------------------------------|--|--------------------------------|---|
| Random sequence generation | Low risk | Low risk | Unclear | High risk |
| Allocation concealment | Low risk | Unclear | Unclear | High risk |
| Baseline outcome measures similar | Low risk | Low risk | Low risk | Unclear |
| Baseline characteristics similar | Low risk | Low risk | Low risk | Low risk |
| Incomplete outcome data | Unclear | Unclear | Unclear | High risk |
| Knowledge of the allocation interventions adequately prevented | Low risk | High risk | High risk | Low risk |
| Protection against contamination | Unclear | High risk | Unclear | Unclear |
| Selective outcome reporting | Low risk | Low risk | High risk | Low risk |
| Other bias | Low risk | Low risk | Unclear | Low risk |

7.4.4 Intervention rationale and theory

The interventions examined in included studies were based on the underlying principle that provision of information or education supports a person's autonomy or sense of control, felt to be a key component of active involvement in healthcare (222-227). In three studies the intervention occurred ahead of making important decisions for which there was no right or wrong answer (for MS patients, this included treatment decisions (225-227); for the proxies of critically ill patients with brain injuries, the choice was between active treatment or comfort care (223, 224)). The interventions aimed to empower patients/ proxies to participate in shared decision-making with healthcare professionals, and to make an informed choice based on their own (or the patient's) values and interests. Authors of two studies also posited that greater autonomy, leading to improved involvement in care and decisions, could result in improved treatment adherence (continuing with DMD therapy long-term (225) or exerting increased therapeutic effort (222)). Pegg et al. also theorised however that the benefits of providing tailored information would be modified by the individual patient's desire for information, and the interpersonal relationship between the patient and information provider; they aimed to assess the effects of these factors in their study (222).

Interventions in three studies were underpinned by formal theories. The two studies considering shared decision-making in-patients with MS cited the Theory of Planned Behaviour (228), which is frequently applied in attempts to understand and modify

health-related behaviour, as the underlying theoretical basis of their intervention (225-227). The theory posits that behaviour, and behavioural intention (the amount of effort a person is likely to exert into that behaviour), is moderated by several factors, namely attitude, subjective norms (the extent to which they believe others wish them to exhibit the behaviour), and perceived behavioural control (their perceived ability to exhibit the behaviour). It was these factors that Köpke et al. attempted to target with information provision, aiming to influence behavioural intention through increasing perceived control, and changing perceptions of social norms and attitudes (225); Rahn et al. also used this theory to guide their training plan for intervention deliverers but provided less detail about the factors they intended to influence (226, 227).

Muehlschlegel et al.'s intervention was based around two frameworks for shared decision-making: the Ottawa Framework for Decisional Support (229) and a conceptual framework for decisional conflict (230). The Ottawa Framework provides a model for the support required for patients/ proxies who are making a decision about a new health condition, for which the potential benefits and risks are uncertain (229). It posits that addressing patients' decisional needs (e.g., for knowledge, support, and resources) through decisional support interventions can improve decisional outcomes (decision quality and process), which may subsequently improve implementation of the selected choice. Decisional support involves a focus on providing tailored information to enable patients to identify the potential benefits and risks of different treatment options for them as an individual, so that they can make an informed choice based on their personal values. Similarly, the conceptual framework for decisional conflict highlights the importance of addressing uncertainties by providing information and support (230). Muehlschlegel et al.'s intervention therefore aimed to address the decisional needs of proxies who were making a decision about patient care (223, 224).

Intervention development in two studies had input from stakeholders (223-225) and in three studies followed established guidance (223-227) from Craig et al. (203) or quality standards for decision aid development (234). One study provided no detail about intervention development (222).

7.4.5 Intervention features

All the interventions were complex, involving multiple, interacting components. These components included providing written information (in booklets (223-225) or online (226, 227)), verbal presentations (225) or discussions (222-227), and patient-completed workbooks/ tools (223, 224, 226, 227). In three studies, this focused on evidence-based generic information, including recent evidence on diagnosis,

prognosis/ disability progression and therapies, including their effects, e.g., risk reduction, benefits, and side effects (223-227). The fourth study did not reference the evidence base in the information provided, but sought to provide personalised information, based on participants' assessment results and treatment plans, alongside generic information about the condition (222).

The authors of all studies referenced the importance of tailoring information to the individual. As described above, Pegg et al. provided personalised information to individual patients alongside generic information within the structure of the intervention (222). In the other three studies, the generic information described above was tailored to the individual through discussion (223-227). Köpke et al.'s study involved group sessions and tailoring occurred through encouragement of discussion and reflection about the personal relevance of the provided information (225), whilst individual opportunities for personalised discussion with healthcare professionals were provided in the other studies, through decision-coaching by MS nurses (226, 227) and review of a completed decision aid with the treating team (223, 224).

Two studies reported using graphics to convey prognostic information visually. Rahn et al. used bar charts to display evidence-based risk reduction information about disability progression and relapses for different treatment options (see Figure 7.2) (226, 227). Muehlschlegel et al. used an icon array, informed by evidence-based prognostic modelling, and personalised to each patient, to display the probabilities of different outcomes for each patient (223, 224). Like Rahn et al.'s graphic, it displayed the probability of a range of outcomes through presentation of 100 people, colouring them differently according to the likelihood of each outcome (alive with mild or no disability, alive with severe disability or did not survive).

All included interventions included an active component. Two included workbooks or worksheets for participants to complete, and all four involved active discussion with a healthcare professional (222-224, 226, 227) or with other participants (225).

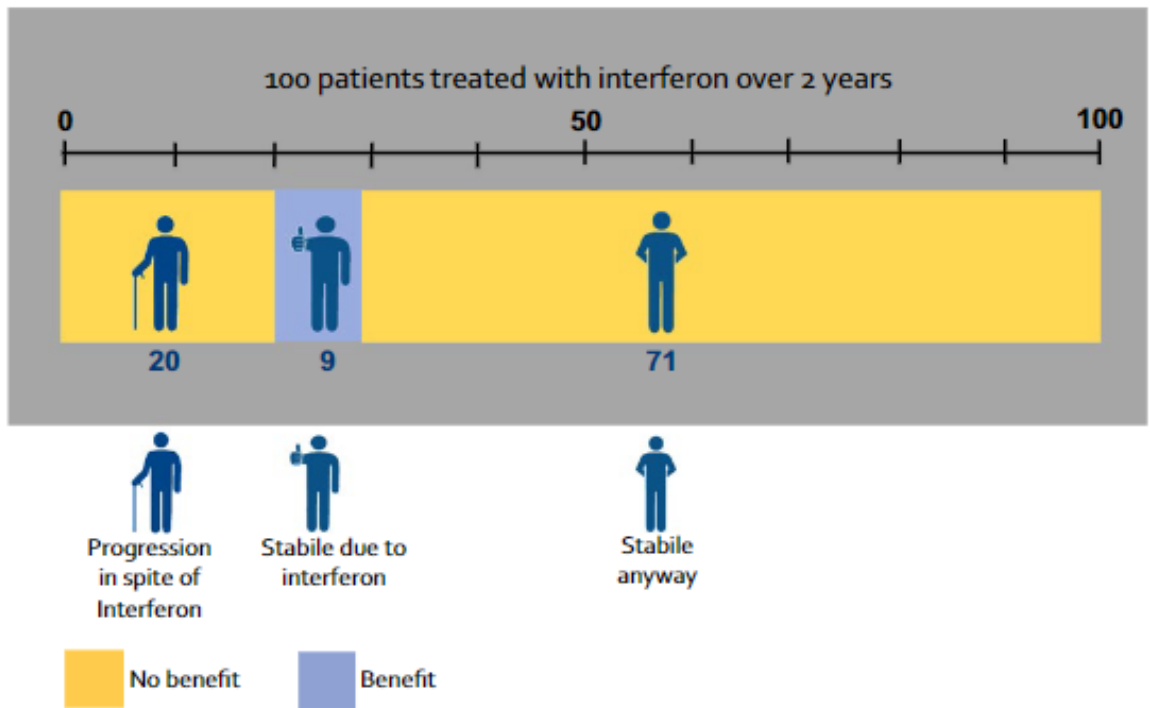


Figure 7.2 Bar chart used in Rahn et al.'s study to display prognostic information (reproduced from Kasper et al., 2017, pp 800 (235))

7.4.5.1 Training to deliver interventions

Only one study provided detailed information about the training provided to intervention deliverers (226, 227). In this study, MS specialist nurses received sixteen hours of training, based on the train-the-trainer principle, which included the use of Power-point presentations, role play with simulated patients, videos, and group discussion. The training aimed to convey knowledge about shared decision-making and evidence-based patient information. Nurses' knowledge was assessed using questionnaires and decision coaching sessions were videotaped, with structured feedback provided. Other interventions were delivered by 'non-medical persons' from the research team (though no detail of their background or training was provided) (225) and the lead researcher (a trainee clinical psychologist; no further details of training specific to the intervention were provided)(222). In Muehlschlegel et al.'s study, the decision aid was provided by trained research assistants (though no detail of their training was provided) and subsequently used to facilitate discussion with the patient's physician and clinical team, who were provided with information about its use (223, 224). As the intervention deliverers in three of these studies were healthcare professionals (222-224, 226, 227), it was perhaps assumed that they already possessed the skills to engage in information delivery and shared decision-making with patients.

7.4.6 Intervention effectiveness

The effects of the studied interventions on each outcome of interest will be considered, followed by other outcomes reported in individual studies. It should be noted that two studies were pilot/ feasibility studies, and as such reported trends, rather than statistical significance between groups (223, 224, 226, 227).

7.4.6.1 Patient and/or carer satisfaction (with the information provided or with overall care)

One study reported the effects of the intervention on treatment satisfaction (222). Pegg et al. (222) identified a significant positive effect of their personalised information provision intervention on patients' overall satisfaction with treatment and satisfaction with information provision when compared with the control group, as measured by the Treatment Satisfaction Questionnaire (231). A significant positive effect was also found on other subscales of this questionnaire, including patients' sense of involvement in treatment, rehabilitation progress and overall rehabilitation unit experience and communication with unit staff (222). This suggests that provision of personalised information improved not only satisfaction with information provision, but more generalised satisfaction across other domains. No significant differences between those with high or low desire for information were found (222). It should be noted however, that the scale used to measure treatment satisfaction was developed by the authors for this study, and no further published validity or reliability data are available, therefore it is unknown whether this tool measures what it purports to.

7.4.6.2 Quality of life

Two studies measured patients' quality of life (225-227). Both used the Hamburg Quality of Life in MS, a validated and widely used questionnaire (236). In both studies (225-227), this outcome was employed as a safety measure, aiming to ensure that the intervention in question did not cause harm or have negative side effects, rather than because improvements were expected. In both studies, quality of life remained stable at baseline and throughout the follow-up period, indicating no adverse effects of the interventions (225-227).

7.4.6.3 Patient adjustment to life with their condition

No studies examined the effects of an intervention on adjustment.

7.4.6.4 Mood

Three studies explored participants' anxiety and depression levels, measured using the Hospital Anxiety and Depression Scale (237), at various time points including at baseline and following intervention delivery (223-227). This measure is validated and commonly used within brain injury and MS populations (238, 239). These outcomes were again employed as safety measures, rather than because improvements were anticipated. In the two studies providing interventions for people with MS, anxiety and depression remained stable throughout the follow-up period, indicating no adverse effects (225-227). However, in Muehlschlegel et al.'s study of proxies of critically-ill TBI patients, the intervention group did demonstrate persistently higher depression and anxiety scores at three-month follow-up, when compared with the control group, whose initially similar mood scores ameliorated by this time (223, 224). This study also measured post-traumatic distress and found a similar effect (223, 224). For depression, anxiety, and post-traumatic distress, the effects were particularly prominent in those participants who selected comfort care for their relative (223, 224). The authors suggest that their decision aid intervention may require delivery alongside a second intervention aimed at limiting distress (223, 224). However, as previously noted, the outcomes in this study were exploratory and underpowered, therefore the observed difference may be random (or unrelated to the intervention). It should also be noted that, unlike the other studies considering participants' mood, participants in this study (223, 224) were required to make significant and difficult choices impacting the survival of their loved ones, and therefore impact on mood may be different, e.g., to those making decisions about their own treatment. Also related to mood, one study measured coping self-efficacy, identifying no differences between those in the experimental and control groups at six-month follow-up (226, 227).

7.4.6.5 Feasibility outcomes

Two studies were pilot/ feasibility trials, whose primary aims related to recruitment and retention of participants, and acceptability and perceived usefulness of their intervention (223, 224, 226, 227). Feasibility of recruitment procedures was ascertained in both studies, with retention of participants at 68% at three-month (223, 224), and 70% at six-month, follow-ups (226, 227), though the amount of missing data in one study was considerable (226, 227). Both interventions were also determined to be feasible, acceptable, and useful to their target populations (223, 224, 226, 227) and intervention deliverers (226, 227).

7.4.6.6 Outcomes related to informed and shared decision-making

Three studies assessed outcomes related to informed and shared decision-making (223-227). Informed choice was measured in two studies (comprising risk knowledge, and congruency between attitude towards DMDs and DMD uptake), with both interventions appearing to demonstrate positive effects (225-227), although statistical significance was not reported in one study (226, 227).

Decisional conflict was measured in three studies and remained low throughout follow-ups in both intervention and control groups (223-227). One study measured decision self-efficacy and confidence, and decision regret, and found no differences between groups (223, 224). Another single study evaluated shared decision-making and showed minor differences between groups (226, 227). Two studies measured decision autonomy and found it was high in both intervention and control groups (225-227). In two studies, autonomy preferences were high in both control and intervention groups (225-227), although there was a trend towards greater autonomy preference two weeks after intervention delivery in the experimental arm in one study (225). Decision satisfaction was reportedly high in both groups (225), although no data were provided. Decision-making process was also assessed in this study, with experimental group participants significantly more critical of DMDs immediately following intervention delivery and significantly less likely to conform to social norms of DMD uptake, although these effects did not persist beyond two weeks (225).

7.4.6.7 Outcomes related to knowledge

Three studies measured the impact of the intervention on knowledge (risk and medical) (223-227). One study demonstrated increased risk knowledge in the intervention group (225), whilst another reported increased risk knowledge in both groups (226, 227), and a third identified no differences between groups in medical knowledge (223, 224). Finally, one study examined prognostic concordance between proxies and clinicians, finding it was similar in both groups, although in the intervention group, proxies perceived the patient to be significantly less likely to survive the hospitalisation than did the clinician (223, 224).

7.4.6.8 Functional outcomes and disability status

Disability status was employed as a safety measure in one study, and demonstrated no differences between those receiving the experimental and control interventions (225). In Pegg et al.'s study, participants who received personalised information demonstrated improved functional outcomes (total score and Cognitive Functioning

subscale of the Functional Independence Measure (240)), when compared to those in the control arm, though no differences were found between those with high or low informational control preferences (222).

7.4.6.9 Therapeutic effort and interpersonal relationships with clinicians

One study demonstrated significantly increased effort in rehabilitation physiotherapy (but not speech and language therapy) in the experimental intervention group when compared to the control group, but saw limited effects of the intervention on interpersonal relationships between patients and therapists (222). Although in one session, patients in the intervention group were perceived by observers to be more dominant in treatment sessions with their therapists (i.e., more assertive with requests for information), this effect was not sustained (222). Trust in the patients' treating physician was measured and was similar over time in one study, with no differences between intervention groups (226, 227). Finally, one study measured proxy perceptions of patient-centredness and quality of communication with clinicians and found no differences between intervention and control groups (223, 224).

7.5 Discussion

7.5.1 Summary of main results

Overall, the results of this review suggest that interventions including information about recovery and prognosis may be promising in improving patient satisfaction with information provided, and with overall care. The results also demonstrate that interventions including provision of such information are unlikely to have negative effects on the quality of life or mood of patients with neurological conditions. It is however important to monitor these effects, to ensure intervention safety. However, due to the small number of studies included and their quality, the strength of the evidence is weak. Of the four included studies, three are likely to have been underpowered; two were pilot/ feasibility studies, which did not report statistical significance, and the third had a total sample size of only 28 participants and cited no power calculation. Nevertheless, the results of the feasibility studies suggest it is feasible to deliver and recruit to such trials.

7.5.2 Comparison with existing reviews

This is the first systematic review, which has attempted to identify, and assess the effectiveness of, interventions designed to improve professionals' communication of information about recovery on the outcomes of patients with neurological conditions and their carers. More evidence exists in the area of improving prognostic

communication with adults with life-limiting illnesses, such as cancer. A recent review by Selim et al reported the effectiveness of interventions including prognosis delivery to adult patients identified 17 RCTs, although only one of these was directly focused on improving prognostic communication, with most aiming to improve communication more broadly (241). Similar to the findings of my review, Selim et al. reported mixed evidence of the effectiveness of interventions, with some educational interventions eliciting positive effects on mood-related symptoms and professionals' communication skills, but variable and limited effects on measures of patients' perceptions of their relationship with professionals, and satisfaction with care and quality of life, respectively (241). Taken alongside my results, this identifies the importance of research to develop understanding of the mechanisms through which such interventions are intended to impact patients' and carers' outcomes.

Notably, most of the included studies in Selim et al.'s review (241) were aimed at improving the communication of prognostic information by doctors (likely by nature of the clinical setting), rather than other healthcare professionals. The studies included in my review did not have a similar focus, however none targeted the communication skills of allied health professionals, who, as revealed in my earlier review (Chapter 1) are frequently involved in delivering information about recovery in neurological settings. Indeed, Parry's review of the effectiveness of interventions designed to improve the communication skills of allied health professionals more generally revealed only five studies, none of which were RCTs (242). Although more interventions have since been developed and assessed e.g., Lonsdale et al. (243), none focused on the delivery of information about recovery could be identified. Given the identified desire and need for training for therapists, particularly in the area of breaking bad news, interventions that are effective in improving their skills, and patients' and carers' outcomes are required.

7.5.3 Strengths and limitations

A strength of this review is the use of a systematic approach to comprehensively search a range of bibliographic databases, using reproducible search strategies. However, as previously noted, terminology around conversations about recovery and breaking bad news is highly diverse (85), and so some studies may have been missed. Initial screening revealed numerous studies assessing the impact of interventions with a minor element of provision of recovery/ prognosis information. Careful judgements were made following in-depth discussion by two independent reviewers who assessed the full text of each identified citation to identify whether information about recovery formed a substantive part of the intervention being studied, before deciding to include the study. There was limited description of interventions in some of the screened

manuscripts, which, although not unusual (244), meant that decisions could be challenging, and some studies may have been missed or different reviewers may have made alternative decisions. In studies of post-stroke information provision interventions, for example, it was common to find description of information about 'symptoms' or 'consequences' of the condition, and it was unclear if this included information about whether/ how these might improve over time. Additionally, inclusion criteria were limited to studies examining intervention effects on patient/ carer outcomes. This means that interventions, which may have been effective in enhancing professional outcomes, e.g., confidence, were not included; such interventions may also have been promising for improving patient/ carer outcomes but to date, have not been tested. Finally, the review aimed to identify interventions, which had been tested for their effectiveness using quantitative methodology. The most recently published MRC guidance suggests other methods may be more appropriate to evaluate intervention effects (205), and therefore such studies may have been missed.

As in previous reviews (245), in the included studies, information about recovery was provided as part of a wider educational or information provision intervention, making it difficult to assess its independent impact on outcomes. None of the included studies specifically aimed to assess the impact of providing information about recovery alone, but rather had wider aims of promoting shared decision-making or greater involvement in care. It was also noted that some information about recovery was provided as part of some of the control conditions, e.g., in the online resource in Rahn et al.'s study (226, 227), although this information was provided passively, which may have limited its effects.

A strength of this review is the assessment of risk of bias using a validated, structured tool (217). However, no studies were judged to have low risk of bias across all domains, and three were judged to have high risk of bias in at least two areas; the results therefore require cautious interpretation. Additionally, only one study reported how those delivering the intervention were trained to do so; this is important in descriptions of intervention content and facilitates replication (220). Finally, although the participants in the included studies were patients with neurological conditions or their proxies, individual study eligibility criteria meant that those with significant communication or cognitive problems were excluded. These difficulties are common in stroke unit patients, and it will be important to ensure any developed intervention meets their needs, and those of their families.

7.5.4 Implications for intervention development

The aim of this review was to synthesise existing evidence relating to interventions that could be used provide information about recovery to stroke survivors and their carers. Although the tested interventions had different aims and included information about recovery/ prognosis as part of a wider intervention, several similar features were evident in each, namely the provision of (evidence-based) information, the personalisation of information to the specific individual, and the active engagement of participants through discussion (vs passive information delivery). This suggests these components, at least theoretically, could be useful to include in a new intervention, through increasing patients' sense of control in an uncertain situation, empowering them in decision-making and increasing therapeutic effort. The use of visual displays of prognostic information and role of developing understanding of patients' preferences for information prior to provision is also worthy of consideration.

Chapter 8 Application of the Capability Opportunity Motivation model of Behaviour (COM-B) to identify potential promising behaviour change techniques

8.1 Background and rationale

In the previous chapter, I attempted, through review of the literature, to identify existing interventions to improve provision of information about recovery, which could be used in, or adapted to, the stroke unit context. Only four interventions, which had been evaluated for their effectiveness in improving patient/ carer outcomes, were identified; all included provision of information about recovery as part of a wider intervention, such that it was not possible to specify the effects of this aspect on outcomes. Therefore, I began development of a new complex intervention, which aimed specifically to improve provision of information about recovery in stroke units.

In line with the guidance for developing complex interventions (203-205) discussed at the beginning of this section, this chapter describes efforts to develop a theoretical understanding of how an intervention might drive behaviour change and the expected changes that might arise.

8.2 The use of theory in complex intervention development

A core component of the Medical Research Council (MRC) Framework for developing and evaluating complex interventions is the use of theory (203, 205), although the model provides limited detail about how to select from the wide range available. Complex interventions require recipients to change their behaviour in some way; thus to develop effective interventions, researchers need to understand the underlying psychological mechanisms that drive this behaviour change, and how they operate (246). In practice, this understanding guides the selection of techniques and components within an intervention, which are theorised to modify these constructs and therefore result in behaviour change (247). Without such understanding, it is difficult to ascertain why some apparently ineffective interventions fail, i.e., whether this is because the intervention does not affect the proposed psychological mechanism, or because the proposed mechanism is not successful in driving the desired change in behaviour (246). More widely, this understanding can both enhance interventions to potentially increase their effectiveness and advance theory (248). Well-articulated theory can also be persuasive to decision-makers and facilitate the transfer of interventions in different contexts (205).

Despite the proposed advantages in using theory to develop complex interventions, the evidence about whether its use results in interventions that are more effective in improving outcomes is mixed. Whilst some systematic reviews have found evidence for increased effectiveness of theory-based interventions (249, 250), others have failed to find an effect, or found the opposite (251). A recent overview of systematic reviews published in 2019 considered the relationship between the use of theory to develop interventions, and their effectiveness (252). Dalgetty et al. found that eight of the nine studies they included failed to find an association between the use of theory to develop interventions and their effectiveness (252). However, proponents of using theory as a basis for intervention development argue that the picture is complex (253-255). They suggest that it is not the use of theory *per se*, which may prove effective, but the way it is applied within the intervention development process (247, 254). For example, some authors suggest that identification of the specific psychological mechanisms targeted by intervention components to elicit behaviour change may hold greater importance than simply categorising interventions according to whether or not theory was used in their development (254, 255).

Additionally, there is no consensus about the best theory to apply from the available range of psychological, sociological, and organisational theories. Examples include Bandura's Social Cognitive Theory (256), Protection Motivation Theory (257), the Social Ecological model (258), the Theory of Reasoned Action (259), and the Theory of Planned Behaviour (228). The latter was cited by two of the studies (225-227) included in my systematic review (Chapter 7) as the basis for intervention development and has frequently been used for this purpose (260). However, like other studies citing this theory, these papers did not provide detailed descriptions of how this theory had been applied (261). Whilst Köpke et al. described how their intervention attempted to change factors moderating behaviour and behavioural intention (namely attitude, subjective norms, and perceived behavioural control), they did not discuss the mechanisms of action through which their intervention components might result in this behaviour change (225). Rahn et al. provided even less detail, in stating only that they had been guided by this theory in developing their training package and that it had been previously used to develop one of their outcome measures (226, 227). The theory has also received criticism for its failure to account for several important influences on behaviour, including roles of impulsivity, habit, self-control, associative learning, and emotional processing (262), such that this evidence was not felt strong enough to endorse its use in the development of a new intervention.

It has been suggested that the wide range of available theories causes difficulties for intervention developers, including the potential for important theories to be overlooked, and the lack of an evidence base to support selection decisions (263). The range of available models of behaviour, and their often-overlapping features, led Michie and colleagues to begin development of a new framework incorporating these models and addressing their limitations (262). Their systematic review work identified nineteen frameworks, which they assessed and synthesised to develop a new model, the COM-B, which lies at the heart of their Behaviour Change Wheel (BCW) framework (262). This model has advantages over the Theory of Planned Behaviour in going beyond reflective aspects of motivation, and also takes into account automatic processing (262). The model was selected to underpin intervention development in this study and is further described below.

8.3 The COM-B model and Behaviour Change Wheel

The BCW (Figure 8.1) is a framework designed to guide intervention developers through a systematic process, from identification and analysis of the problem the intervention is aiming to address, to selecting potential options for intervention design, including intervention functions, supportive policies, specific behaviour change techniques and modes of delivery (206). The COM-B model sits at the wheel's centre and posits that for an individual to exhibit any behaviour, they must have the capability and the opportunity, and be motivated to do so, more than any other or no behaviour (206). *Capability* can be physical (e.g., strength) or psychological (e.g., skills); *Opportunity* can be physical (afforded by the environment) or social (interpersonal influences or social cues); and *Motivation* can be automatic (e.g., emotional reactions) or reflective (e.g., conscious plans and beliefs) (206). These interacting components (or combinations of them) represent the sources of the behaviour that could potentially be targeted by an intervention (206).

The spokes of the wheel, which surround the COM-B model, represent nine intervention functions. These, alongside the associated policy categories were identified through Michie et al.'s synthesis of behaviour change frameworks (264). The COM-B components are each linked to one or more intervention functions, defined by Michie et al. as "*broad categories of means by which an intervention can change behaviour*" pp. 109 (206). For example, barriers relating to *Physical Capability* can be addressed using the intervention function of Training (involving imparting skills) (206). The seven policy categories (forming the wheel's outer layer) represent options available to authorities to support intervention delivery and are linked to the intervention

functions (206). For example, the policy categories linked to the function of Training include Guidelines (creating documents that recommend/ mandate practice) and Regulation (establishing rules of practice), amongst others (206).

Intervention content is determined through identification of more specific Behaviour Change Techniques (BCTs). BCTs are defined as “*observable, replicable and irreducible components of an intervention designed to change behaviour and a postulated active ingredient within the intervention*” pp. 145 (206). Through their synthesis of published interventions and expert consensus, Michie et al. identified a taxonomy of 93 BCTs associated with effective interventions, which can be employed individually but usually exist in combination within an intervention (265). The BCTs were subsequently linked to intervention functions by expert consensus (206). For example, some of the BCTs most commonly used to deliver the function of Training include demonstrations and instructions on how to perform a behaviour and feedback on its delivery and outcome (206).

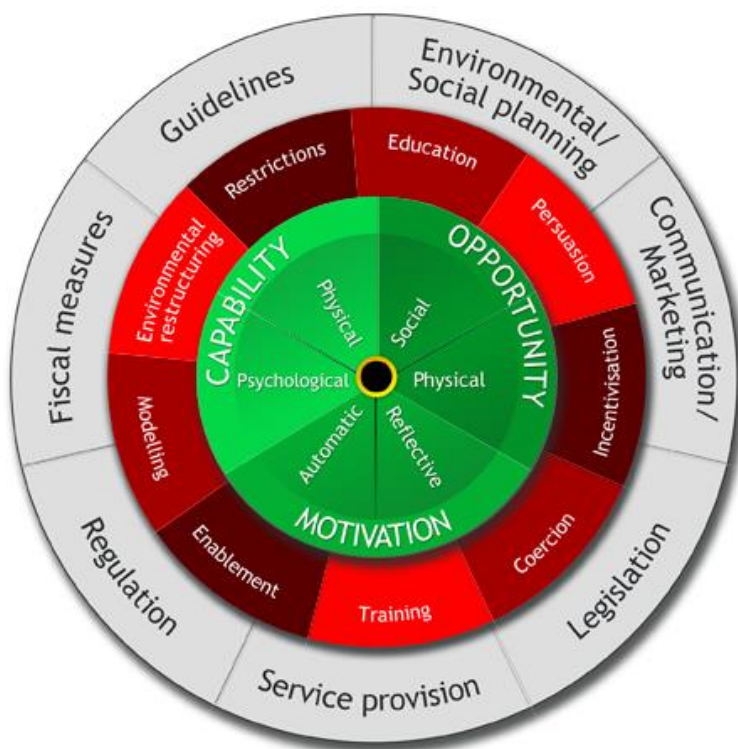


Figure 8.1 The Behaviour Change Wheel, reproduced from Michie et al., 2011, pp. 7 (262)

The BCW has been applied to develop behaviour change interventions in stroke rehabilitation, targeting the reduction of sedentary behaviour (266) and increasing upper limb activity (267) and active practice (268), as well as strengthening the role and functions of nurses (269). Although earlier health interventions developed using

the BCW have aimed to improve health-related behaviours in service user populations, e.g., encouraging smoking cessation (270) or increasing condom use (271), all of the interventions identified in stroke rehabilitation targeted the behaviour (at least to some extent) of the professionals' delivering services, as is the aim of this study. The BCW has been designed so that it can be applied equally in both scenarios (206). The BCW framework was therefore selected as an appropriate theory on which to base an intervention in this study. Although there is no evidence that interventions developed using this model are more effective, the idea of a systematic and transparent process was appealing, and developing an understanding of the mechanisms underlying behaviour change appeared logical.

8.4 Developing a complex intervention to improve recovery conversations using the BCW

Within the model of the BCW, intervention development progresses through a series of stages. Although these stages appear linear, some authors have suggested that the steps may be applied iteratively along the process (272). This section details application of the BCW framework to begin development of an intervention to tackle the challenges in providing and receiving information about recovery in stroke units, informed by my previous qualitative work (Section 2).

8.4.1 Stage 1: Understand the behaviour

The process begins with developing an understanding of the problem. Michie et al. posit that this is a critical stage in intervention development, which is often overlooked; they argue that greater understanding of the desired or 'target' behaviour is likely to result in greater success in modifying it (206). Through four steps, intervention developers are directed to define the problem in behavioural terms, before identifying behaviour(s) to target with an intervention, specifying these behaviours and identifying what needs to change such that they will be realised (206). Michie et al. recommend collection of primary data to understand what needs to change from multiple stakeholder perspectives, and triangulation of data from a range of sources to increase confidence (206). These data inform the behavioural analysis, which is conducted using the COM-B model to categorise these identified barriers to achieving the desired behaviour (206). What needs to change can be further classified using the Theoretical Domains Framework (TDF (273)) in an additional optional step, should more detailed understanding of the behaviour be needed (206). The TDF was developed to make theory more accessible to researchers and incorporates a range of behaviour change

theories (273). The resulting framework consists of fourteen domains (listed in Table 8.1), which represent theoretical constructs, each linked to COM-B components (273).

Step 1 involves defining the problem in behavioural terms (206). The problem to be addressed by this research was patients' and families' dissatisfaction with the information they receive about recovery on the stroke unit. The results of my earlier qualitative work identified their perceptions that information was not provided proactively, highlighted inequity in the opportunities offered to patients and families, and suggested provision of unclear or inconsistent information from different professionals. Therefore, the problem was defined in behavioural terms as "*Patients and families do not receive adequate information about recovery after stroke.*" The location of the problem was defined as in-patient stroke units, with the people involved defined as stroke unit professionals, patients, and their families.

Steps 2 and 3 involved selecting and specifying the target behaviour. Michie et al. recommend identifying a list of potential target behaviours and evaluating them based on how promising they are (206). Potential target behaviours were identified following review of the previously-collected qualitative data and consideration of the potential impact and likelihood of changing the behaviour, how changes could be measured and whether such behaviour changes would result in any 'spillover' effects to other behaviours (206). Two potential targets were considered. Firstly, consideration was given to designing an intervention targeting the behaviour of stroke survivors and their families, i.e., encouraging and empowering them to seek out information about recovery from stroke unit professionals. Although it was felt likely that patients' and families' behaviour could be changed, and that this behaviour could be measured (e.g., via the number of requests for information), the potential impact of changing this behaviour, and potential spillover effects to professionals' behaviour, were felt to make it unpromising. For example, the range of issues highlighted by professionals, including difficulty in predicting recovery in some situations, and the emotional cost to themselves (Chapter 5), meant they might be unprepared to manage requests for information and the emotionally challenging conversations that might ensue. Stroke survivors' identified preferences for the delivery of this information also meant that changing their own behaviour may not result in their information needs being met (Chapter 6).

Targeting professionals' behaviour was felt to be more promising, both in the impact and likelihood of behaviour change. Additionally, the potential for 'spillover' effects were identified, in which the culture of the unit could change, with discussions about recovery regularly taking place, thus potentially empowering patients to seek

information more readily. Therefore, the selected target behaviour focused on staff and was “*providing information about recovery by stroke unit professionals to patients and their carers.*” The behaviour was further specified more precisely, based on findings from Section 2:

- *What:* Providing information to patients and their families, including both generic and personalised information, in an appropriate format to meet the information recipient’s needs, e.g., verbal, written (including accessible).
- *Who:* As qualitative work highlighted professionals’ perceptions that provision of information about recovery was the responsibility of all staff, the people involved in the behaviour are defined as multidisciplinary stroke unit staff, including both qualified professionals (e.g., doctors, nurses, therapists) and other staff members (e.g., therapy and healthcare assistants, housekeepers, ward clerks, porters).
- *With whom:* Information should be provided to patients (where appropriate to their level of understanding and their wishes) and/ or their carers (with the patient’s express permission where they are able to provide it or in their best interests if not).
- *When:* Qualitative work identified that at least some information could be provided during the in-patient stay (even when this was short). Although the type of information may change over the course of the hospitalisation, e.g., generic information is more likely to be provided in the acute phase, before individual assessments and multidisciplinary discussions have taken place; there is a role for regular information provision from admission, through to discharge.
- *How often:* Information should be provided as often as is required, but at a minimum, information should be offered at least once during the hospital admission.
- *Where:* On the stroke unit/ therapy unit or other location in the hospital, preferably in a quiet, private and accessible area.

The final step of stage 1 involved conducting a behavioural diagnosis, to identify the change required, using the COM-B model (206). Michie et al recommend gathering data from stakeholders, using a variety of methods, to develop an understanding of what needs to change (206). In this study, these data were previously collected through interviews with stroke unit professionals (the target population for this intervention). Qualitative data were reviewed and mapped to the COM-B model, to identify professionals’ *Capability* (physical and psychological) to perform the target

behaviour, *Opportunity* (physical and social) for the behaviour to occur and their *Motivation* (automatic and reflective) to engage in the behaviour (see Table 8.1).

Fifteen barriers (areas where change was potentially required to improve provision of information about recovery) were identified and classified (detailed in Table 8.1). Overall, the analysis revealed four components of the COM-B model where changes were potentially needed: *Psychological Capability* (six barriers), *Physical Opportunity* (two barriers), *Reflective Motivation* (five barriers) and *Automatic Motivation* (two barriers). No changes were identified within the *Physical Capability* or *Social Opportunity* components, as these were not felt relevant to the target behaviour. The TDF was also used to expand on the COM-B components and further classify the identified barriers, for example, categorising behaviours within *Psychological Capability* into Knowledge; Cognitive and interpersonal skills; Memory, attention, and decision process; and Behavioural regulation.

Table 8.1 Behavioural diagnosis for the target behaviour of providing information about recovery¹

| COM-B | TDF | What needs to happen for the target behaviour to occur? |
|---|---|---|
| Physical capability | Physical skills | N/A |
| Psychological capability | Knowledge | Knowledge to make predictions about individual patients' recovery |
| | | Knowledge about their own and others' professional roles in providing information about recovery |
| | Cognitive and interpersonal skills | Possess the required communication skills to deliver information sensitively and compassionately |
| | | Ability to assess whether and how much information patients and families want to know about recovery |
| Memory, attention, and decision processes | Ability to decide when and in what format to provide information to individual patients/ families | |
| Physical opportunity | Environmental context and resources | Availability of quiet and private spaces to provide information, to promote confidence and facilitate patients' and families' receipt of the information |
| | | Availability of written generic information to use to support conversations about recovery with patients and families |
| Social opportunity | Social influences | N/A |
| Reflective motivation | Professional/ social role and identity | Perception that talking about recovery is part of professional role |
| | Beliefs about capabilities | Confidence in own ability to share information about recovery with patients and families |
| | Optimism | N/A |
| | Beliefs about consequences | Belief that providing information about recovery provides benefits to patients and families and awareness of the risks of not providing such information |
| | | Belief that conveying predictions about recovery will not have longer-term negative consequences, e.g., if predictions they make do not come to pass |
| | | Belief that providing information about recovery will not have immediate negative consequences, e.g., reducing patient motivation and impacting mood |
| Intentions | N/A | |
| Goals | N/A | |
| Automatic motivation | Reinforcement | N/A |
| | Emotion | Do not feel anxious about conversations about recovery before they occur Ability to manage own distress following difficult conversations about recovery |

¹ COM-B: Capability Opportunity Motivation model of Behaviour; TDF: Theoretical Domains Framework

8.4.2 Stage 2: Identify intervention options (functions and policy categories)

The second stage involves identifying intervention options (206). This includes selecting from the nine intervention functions those most likely to be effective in addressing the barriers identified in the behavioural analysis, and subsequently identifying policy categories to support their implementation (206). A comprehensive list of all intervention functions, which might theoretically be effective in modifying the target behaviour, is initially devised, such that potentially effective options are not overlooked (262). Judgements about the intervention functions and policy categories most appropriate to the intervention context are then made, according to their Affordability, Practicability, Effectiveness and cost-effectiveness, Acceptability, Side-effects/ safety, and Equity, known as the APEASE criteria (206).

In this study, all nine intervention functions were linked to the identified COM-B components and considered as options. The APEASE criteria were applied to make judgements about the intervention functions, which were most appropriate for the context in which behaviour change was required in this study. The six selected intervention functions were: Education, Persuasion, Training, Environmental Restructuring, Modelling and Enablement (see Table 8.2). Although Incentivisation and Coercion were linked to the component of Automatic Motivation, creating expectations of reward or punishment were judged to be impractical and potentially unacceptable in this context. Restriction (using rules to increase the target behaviour by reducing the opportunity to engage in competing behaviours) was linked to *Physical Opportunity* but was also considered impractical.

The seven policy categories to facilitate delivery of the intervention functions were then reviewed, based on those linked to the selected intervention functions and the APEASE criteria. Following consideration of these criteria, two policy categories were established as being potentially useful in this context: Guidelines and Service provision. Currently UK guidelines for stroke care include the National Clinical Guideline for Stroke (23) and the Stroke Rehabilitation in Adults guidance published by the National Institute for Health and Care Excellence (NICE) (274). The former highlights the importance of information provision in general and specifically recommends that information about functional prognosis and likelihood of goal achievement is used to manage patients' expectations and that carers also receive information about the consequences and prognosis of stroke, within the context of a wider educational programme (23). NICE also recommends identification of patients' and carers' information needs and how they might be delivered (274), and refers to more generic patient experience guidance highlighting the importance of providing consistent,

evidence-based, and tailored information to promote active involvement in care (275). These guidelines may act as enablers for intervention implementation. Service provision was also highlighted as an enabler, as the delivery of information about recovery to patients and carers must take place in the context of the service provided in the stroke unit. Other policy options were considered impracticable within the context of this intervention.

8.4.3 Stage 3: Identify content (BCTs) and implementation options (mode of delivery)

In the final stage of intervention development, the selected intervention functions are linked to more specific BCTs to determine the content of the intervention (206). The list of potential BCTs is narrowed down to those most appropriate to the context of the intervention, using both the APEASE criteria, and guidance around those used most frequently to serve each of the selected intervention functions (206). Finally, the mode of delivery is determined, with options including face-to-face or distanced delivery, and individual or group approaches, selected using the APEASE criteria and consideration about evaluation techniques (206).

In this study, potential BCTs to deliver each of the selected intervention functions (as identified by Michie et al. (206)) were initially chosen. The APEASE criteria were then used to make judgements about which were most likely to be appropriate to consider in the context of developing an intervention to improve provision of information about post-stroke recovery. This list of BCTs was then reviewed, alongside the identified barriers and intervention functions, by a research colleague and supervisors. Further revisions then took place through discussion. The final list comprised 29 potentially relevant individual BCTs (with some used to address multiple barriers) (see Table 8.2).

The final step was to identify the intervention delivery mode and evaluate these options using the APEASE criteria. Options for delivery of this intervention were deemed likely to include face-to-face and in a group setting, representing greater value for money and more efficient use of intervention deliverers' time than an individually-targeted intervention. There was potential however for some BCTs to be delivered at a distance, either individually or in groups, e.g., using webinars for group delivery or online materials such as videos that can be accessed individually. Feasibility and acceptability to intervention recipients were particularly important in this context of development of an intervention for use within stroke units, where professionals receiving the intervention are likely to have substantial time pressures, and where

continued professional development is likely (and rightly) prioritised below direct patient care.

As the list of potentially appropriate BCTs remained long, this was felt an appropriate stage in intervention development to consult stakeholders. As the BCTs aimed to target professionals' behaviour, their views around which of the identified barriers would be most important to address in an intervention, and on the acceptability and feasibility of the identified BCTs and how they might be delivered, were particularly important. This work further focused the intervention strategy, and is detailed in Chapter 9.

Table 8.2 Behavioural diagnosis using the COM-B model, suggested intervention functions and associated Behaviour Change Techniques¹

| COM-B component | TDF | Relevance of domain (facilitators to performing behaviour identified through qualitative work) | Barriers (what needs to change) | Intervention functions | Individual BCTs |
|---------------------------------|------------------------------------|---|---|------------------------|--|
| <i>Psychological capability</i> | Knowledge | Professionals have the knowledge to make predictions about individual patients' recovery | Some professionals (particularly junior staff) describe feeling unable to predict recovery | Training | Provide information on factors to consider, which may impact recovery after stroke (Instruction on how to perform a behaviour) |
| | | Professionals have knowledge about their own and others' professional roles in providing information about recovery | There are no standard guidelines about who should provide information about recovery, when and why. As a result, professionals may be unclear about who should provide information about recovery | Modelling | Provide examples of the roles and responsibilities of each professional and the team in providing information for them to aspire to (Demonstration of the behaviour) |
| | Cognitive and interpersonal skills | Professionals possess the required communication skills to deliver information about recovery sensitively | Some professionals perceive that they do not have the required communication skills to deliver information about recovery, particularly when this | Training | Provide instruction about how to discuss recovery sensitively and compassionately (Instruction on how to perform a behaviour) Demonstrate how to deliver information about recovery sensitively and compassionately (Demonstration of the behaviour) Prompt practice of conversations about recovery through role play with peers (Behavioural practice/ rehearsal) |

¹ COM-B: Capability, Opportunity, Motivation model of Behaviour; TDF: Theoretical Domains Framework; BCT: Behaviour Change Theory; MDT: Multidisciplinary Team.

| | | | | | |
|---|---|--|---|--|--|
| | | and compassionately | involves breaking bad news | | Provide feedback following observation of practice conversations with peers (Feedback on behaviour) |
| | | Professionals are able to assess whether and how much information patients and families want to know about recovery | Some professionals may find it difficult to assess whether and how much information about recovery to provide to individual patients and few report directly asking patients and families about how much information they would like to receive | Training | Advise on how to ask patients and carers about whether and how much information about recovery they wish to receive (Instruction on how to perform a behaviour) Demonstrate how to ask patients and carers about whether and how much information about recovery they wish to receive (Demonstration of the behaviour) Prompt practice of asking how, whether and how much information is wanted through role play with peers (Behavioural practice/ rehearsal) Provide feedback following observation of practice conversations with peers (Feedback on behaviour) |
| Memory, attention, and decision processes | Professionals are able to decide when and in what format to provide information to individual patients/ families | Some professionals find it difficult to decide when and in what format to provide information about recovery to meet individual patients' needs, e.g., where patients have cognitive or communication problems | Training, enablement | Advise on how to decide when and in what format to provide information to individual patients/ families (Instruction on how to perform a behaviour) Demonstrate examples of conversations occurring in different ways (e.g., at different times, supported by written documentation or not) with patients with different needs (Demonstration of the behaviour) Prompt practice of making decisions about when and in what format to provide information to individual patients/ families using vignettes (Behavioural practice/ rehearsal) Provide feedback following discussions based on vignettes (Feedback on behaviour) Advise on requesting support from colleagues across the MDT when making decisions about when and in what format to provide information (Social support (practical)) | |
| Behavioural regulation | Standard procedures are in place to monitor whether, when and to whom information has been provided, to promote consistency across patients | Professionals do not routinely provide information about recovery to all patients, potentially resulting in inequity | Education, Training, Enablement | Encourage a unit-specific plan to provide information about recovery, e.g., at specific time-points/ in specific contexts (Action planning) Prompt conversations about recovery at specific time-points during admission, e.g., every 2 weeks (Prompts/cues) Agree on a goal of having a conversation about recovery with all patients/ families at certain timepoints in their admission, e.g., every two weeks (Goal-setting behaviour) . Examine how performance fits with agreed goal | |

| | | | | | |
|-----------------------------|-------------------------------------|--|---|--|--|
| | | | | | <p>(through audit) and consider modification if needed (Review behaviour goals).</p> <p>Put in place physical reminders (e.g., in patients' records), or verbal prompts (e.g., at MDT meetings) to alert professionals at the time when a conversation about recovery is due (Prompts/ cues)</p> <p>Establish a single shared record for the MDT to monitor whether information has been provided and record the outcome of conversations (Self-monitoring of behaviour)</p> <p>Arrange for professionals to remind each other about providing information, e.g., through regular prompting at formal meetings or informal supervision (Social support (practical))</p> <p>Prompt professionals to identify barriers when conversations about recovery have not taken place and discuss ways to overcome them as a team (Problem-solving)</p> |
| <i>Physical opportunity</i> | Environmental context and resources | <p>Quiet and private spaces to provide information about recovery are available on the ward, to promote confidence and facilitate patients' and families' receipt of the information</p> | <p>Professionals may lack opportunities to provide information about recovery due to the absence of appropriate private and quiet spaces to speak with patients/ families, felt to be necessary for patient confidentiality and to support receipt of the information, e.g., noise/ distractions can result in difficulties taking in information</p> | <p>Training, Environmental restructuring, Enablement</p> | <p>Advise on importance of providing information about recovery in a private and quiet area, and how to prevent interruptions (Instruction of how to perform a behaviour)</p> <p>Advise on allocation of designated areas as quiet and private areas to discuss recovery (Restructuring the physical environment)</p> |
| | | <p>Written generic information about recovery is available for professionals to use to support conversations about</p> | <p>Little written information about recovery is available for professionals to support conversations, particularly for patients/ families with cognition</p> | <p>Training, Environmental restructuring, Enablement</p> | <p>Provide (or support professionals to identify) generic written information to provide to patients/ families (Adding objects to the environment)</p> <p>Ensure written information is readily available in a specific location for professionals to access when required (Prompts/ cues)</p> |

| | | | | | |
|------------------------------|---------------------------------------|---|---|------------------------|--|
| | | recovery with patients and families | or communication problems | | |
| <i>Social opportunity</i> | Social influences | N/A | N/A | N/A | N/A |
| <i>Reflective motivation</i> | Professional/social role and identity | Professionals view talking about recovery as part of their professional roles | Some professionals, e.g., nurses, may not view discussing recovery as part of their role. | Education, Persuasion | <p>Tell professionals that other members of the MDT appreciate their contributions to provision of information about recovery (Information about others' approval)</p> <p>Present communication by someone senior with each profession about the importance of talking about recovery as part of their professional role (Credible source)</p> <p>Inform the professional that if they provide information about recovery, this will set a good example to other members of their discipline (Identification of self as role model)</p> |
| | Beliefs about capabilities | Professionals feel confident in their ability to share information about recovery with patients and families | Professionals (particularly junior staff) report a lack of confidence in sharing information about recovery with patients and families, which may lead them to avoid providing information or providing vague information | Persuasion, enablement | <p>Tell the professional they have the skills and experience to successfully share information about recovery with patients and families (Verbal persuasion about capability)</p> <p>Encourage professionals to think about times they have successfully shared information with patients and families and information was well-received (Focus on past success)</p> <p>Advise professionals to imagine discussing recovery with patients and families and the information being well-received (Mental rehearsal of successful performance)</p> <p>Encourage professionals to provide support and encourage their colleagues when they have had discussions with patients and families about recovery (Social support (unspecified))</p> |
| | Optimism | N/A | N/A | N/A | N/A |
| | Beliefs about consequences | Professionals believe that providing information about recovery provides benefits to patients and families and unaware of the risks | Some professionals are unaware of the benefits of providing recovery information to patients and families (e.g., making future plans or adjusting to life post-stroke), and risks to not | Education, Persuasion | <p>Provide information on patients' and carers' information needs about recovery from established literature (Information about social and environmental consequences)</p> <p>Present a speech by an expert (researcher or professional) outlining the known benefits and risks to providing information about recovery (Credible source)</p> |

| | | | | | |
|--|--|---|--|--|--|
| | | to not providing such information | providing information, (e.g., limiting ability to plan, preventing adjustment) | | <p>Present a speech by an expert (stroke survivor or carer) outlining the known benefits and risks to providing information about recovery (Credible source)</p> <p>Provide information about the emotional consequences for patients and carers if information about recovery is not provided effectively (Information about emotional consequences)</p> <p>Ask professionals to try providing information about recovery (after structured training and as part of supervised practice) and to note patients' and families' reactions (Behavioural experiments)</p> <p>Encourage audit of patient and family feedback about the benefits and disadvantages of providing information about recovery (Feedback on outcome(s) of behaviour)</p> <p>Encourage professionals to ask patients and families about the benefits of receiving information about recovery and the problems with not receiving such information (Self-monitoring of outcome(s) of behaviour)</p> |
| | | Professionals do not believe conveying predictions about recovery will have longer-term negative consequences, e.g., if predictions they make do not come to pass | Some professionals believe there are negative consequences to providing certain information about recovery, due to the uncertainty of stroke recovery and the impact if these later transpire to be false (negative emotional reactions from patients and families, possibility of complaints) | Education, Persuasion, Modelling | <p>Explain the benefits of providing information about recovery to patients and families, e.g., to support adjustment, enable planning, but steps should be taken to ascertain how much/ the type of information they want to receive and to convey uncertainty (Information about social and environmental consequences)</p> <p>Demonstrate how to convey uncertainty when providing information about recovery and how to manage patients' and families' emotional responses when they occur (Demonstration of the behaviour)</p> <p>Present a speech by an expert (stroke survivor or carer) outlining the benefits of providing information about recovery, even where it might be uncertain (Credible source)</p> <p>Advise the professional to list and compare the advantages and disadvantages of providing information about recovery (Pros and cons)</p> |
| | | Professionals do not believe that providing information about recovery may have immediate negative consequences, e.g., reducing patient | Some professionals believe there are negative consequences to discussing recovery with patients and families when the outlook is suboptimal and there is potential | Education, Persuasion, Modelling, Enablement | <p>Explain the benefits of providing information to patients if provided sensitively and compassionately, e.g., to support adjustment, enable planning (Information about social and environmental consequences)</p> <p>Demonstrate how to provide information about recovery in positive ways, to foster hope and motivation (Demonstration of the behaviour)</p> |

| | | | | | |
|-----------------------------|---------------|---|---|------------------------|---|
| | | motivation and impacting mood | for long-term disability, and the potential impact this may have on patients' mood and subsequent motivation to engage with therapy | | Present a speech by an expert (stroke survivor or carer) outlining the benefits of providing information about recovery, even where it may involve 'bad news' (Credible source) Advise the professional to list and compare the advantages and disadvantages of providing information about recovery (Pros and cons) |
| | Intentions | N/A | N/A | N/A | N/A |
| | Goals | N/A | N/A | N/A | N/A |
| <i>Automatic motivation</i> | Reinforcement | N/A | N/A | N/A | N/A |
| | Emotion | Professionals do not feel anxious about conversations about recovery before they occur | Some professionals feel anxious about approaching conversations about recovery, particularly when breaking bad news, which may lead them to avoid providing information or providing information about a patient's outcome that is more positive than they anticipate | Persuasion, Enablement | Advise on the use of stress management skills to reduce anxiety when approaching conversations about recovery which are perceived to be challenging (Reduce negative emotions) Arrange emotional support from within the MDT or from service managers to support professionals prior to difficult conversations (Social support (emotional)) Advise professionals to share responsibility/ approach difficult conversations alongside colleagues where possible/ appropriate (Conserve mental resources) |
| | | Professionals feel able to manage their own distress following difficult conversations about recovery | Professionals may feel distressed following provision of information about recovery, sometimes due to patient and family responses to the information | Persuasion, Enablement | Normalise the negative emotions experienced by professionals following difficult conversations (Information about emotional consequences) Advise on the use of stress management skills to reduce anxiety (Reduce negative emotions) Arrange emotional support from within the MDT or service managers to support professionals (Social support (emotional)) |

8.5 Discussion

This is the first study to apply the COM-B model to understand the barriers to providing information about post-stroke recovery and identify potential strategies to address them. The model has provided a theoretical grounding to intervention development, guiding the selection of intervention functions and potential BCTs through which behaviour change could be achieved. The next stage in intervention development was to consult stakeholders, to help identify the most appropriate BCTs to include, based on their views of acceptability and feasibility.

A strength of using the BCW to underpin development of this intervention is in the provision of a comprehensive, clear, and systematic process. In line with the MRC framework (205), it focuses on developing a theoretical understanding of how the specific components of an intervention are proposed to act to change the behaviour of the target population, with clear links between intervention functions and BCTs (276). Another benefit of the BCW process is that it incorporates the context in which the intervention will be delivered within the *Opportunity* component (262). This is in line with the MRC's intervention development framework, which highlights consideration of context (205). This study incorporated qualitative data previously collected in the stroke unit context, to develop an understanding of the potential barriers to providing information about recovery, and how they might be addressed. However, stroke units vary widely in their physical environments, management, and processes, such that some barriers might be vastly important in some units, but not in others. For example, in some units, where private spaces are available and used, addressing barriers related to *Physical Opportunity* might have little impact. The MRC framework highlights the potential for interventions to be effective in some contexts and ineffective, or even harmful in others, accentuating the importance of flexibility (205). It is likely therefore that the final intervention will consist of core components and permit the flexibility for others to be delivered where needed in different contexts.

A criticism of the BCW lies in its reliance on the subjectivity of intervention developers, who are required to use their judgement to select the most appropriate policy categories, intervention functions and modes of delivery (277). Although the authors provide the APEASE criteria as guidance, their application still requires a level of personal judgement, which has the potential to introduce bias. However, Michie et al. argue that this permits intervention developers to make the most appropriate decisions for the context in which individual interventions will be delivered (206), and others have made suggestions about how transparency can be improved through the reporting of these decisions (269). In this study, decisions were subject to discussion with my

supervisors and research colleagues with experience in using the BCW and the range of options available at each stage have been reported, alongside reasoning about the decisions made to increase transparency. Final recommendations about barriers to target in an intervention and BCTs to address these barriers were made following additional consultation with stakeholders, to limit the reliance on my own decision-making (see Chapter 9).

Although the BCW is helpful in identifying strategies that are likely to be effective to target behaviour within interventions, it is important to note that there is currently no evidence to suggest interventions developed using the BCW framework are more effective than those which are not. Further evaluation, beginning with pilot and feasibility testing of intervention components, in line with the MRC framework (205), will be necessary to understand whether the selected BCTs function as expected.

Finally, the initial stages of the process informed by the BCW involved developing an understanding of the behaviour requiring change. In this study, it was decided that professionals' behaviour would be targeted by the intervention, a decision which then informed subsequent development. Should different decisions have been made, e.g., focusing on the behaviour of patients and/ or carers, or all three groups, the intervention function and BCTs are likely to have been different. Additionally, the aim of the intervention was focused on changing professionals' behaviour, rather than driving change at the organisational level. It may be that organisational change would be required to facilitate a cultural shift to a mode of working where information is readily shared and available for patients and families, such that they feel empowered to request it.

Chapter 9 Survey study to establish healthcare professionals' views of potential behaviour change techniques

9.1 Background and rationale

In the previous chapter, I began development of a new intervention designed to improve provision of information about recovery by stroke unit professionals to patients and carers. Informed by qualitative findings from Section 2, I used the Behaviour Change Wheel (BCW) (262) to conduct a behavioural diagnosis of the problem, then to identify intervention functions and Behaviour Change Techniques (BCTs), which may result in the required behaviour change. In this chapter, I detail consultation with stakeholders, through an online survey study of UK-based stroke unit professionals, to further inform intervention development.

9.1.1 Aims and objectives

This study aimed to seek the views of stroke unit professionals to inform the development of a professional-focused intervention to improve conversations about post-stroke recovery. Its objectives were to:

- Establish the external validity of the barriers identified in previous qualitative work amongst a wider population of UK-based stroke professionals;
- Identify which barriers professionals felt were most important to address in an intervention;
- Ascertain professionals' perceptions of the usefulness and clinical feasibility of the BCTs identified to address these barriers;
- Identify any alternative strategies, which professionals felt may be effective in changing their behaviour or that of their peers.

9.2 Methods

9.2.1 Research design

As an objective of this study was to understand the views of stroke unit professionals across the UK, a questionnaire-based survey approach was selected. This approach permits simple and efficient sampling of the views of a larger number of participants than do qualitative interviews or focus groups, and may encourage greater honesty from participants, who may be afraid to express their true views when face-to-face with a researcher (278). The survey was delivered online, as online surveys are quicker to

conduct, cheaper and more environmentally-friendly than paper-based approaches, eliminating costs associated with printing and distribution (279). In this case, an online survey was felt particularly appropriate to extend the geographical reach of the survey across the UK.

9.2.2 Ethical considerations

Ethical approval was gained from The University of Leeds School of Medicine Research Ethics Committee (ref: MREC 21-013; see Appendix K) in February 2022. The approved participant information sheet is available in Appendix L.

9.2.2.1 Informed consent and withdrawal of data

Study information was presented on the survey website, with a downloadable copy of the participant information sheet. Consent was taken online, with participants asked to indicate that they had read this information and their agreement to participate. For data to be gathered, the participant was required to complete the survey and submit their responses, therefore withdrawal prior to this point was possible without any data having been collected. Following submission, participants were presented with a completion receipt containing a unique, randomly generated code, and advised that they may withdraw their data anonymously within 14 days by contacting the researcher and quoting this number.

9.2.2.2 Confidentiality

Participant confidentiality was maintained throughout the conduct of the study. Direct identifiers, including participants' names, addresses and dates of birth, were not collected as they were not required (participants were not subsequently contacted). Participants were assured that their responses would remain confidential and asked not to reveal any personal information from which they could be identified. Should any respondent reveal personal information, this was removed prior to analysis.

Data were collected using the platform Online Surveys (www.onlinesurveys.ac.uk), which is GDPR-compliant and is The University of Leeds' recommended platform for survey research. Participants were assured that no attempts were made to collect any data, e.g., IP addresses, which they did not voluntarily provide.

9.2.3 Recruitment and sampling

9.2.3.1 Participant inclusion criteria

Inclusion criteria were broad, with participants self-identifying as a qualified healthcare professional of any discipline (including, but not limited to, doctors, nurses, physiotherapists (PTs), occupational therapists (OTs) and speech and language therapists (SLTs)) currently working in a UK stroke unit. As the survey aimed to inform development of an intervention for in-patient stroke professionals in the UK, participants were excluded if they worked in community or non-stroke settings or in countries outside of the UK, where alternative training may be provided or stroke care organised in different ways, such that the feasibility of the proposed BCTs might be variable.

9.2.3.2 Recruitment

The recruitment strategy for this study aimed to reach as many potential participants from across the UK as possible, in freely available ways (due to budget constraints). This primarily involved distribution of the study invitation and link to the survey webpage (including participant information sheet) via social media and professional bodies of which potential participants were likely to be members.

The survey was primarily advertised using Twitter, which permitted presentation of a 280-character study invitation highlighting the nature of the research, the intended audience, and a request to share with others who may be interested alongside the survey link. Hashtags such as 'stroke' and 'research' were used to enable those interested in these subjects to locate the invitation, and high-profile individuals or organisations whose followers included members of the target audience were targeted with sharing requests. A Twitter advert to accompany each post (Figure 9.1) was designed to be colourful and eye-catching. I regularly posted study invitations from my personal Twitter account (unused prior to the study) throughout the recruitment period. Additionally, a study invitation was placed on the Stroke Network online forum of the FutureNHS Collaboration platform, which supports an online community of health and social care staff to share information about practice and resources (<https://www.england.nhs.uk/futurenhs-platform>).

Each of the core professions providing input into stroke units has at least one professional body, which supports their members through education and training, and promotes evidence-based practice and research. Such organisations maintain regular contact with their thousands of members and are ideally placed to circulate

advertisements for research participants. Professional bodies were identified through online searching and assistance was requested to distribute the study invitation to their members. Specialist sections of these organisations or specific organisations relating to the area of stroke/ neurology were targeted, to ensure those most likely to be eligible were reached. Of the six bodies identified and contacted, most agreed to provide support, either through their regular newsletter communications with members or social media (Table 9.1).

Finally, participants from the qualitative study (Section 2), who had agreed to be contacted about new research were also e-mailed a study invitation, including a request to share this information with others, whom they felt may be interested in taking part.

Participants were recruited at the point when they submitted their survey responses.

We're looking for healthcare professionals working in **stroke care** to complete a brief survey to help improve conversations about recovery after stroke!

For more information or to take part, please contact louisa.burton@bthft.nhs.uk or visit: https://leeds.onlinesurveys.ac.uk/talking_about_recovery_after_stroke

volunteers needed!

Study title: Developing strategies to improving talking about recovery on the stroke unit v2.0
28/11/21. Ethical approval received from University of Leeds, ref number: MREC 21-013

UNIVERSITY OF LEEDS

Figure 9.1 Twitter advertisement

Table 9.1 Distribution of survey link by professional bodies

| Body approached | Action taken |
|--|--|
| Association of Chartered Physiotherapists in Neurology | Offer to distribute study invitation to members for a cost – did not proceed |
| British Association of Stroke Physicians | No response received |
| National Stroke Nursing Forum | Inclusion of study invitation in regular newsletter to members |
| Organisation for Psychological Research into Stroke | Inclusion of study invitation in regular newsletter to members |
| Royal College of Occupational Therapists | Support for Twitter advertising (likes/retweets) Inclusion of study invitation in regular newsletter to members of the Neurological Practice specialist section |
| Royal College of Speech & Language Therapists | Inclusion of study invitation in regular newsletter to members Inclusion of study invitation in Clinical Excellence Network correspondence |

9.2.3.3 Sampling strategy

Survey research frequently attempts to use probability sampling, either making attempts to sample an entire population or a representative subset of this population (280). Representative sampling can however be a challenge for online survey research, with researchers lacking control over who views, and responds to, the survey advert, potentially leading to concerns around sample validity (281). Generating a representative sample was not essential in this study, which aimed to gather a snapshot of views from UK-based stroke professionals and develop some understanding about the reasons why identified BCTs might be useful and/ or feasible. Non-probability, convenience sampling was therefore employed. A snowball sampling strategy was also used; I requested 'retweets' on Twitter (from organisations or individuals) within the text of each post and asked individuals who had previously expressed an interest in the research to share the study link with their colleagues. Such strategies can serve to increase the number of potentially eligible participants, who view the advert and engage with the research (282).

9.2.3.4 Sample size

The recruitment target was a minimum of 30 participants, but no upper limit to the number of respondents was in place. This was thought to be sufficient to gather a snapshot of views from professionals working in stroke units.

9.2.4 Development of the survey instrument

Surveys may include the collection of quantitative data, qualitative data or both; what is common to them is the standardised collection of the same set of data from each participant (79). Whilst closed questions permit the generation of quantitative data, which can be quick to code and subject to numerical comparison, open questions can provide detailed qualitative data to help interpret such responses (283). To address the study objectives, a mixed-methods approach was employed, using both rating scales (for professionals to rate the importance of barriers to recovery conversations, and the usefulness and feasibility of proposed BCTs) and open questions (to provide more detail on their responses and suggest any additional strategies they felt may be useful/feasible).

The questionnaire was based upon the barriers to provision of information about recovery identified in the previous chapter, with a focus on rating the importance of each barrier and the perceived usefulness and feasibility of the identified BCTs to address it. Likert scales were selected for participants to rate their perceptions quickly and easily, with optional open questions for them to elaborate on their responses. Demographic details (see below) were collected only to characterise the sample, as the intended sample size was not likely to be large enough to draw comparisons between the views of subsets of participants. The questionnaire was constructed using the OnlineSurveys platform.

I initially constructed a draft version of the questionnaire, which was subsequently reviewed by members of the research team. All attempts were made to keep the questionnaire as brief as possible, to encourage participation and reduce participant burden. As such, where overlap between two barriers was identified (e.g., they addressed a similar issue) and similar BCTs were suggested to address them, they were consolidated into a single barrier. This resulted in a reduction of three barriers, with consolidation of barriers relating to professionals' emotions, negative beliefs about consequences and understanding of professional roles. Additionally, all attempts were made to ensure the language used was easy to understand and questions were not leading or double-barrelled.

The questionnaire was subsequently piloted with a sample of seven researchers with previous professional stroke unit experience, who thus represented the target audience but were not currently eligible to be study participants. Those involved in this pilot completed the questionnaire online alongside a form, asking them to comment on: ease of navigation; understanding of the language used; clarity of the instructions;

question order; and survey length. Their feedback was subsequently used to refine the questionnaire prior to the study opening; changes included re-ordering some of the questions and minor clarifications to language used.

The final questionnaire comprised an initial page introducing the project (Appendix M), including the research team contact details, a link to the downloadable participant information sheet and information about ethical approval, followed by a consent form and multiple-choice demographic questions (age group, gender, profession, and time working in stroke care). The main body of the questionnaire was introduced with a statement of the research aims and a definition of the meaning of 'information about recovery' as used in the survey (covering both general information and individual predictions).

Each subsequent page (12 in total) was organised as follows (see Appendix N for a sample page):

- A statement of an identified barrier and a question about how important the respondent felt it would be to address this barrier in an intervention (5-point Likert scale: not at all/ slightly/ moderately/ very/ extremely important);
- A list of potential strategies (BCTs) to address the barrier with a question about how feasible the respondent felt the strategies would be (4-point Likert scale: very unlikely/ unlikely/ likely/ very likely to be feasible);
- A list of potential strategies to address the barrier with a question about how useful the respondent felt the strategies would be (4-point Likert scale: very unlikely/ unlikely/ likely/ very likely to be useful);
- An open question with free text space regarding the participants' views of whether the specific strategies would be feasible/ unfeasible, useful/ not useful;
- An open question with free text space requesting the participant to identify potential additional strategies to address the barrier.

9.2.5 Data analysis

Responses to forced-choice questions were coded in SPSS Statistics (v27) and analysed descriptively. Median participant ratings of the importance of each barrier were calculated, as was the percentage of participants who rated each barrier as either very or extremely important to address in an intervention. These barriers were then ranked in their order of their perceived importance. Subsequently, the percentage of participants who rated each BCT as likely to be useful or very useful, and feasible or very feasible was calculated. The BCTs suggested to address the most important

barriers were then ranked in terms of their usefulness; those perceived as most useful were then ranked according to their perceived feasibility.

Qualitative data gathered from free text responses were subjected to directed content analysis (284). Responses were imported into Microsoft Excel. The author initially read through all the comments related to each question, then coded them according to the study objectives (i.e., whether they related to the importance of addressing a barrier; perceived usefulness of a suggested BCT; perceived feasibility of a suggested BCT; or an alternative strategy to address the barrier). Descriptive summaries of participants' responses were then developed.

9.3 Results

The study was open for a period of four months (15th February-15th June 2022). During this time, 48 participants were recruited and completed the online survey.

9.3.1 Participant demographics

The study sample included a range of professionals from across the multidisciplinary team (MDT), including PTs (n=16; 33%), SLTs (n=13; 27%), OTs (n=5; 10%) and nurses (n=5; 10%; see Figure 9.2). Smaller numbers of participants came from other disciplines, including doctors (n=2;4%), clinical psychologists (n=2; 4%), orthoptists (n=2; 4%) and dietitians (n=2; 4%). One participant described their role as a patient mentor.

Most respondents were female (n=43; 90%) and over 30 years old (n=43; 90%; see Figure 9.3). Most (n=31; 65%) had worked in stroke care for more than ten years, whilst 29% had between one- and ten-years' experience (n=14; see Figure 9.4). A minority had less than one year of stroke experience (n=3; 6%).

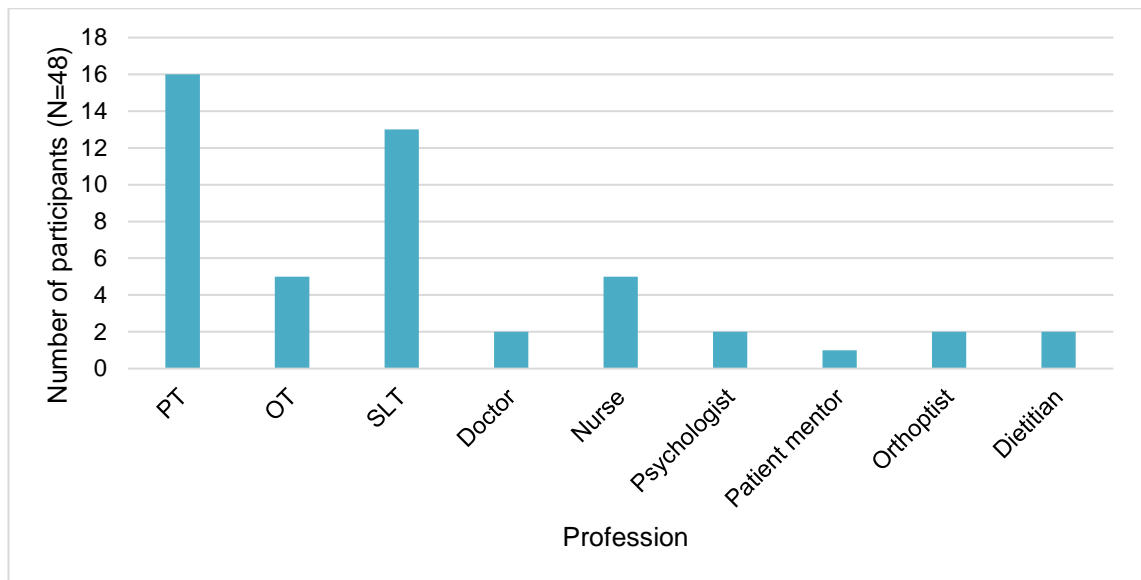


Figure 9.2 Professional background of study participants

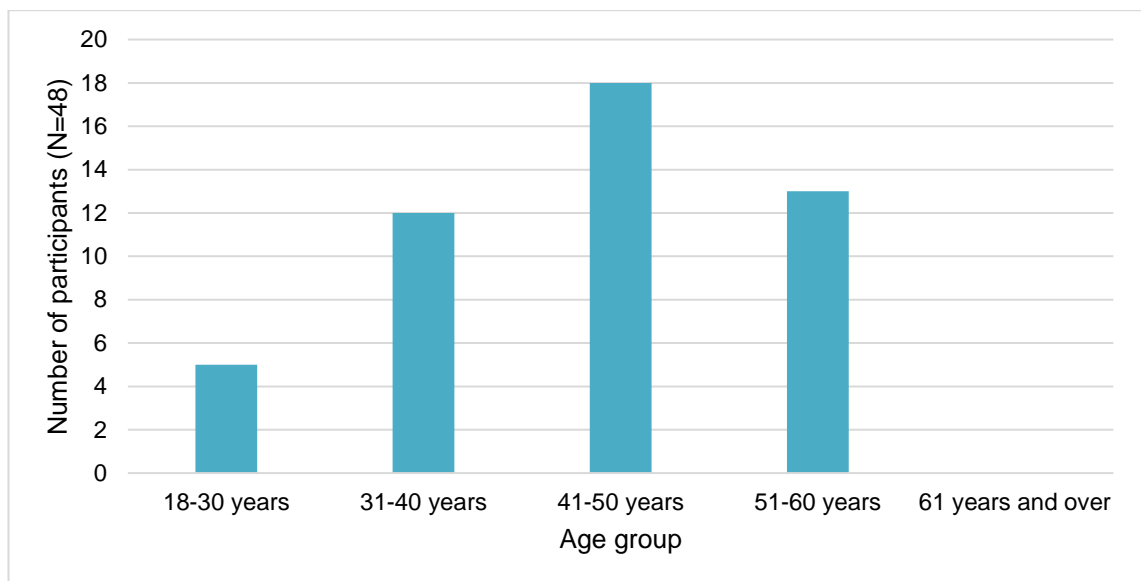


Figure 9.3 Age group of study participants

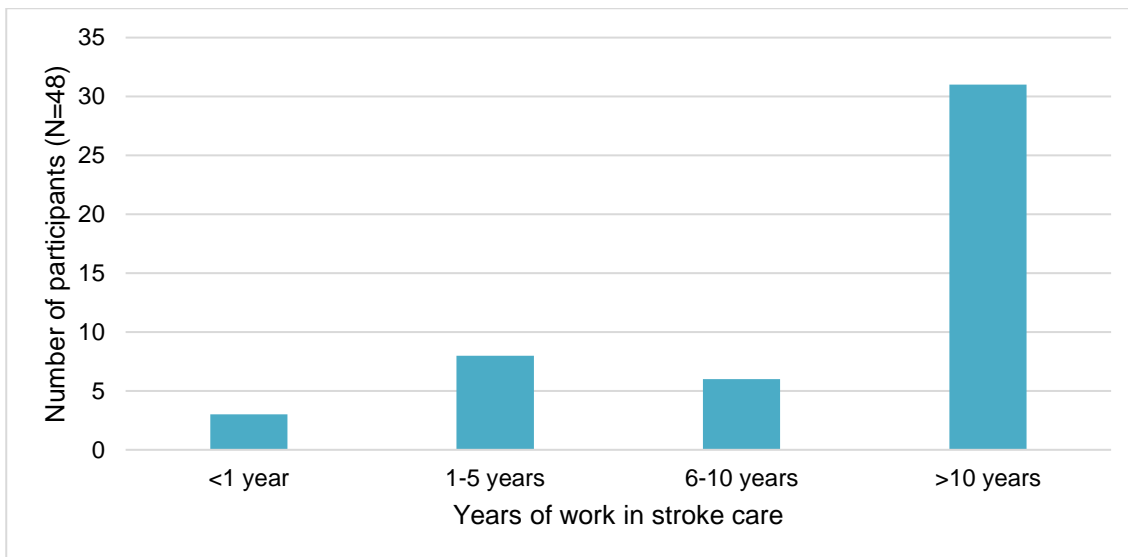


Figure 9.4 Number of years worked in stroke care by study participants

9.3.2 Importance of addressing identified barriers in an intervention

The median importance rating for all barriers ranged from 4 (very important) to 5 (extremely important), suggesting that they were felt important to address in an intervention by the professionals who took part and thus establishing their validity outside of those initially sampled in my earlier qualitative work. All identified barriers were rated as very or extremely important to address by a minimum of 70% of participants (range=70-94%; see Figure 9.5 and Table 9.2). The barrier rated by the least participants as very or extremely important to address was an inability to predict recovery (70%), suggesting that professionals may be less concerned about this issue.

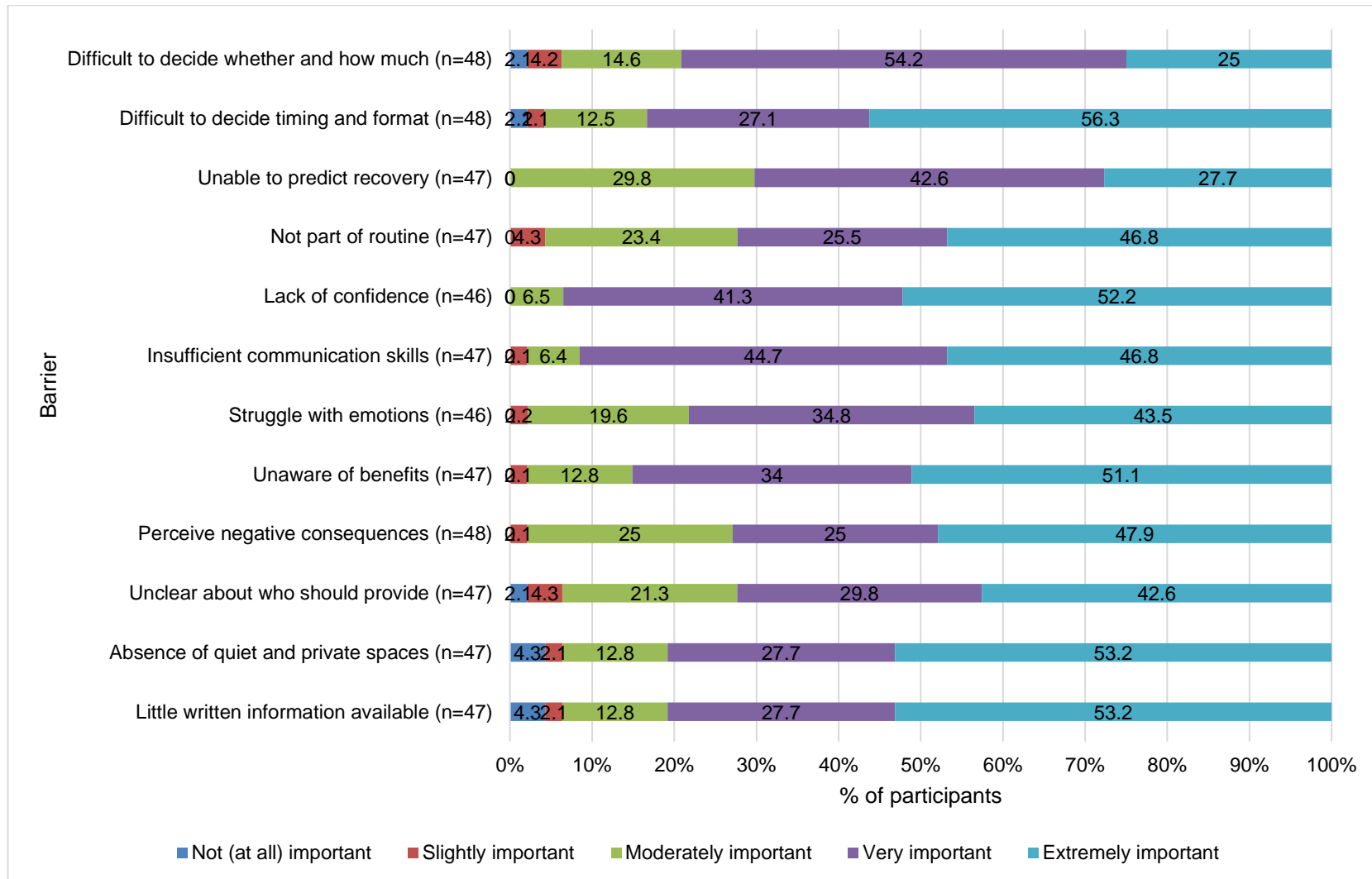


Figure 9.5 Importance of identified barriers to study participants

Table 9.2 Percentage of participants rating each barrier as very or extremely important; and percentage of participants who rated each proposed Behaviour Change Technique as likely to be feasible or very feasible, and likely to be useful or very useful¹

| Barrier | % rating barrier as very or extremely important to address (n=48) | Behaviour Change Techniques aiming to address barrier | % rating BCT as likely or very likely to be useful (n=48) | % rating BCT as likely or very likely to be feasible (n=48) |
|---|---|--|---|---|
| Some professionals find it difficult to assess whether and how much information patients and families want to know about recovery | 79% | Receive advice on how to ask patients and carers about whether and how much information about recovery they wish to receive | 81% | 92% |
| | | See someone demonstrate how to ask patients and carers about whether and how much information about recovery they wish to receive | 92% | 98% |
| | | Practice asking how, whether and how much information is wanted through role play with peers | 79% | 73% |
| | | Receive feedback following observation of practice conversations with peers | 88% | 81% |
| Some professionals find it difficult to decide when and in what format to provide information about recovery to meet individual patients' needs, e.g., where patients have cognitive or communication problems. | 83% | Receive advice on how to decide when and in what format to provide information to individual patients/families | 81% | 96% |
| | | See someone demonstrate examples of conversations occurring in different ways (e.g., at different times, supported by written documentation or not) with patients with different needs | 96% | 94% |
| | | Practice making decisions about when and in what format to provide information to individual patients/families using vignettes | 92% | 88% |
| | | Receive feedback following discussions based on vignettes | 92% | 88% |
| | | Receive advice on requesting support from colleagues across the MDT when choosing the timing and format for providing information | 92% | 92% |
| Some professionals describe feeling unable to predict recovery | 70%* | Receive information on (evidence-based) factors to consider, which may impact recovery after stroke | 88% | 94% |
| Some professionals do not routinely provide information about recovery to all patients, potentially resulting in inequity | 72%* | Develop a unit-specific plan to provide information about recovery, e.g., at specific time-points/ in specific contexts | 90% | 88% |
| | | Agree on a goal of having a conversation about recovery with all patients/ families at certain timepoints in their admission, e.g., every two weeks, then audit the extent to which this goal has been achieved and consider modification if needed. | 83% | 81% |
| | | Use physical reminders (e.g., in patients' records) or verbal prompts (e.g., at MDT meetings) to alert professionals at the time when a conversation about recovery is due | 85% | 79% |
| | | Establish a single shared record for the team to monitor whether information has been provided and record the outcome of conversations | 90% | 94% |

¹ MDT=Multidisciplinary Team; *n=47; **n=46

| | | | | |
|--|-------|---|------|-----|
| | | Identify barriers when conversations about recovery have not taken place and discuss ways to overcome them as a team | 94% | 92% |
| Some professionals report a lack of confidence in sharing information about recovery with patients and families, which may lead them to avoid providing information or providing vague information | 94%** | Be reminded that you have the skills and experience to successfully share information about recovery with patients and families | 75% | 90% |
| | | Be encouraged to think about times you have successfully shared information with patients and families and information was well-received | 88% | 96% |
| | | Imagine discussing recovery with patients and families and the information being well-received | 60% | 73% |
| | | Be encouraged to provide support and encourage your colleagues when they have had discussions with patients and families about recovery | 96% | 96% |
| Some stroke professionals perceive that they do not have the required communication skills to deliver information about recovery, particularly where this involves breaking bad news | 92%* | Be provided with instructions about how to discuss recovery sensitively and compassionately | 83% | 88% |
| | | See someone demonstrate how to deliver information about recovery sensitively and compassionately | 98% | 96% |
| | | Practice conversations about recovery through role play with peers | 85% | 83% |
| | | Receive feedback following observation of practice conversations with peers | 92% | 88% |
| Some professionals may struggle with their emotions when talking about recovery, e.g., feeling anxious when preparing to discuss recovery, or experiencing distress following such conversations (e.g., due to patient/family responses) | 78%** | Receive advice that it is not unusual to experience negative emotions following difficult conversations | 90% | 98% |
| | | Receive advice on the use of stress management skills to reduce anxiety | 92% | 96% |
| | | Access emotional support from within the MDT or service managers following provision of recovery information | 94% | 79% |
| | | Share responsibility/ approach difficult conversations alongside other MDT members where possible/ appropriate | 98% | 94% |
| Some professionals are unaware of the benefits of providing recovery information to patients and families (e.g., making future plans or adjusting to life post-stroke), and the risks of not providing information (e.g., limiting ability to plan, preventing adjustment) | 85%* | Receive information on patients' and carers' information needs about recovery from established literature | 94% | 96% |
| | | Watch a speech by a researcher or professional outlining the known benefits and risks to providing information about recovery | 81% | 83% |
| | | Watch a speech by a stroke survivor or carer outlining the known benefits and risks to providing information about recovery | 100% | 94% |
| | | Receive information about the emotional consequences for patients and carers if information about recovery is not provided effectively | 98% | 98% |
| | | Be encouraged to try providing information about recovery (after structured training and as part of supervised practice) and to note patients' and families' reactions | 94% | 98% |
| | | Complete an audit of patient and family feedback about the benefits and disadvantages of providing information about recovery | 73% | 69% |
| | | Be encouraged to ask patients and families about the benefits of receiving information about recovery and the problems with not receiving such information | 92% | 81% |
| Some professionals perceive that there are negative consequences of providing | 73% | Receive information about the benefits of providing information about recovery to patients and families including where this includes uncertain or negative information | 88% | 96% |

| | | | | |
|--|------|---|-----|-----|
| information about recovery, e.g., due to the impact of uncertain predictions later proving incorrect, or predictions about a negative outcome impacting patient mood/ motivation | | See someone demonstrate how to convey uncertainty and foster hope and motivation when providing information about recovery | 98% | 92% |
| | | Watch a presentation by a stroke survivor/ family member outlining the benefits of providing information, even when it may be negative or uncertain | 98% | 98% |
| | | Make a list and compare the advantages and disadvantages of providing information about recovery | 71% | 85% |
| There are no standard guidelines about who should provide information about recovery, when and why. As a result, some professionals are unclear about who should provide this information. | 72%* | Be provided with examples of the roles and responsibilities of each professional and of the team in providing information about recovery | 85% | 92% |
| Professionals may lack opportunities to provide information about recovery due to the absence of appropriate private and quiet spaces to speak with patients/ families | 81%* | Receive advice on the importance of providing information about recovery in a private and quiet area, and how to prevent interruptions | 75% | 85% |
| | | Allocate designated areas as quiet and private areas to discuss recovery | 83% | 52% |
| Little written information about recovery is available for professionals to support conversations, particularly for patients/ families with cognitive or communication problems | 81%* | Be provided with, or receive support to identify, generic written information to give to patients/ families | 90% | 96% |
| | | Make written information readily available in a specific location to access when required | 94% | 94% |

9.3.3 Feasibility and usefulness of BCTs to address the most important barriers

Overall, participants were positive about most strategies proposed to address the identified barriers, with each individual BCT rated as either useful or very useful by a mean of 88% of participants (range=60-100%), and feasible or very feasible by 89% (range=52-98%; Table 9.2).

An exploratory approach was undertaken to select the BCTs most likely to be useful and feasible to incorporate into a final intervention. Firstly, to ensure the barriers participants believed were most important were addressed, the barriers were ranked according to the percentage of participants who rated them as very/ extremely important to address in an intervention (highest to lowest). The aim was to identify the five most important, however there was a tie between those ranked fifth and sixth, therefore both were included. These concerned a perceived:

- Lack of confidence (94%);
- Insufficient communication skills (92%);
- Lack of knowledge of the benefits (85%);
- Difficulties in deciding when and in what format to provide information (83%);
- Absence of private and quiet spaces for discussions (81%);
- Lack of generic written information to support conversations (81%).

Secondly, the BCTs selected to address each of these barriers were compiled, forming a list of 24. These BCTs were then ranked according to the percentage of participants who rated them as likely to be useful or very useful, to reveal the twenty highest ranking BCTs perceived to be most useful to address the selected barriers. The remaining BCTs were again ranked, this time according to the percentage of participants rating them as likely or very likely to be feasible within an intervention. Those rated as least likely to be feasible were removed, with the remaining twelve suggested for inclusion within the final intervention.

The selected BCTs are presented alongside relevant intervention functions and the Capability Opportunity Motivation model of Behaviour (COM-B) (206) components they are intended to address in Table 9.3 and discussed further below, alongside participants' comments. These BCTs related to the intervention functions of training, enablement, persuasion, and environmental restructuring. They encompassed techniques that could be used to enhance the skills and increase the confidence of stroke unit professionals when providing recovery information, strategies to persuade them of the benefits, and approaches to adapt the physical environment to facilitate information provision.

9.3.3.1 Improving skills

Psychological capability was identified as one area of the COM-B where important barriers required addressing. Within this component, participants rated barriers relating to perceptions of insufficient communication skills and difficulties in making decisions about when and in what format to provide information as important to address within an intervention. The areas of the Theoretical Domains Framework (273) in which these barriers fall are cognitive and interpersonal skills and memory, attention, and decision processes; these are associated with the intervention functions of training and enablement. Nine BCTs were suggested to address these two barriers, with four selected by survey participants as feasible and useful. These included watching demonstrations of how to deliver information sensitively and compassionately, and in different ways to meet individual patients' needs, as well as receiving advice on how to make decisions about when and in what format to provide information, including requesting support from the MDT. The BCTs not selected (due to perceived insufficient feasibility) related to practicing making decisions and communicating information through role play and vignettes and receiving feedback, as well as receiving instruction about how to discuss recovery with sensitivity and compassion.

In general, participants expressed that training to improve their communication skills would be welcomed, particularly for developing their skills in breaking bad news, although some felt that clinical experience was required to refine these skills. They were supportive of watching demonstrations of conversations from which to learn, though some expressed concerns about the use of strategies such as role play, which they felt could be deter potential intervention participants from taking part, due to a lack of confidence. Others however felt they represented a useful way to support active learning. As such, although practice of newly acquired skills through role-play did not meet the cut-offs for feasibility in this study, it may be useful to consider them further in intervention development and consider how a safe environment for such practice might be provided.

“Best learning I’ve had is observing more experienced clinicians deliver bad news.” PT, 6-10 years’ experience

“Role play is not popular as staff feel self-conscious.” PT, 6-10 years’ experience

In terms of making decisions about the timing and format of information, participants discussed the importance of individualising information provision according to each individual patients' needs; they felt training could be beneficial in helping them to do this. Some discussed how receiving advice and support from their colleagues was crucial in their decision-making, particularly from SLTs when patients had

communication difficulties. However, blanket advice about the timing of information provision was felt to be challenging, with meeting patients' individual information needs at the right time seen as important.

"Time-frame should be patient-specific due to the rate/ extent of their recovery." PT, >10 years' experience

9.3.3.2 Improving confidence

It appeared that a lack of confidence in providing information resonated highly with the survey respondents. In their comments, participants suggested that understanding the reasons for a lack of confidence would be important in addressing this barrier; in line with findings from my qualitative study (see 5.2.3), some suggested that a lack of confidence was underpinned by worries about eroding patient motivation or making incorrect predictions about individual recovery. Participants comments suggested that confidence in sharing information about recovery was underpinned by a combination of professionals' knowledge, e.g., confidence in the accuracy of the information they were providing, and skills, enabling them to provide such information sensitively. In terms of knowledge, they referred to both the knowledge to predict patient outcomes and a more general understanding of stroke, including both the changes to the brain, which underly a patient's deficits, and the way that they deficits might recover over time and with therapy. A third factor felt to underpin confidence was practical experience, and a fourth was support from colleagues.

"There needs to be a more concrete way to improve confidence, and that starts with determining why a professional has decreased confidence in this area. For example, a person may have decreased confidence due to a lack of knowledge in this area [...]. In this case, encouragement may not impact confidence and [...] provision of education would be more beneficial than encouragement and positive recollections." OT, 1-5 years' experience

"Support from colleagues and experience will enable an individual to build their confidence alongside practical experience of sharing information." SLT, < 10 years' experience

Four BCTs specifically designed to address the barrier of staff confidence in talking about recovery were included within the survey. The suggested intervention functions to address this problem (related to reflective motivation within the COM-B model) were through persuading staff that they are already capable of providing information about recovery effectively or through provision of social support from the MDT. Only two of the suggested BCTs were however rated as useful and feasible by survey participants. BCTs relating to mental rehearsal and verbal persuasion about capability were deemed to be feasible, but not useful in addressing this barrier, whilst focusing on past success and receiving support and encouragement from the MDT were rated highly for both

aspects. This fits with participants' comments, addressing the issues about support from colleagues and the need for experience to facilitate confidence. However, a range of BCTs selected for inclusion, which were designed to address other barriers, are also likely to address staff confidence. For example, if it is the case that possessing improved skills increases confidence, the BCTs outlined in 9.3.3.1 should also prove effective. In terms of knowledge, one BCT was proposed to address staff understanding of the factors that could impact recovery, however the barrier which it aimed to address (lack of knowledge to make predictions about recovery) was endorsed by only 70% of the survey sample. It may therefore be the case that professionals feel that knowledge about stroke and recovery more generally should already be possessed by staff or should not be addressed within this specific intervention.

9.3.3.3 Being persuaded of the benefits

The COM-B model suggests that barriers relating to beliefs about consequences (e.g., a lack of knowledge about the benefits of providing information) are representative of reflective motivation and can be addressed using the intervention functions of education and persuasion. Seven BCTs were proposed to survey participants, with four selected as likely to be useful and feasible; three involved learning about the (emotional) consequences of (not) providing information, both directly from stroke survivors and through presentation of evidence-based literature. The fourth involved behavioural experiments, in which intervention recipients would try providing information and note patients' and families' reactions. Gathering such feedback through audit was felt to be neither useful nor feasible and being encouraged to ask patients and families about benefits was felt useful, but less feasible, as was watching a speech from a researcher or clinician.

Participants' comments suggested that these strategies would have benefits for staff at all levels, with particular support for hearing stroke survivors'/ carers' voices, which participants felt would be particularly powerful in persuading them of the benefits of providing information about recovery. One PT suggested an additional strategy of persuading staff of the benefits by asking them to empathise with the patients' situation; this would be classified as the BCT, framing/ reframing (the adoption of a new perspective in order to change cognitions or emotions), which can also be used to achieve the function of persuasion and may be worthy of consideration.

"Feel that this is at the heart of why some staff don't discuss recovery...key!!!" SLT, >10 years' experience

"I think stroke survivors' or their relatives' insight would be priceless." OT, 1-5 years' experience

"Starting by asking clinicians to be a patient, ask them to reflect on what it feels like if you have not been given information. Use an example or ask them to share an experience where they have had to achieve something with less than adequate information." PT, >10 years' experience

9.3.3.4 Making changes to the physical environment

Barriers relating to physical opportunity were rated as important to address within an intervention. Such barriers (i.e., the lack of availability of private spaces in which to provide information and the absence of written information to support conversations) can be addressed using the intervention functions of environmental restructuring. The suggested BCTs relating to the availability of written information (being provided with generic written information and ensuring this was readily available) were both rated as useful and feasible by survey participants, whilst those relating to the availability of private spaces (advising on the allocation of dedicated private areas to discuss recovery and the importance of providing information in such areas) were deemed infeasible (designating areas) or not useful (receiving advice).

In their comments, participants elaborated on the reasons they felt that the suggested BCTs lacked feasibility and usefulness in addressing the barrier relating to an absence of private spaces. Although they agreed that private spaces were important, they described that available spaces were lacking in the hospital environment (particularly due to increased patient numbers during the pandemic), and where they were available, it was sometimes impossible to move patients to them due to their physical disabilities. As a result, they felt that they were not the right stakeholders to direct these issues to and suggested instead targeting building planners.

"Space...truly the final frontier! Go get a coffee so that my office can be used for information giving!" Nurse, >10 years' experience

"Oftentimes, the information must be provided in the patient's room. Due to time constraints, disabilities, and work requirements, it is often not feasible to bring the patient and family to another room." OT, 1-5 years' experience

In relation to the provision of written information, whilst a lack of resources was rated as an important barrier, some participants suggested that written information was already available, e.g., from The Stroke Association, or the Bridges Self-Management programme (285). Others expressed concerns around the storage of written resources (e.g., displaying information presents challenges due to infection control procedures) and associated costs (e.g., designing, printing). Finally, some participants expressed a concern that written information should be used to support, rather than replace

personalised conversations about recovery. As a result, they felt the most effective resources would be those that were easily tailored to meet the needs of their individual patients.

“All info should be patient specific and delivered using empathy...achieved through teaching, training and experience, not a script.” PT, >10 years' experience

“Designing digital resources that allow staff to also quickly prepare personalised resources as well as standardised/ pre-prepared.” SLT, >10 years' experience

9.3.3.5 Mode of delivery

Finally, in terms of overall feasibility, the most cited barrier to the suggested BCTs was a lack of staff time and capacity. However, many participants reported that support to deliver recovery information was much needed, as it was a key part of their clinical practice, and therefore, an important use of their time. They suggested a range of ways that the selected BCTs could be feasibly delivered, including making use of technology and existing ward processes and resources, such as in-service training sessions and experienced professionals. For example, participants suggested that online videos of presentations and demonstrations could be made available, generic written resources could be available online and webinars and online discussion groups could support their learning.

“Time and workload pressures [affect feasibility]. However, would be invaluable education and would improve the quality of practice.” OT, 1-5 years' experience

“I think receiving advice or seeing someone demonstrate how to ask patients and carers is feasible as this could be done via videos that people can watch at a time that suits them or via an online training session.”
Dietitian, 6-10 years' experience

Table 9.3 Suggested core components of a professional-focused intervention to improve provision of information about recovery¹

| Selected intervention functions (206) | COM-B components served by intervention functions | Selected BCTs to deliver intervention functions | Intervention components |
|---|--|--|---|
| Training (imparting skills) | Psychological capability: Increasing professionals' skills, confidence, and comfort in providing information | Instruction on how to perform a behaviour Demonstration of the behaviour | Advise on how to decide when and in what format to provide information to individual patients/ families Demonstrate: - how to deliver information about recovery sensitively and compassionately - examples of conversations occurring in different ways (e.g., at different times, supported by written documentation or not) with patients with different needs |
| Enablement (increasing means/ reducing barriers to increase capability or opportunity) | Psychological capability and reflective motivation: Increasing professionals' capability and confidence through encouraging team-working and support | Social support (practical) Social support (unspecified) | Advise on requesting support from colleagues across the MDT when making decisions about when and in what format to provide information Encourage professionals to provide support and encourage their colleagues when they have had discussions with patients and families about recovery |
| Persuasion (using communication to induce positive or negative feelings or stimulate action) | Reflective motivation: Increasing professionals' understanding about patients' and families' information needs and the importance of meeting them, and encouraging self-reflection to increase their confidence in their own capabilities | Information about societal and environmental consequences Information about emotional consequences Credible source Focus on past success Behavioural experiments | Provide information on patients' and carers' information needs about recovery from established literature Provide information about the emotional consequences for patients and carers if information about recovery is not provided effectively Present a speech by an expert (stroke survivor/ carer) outlining the known benefits and risks to providing information about recovery Encourage professionals to think about times they have successfully shared information with patients and families and information was well-received Ask professionals to try providing information about recovery (after structured training and as part of supervised practice) and to note patients' and families' reactions |
| Environmental restructuring (changing the physical or social context) | Physical opportunity: Providing physical resources to support professionals during recovery conversations and instructions to ensure they are readily available | Adding objects to the environment Prompts/ cues | Provide (or support professionals to identify) generic written information to provide to patients/ families Ensure written information is readily available in a specific location for professionals to access when required |

¹ COM-B: Capability, Opportunity, Motivation model of Behaviour; MDT: Multidisciplinary Team

9.4 Discussion

9.4.1 Summary of findings

The results of this survey study suggest that professionals working in stroke units want and need interventions to improve the provision of information about recovery. All identified barriers to such conversations were endorsed by >70% of respondents and may therefore be important to consider in an intervention. These findings add validity to the qualitative work described in previous chapters and suggest the identified barriers are experienced more widely by professionals across UK stroke units.

The COM-B model has been successfully applied to identify a range of BCTs that may be effective in changing professionals' behaviour regarding conversations about recovery. The barriers rated as most important to address within an intervention were related to professionals' *psychological capability* (including cognitive and interpersonal skills (possessing required communication skills), and decision processes (making decisions about when, how and in what format to provide information), with training (imparting skills) rated as likely to be useful and feasible to include in an intervention. *Reflective motivation* was also rated as an important barrier, with professionals lacking confidence to share information and an awareness of the benefits and consequences to (not) providing information. Information about (emotional) consequences, particularly when provided by a credible source (stroke survivor or carer) were rated as most likely to be useful, as well as social support from the MDT. *Physical opportunity*, including having an appropriate environment to hold conversations and availability of supporting written information were seen as somewhat important, though only some environmental restructuring (adding objects (written resources) to the environment) was felt to be within clinical staff control; restructuring the physical environment to designate quiet space to discuss recovery was not seen as feasible.

9.4.2 Comparison with existing literature and implications for intervention development

9.4.2.1 Intervention content

A perceived lack of confidence and insufficient communication skills were highlighted as important barriers to provision of information about recovery in this study.

Communication skills are an essential component of high-quality care and thus an important focus for student doctors, nurses, and other health professionals, with graduates expected to be able to communicate sensitively and effectively to meet a range of individual needs (286-289). Training to improve communication skills is

founded on the idea that such skills can be learned and used in practice to improve both patients' and providers' outcomes, particularly well-being (290, 291). It seeks to increase professionals' empathy and understanding of the individual patient's perspective and needs, which can be employed during information provision, shared decision-making, and challenging conversations (291). Whilst training interventions delivered as part of continuing professional development for practicing professionals are available, they are largely offered to medical staff, and particularly those working in cancer services or end-of-life care. For allied health professionals in particular, it has been suggested that the focus on learning physical rehabilitation skills may dominate (292). It is clear from these results that the range of professionals working in stroke services, particularly those involved in providing information about recovery, would welcome such training, with specific attention paid to using these skills when communicating with those with neurological impairments.

The effectiveness of such training interventions has been widely studied in oncology and palliative care, with training being demonstrated to be effective in improving professionals' empathy towards patients and increasing their ability to deliver tailored patient-centred communication, as well as increasing their own confidence (245, 291, 293). However, studies of the effectiveness of communication skills training specific to stroke care are lacking, and the effects of such training on patient outcomes are less well-documented (245, 294). It is perhaps surprising that communication skills training in stroke care has not demanded more attention, with most studies of interventions focused on improving professionals' communication with patients with aphasia, who represent around a third of patients with stroke (295)). More general communication skills training may well be of value in a situation where professionals need to convey uncertainty, including the probability of some, but potentially incomplete, recovery, as is the case in neurological conditions. Specific challenges require professionals to both carefully manage patients' hope and motivation, such that they can receive optimum benefit from rehabilitation, whilst also preparing them for the potentially long-term and life-changing effects of stroke. Developing professionals' communication skills so that this can be achieved sensitively and confidently is likely to therefore be an important component of an intervention aiming to improve the process of providing information about recovery and could have benefits for both patients and professionals.

Communication skills training frequently focuses on adapting communication to meet the needs of patients and families. This ability to tailor information provision was a key concern of participants in this study, who described concerns about the standardisation of practices and procedures in discussions about recovery. Professionals emphasised

the importance of being able to tailor or personalise recovery conversations to individual patients and families, according to their wishes and needs, including phase and speed of recovery, and cognitive and communication levels. For these participants, strategies involving promoting a standardised time, type or format of information or nominated person to deliver information, as presented in some of the suggested BCTs, were therefore troubling.

Research supports the idea that the information needs and preferences of people with stroke and their carers may change over time (56, 58, 59). For example, the 'Timing It Right' framework details how carers' needs change over five phases, three of which (admission to acute care, patient's medical stabilisation, and preparation for discharge home) occur during the patient's in-patient stay; during the first two stages, information about prognosis is required (59). Mauk's model of post-stroke recovery also suggests that patients go through six recovery stages on the road to adaptation, during which their needs for information and prognostic messaging change (296). This model encourages clinicians to consider the patient's individual mindset and tailor their communication accordingly. For example, during the second stage of fantasising (expecting the stroke's effects to disappear), professionals are encouraged to simply try to motivate patients without raising their hopes and expectations, whilst in the fourth stage (blending; in which the process of adjustment to the effects of stroke begins), they should begin to provide realistic recovery information (296). Similarly, Lutz describes three phases of the stroke trajectory, during which the patient and carer move forward from a stage of initial shock and uncertainty on admission, through an expectation of recovery during therapy, towards a final stage of adaptation at discharge (297). The emotional responses of patients and carers within each stage require consideration in information provision, for example, to meet initial needs for information about prognosis by discussing survival rather than the potential for long-term deficits.

Findings from the present study, taken alongside this evidence, highlight the importance of allowing professionals the flexibility to tailor the delivery of information about recovery to best meet patients' and families' needs. It is not uncommon for complex interventions intended to be implemented in a range of contexts to include a set of core, necessary components, whilst allowing flexibility for the tailoring of aspects according to individual need (205). Further development of this intervention is likely therefore to focus on helping professionals to best identify patients' and carers' needs for information and to tailor their communication to meet these needs, rather than dictating specific time-points and formats of delivering information.

In terms of strategies that are likely to be useful to incorporate into an intervention, participants in this study valued active and experiential approaches to learning, particularly when addressing barriers relating to improving communication skills and building confidence. This is in line with previously published work, which suggests experiential learning is key to learning communication skills (292, 298). Being provided with information and observing demonstrations were viewed positively by professionals in this study but were seen as more useful if followed by active practice and feedback (if delivered in a 'safe space' such as within clinical supervision). A review by Gysels et al. suggests this combination is very effective in improving communication skills (299). One experiential strategy, that of role-play, was however controversial within the sample, with some suggesting it could be off-putting to intervention recipients. Role-play is an experiential learning approach, which involves a clinical scenario acted out by peers, who alternate between the roles of professional and patient/ carer to practice newly learned communication skills. This technique has advantages in providing opportunities for participants to practice their skills in a safe learning environment, and allowing them to empathise with the patient's perspective, with subsequent opportunities for feedback and reflection (299). There is evidence however that learners may find the process embarrassing and unrealistic, although methods have been suggested to improve experiences, e.g., clear direction by enthusiastic trainers (300). Role-play has been demonstrated as an effective technique in developing communication skills (301) and therefore should be considered when further developing an intervention, with appropriate care taken to ensure participants' comfort.

As well as experiential learning, participants felt that being presented with patient and carer voices would be a useful strategy, facilitating behaviour change by persuading professionals, for example, of the benefits of conversations about recovery or the repercussions of not being provided with this information. Participants' comments suggested hearing patients' stories through speeches or video materials could help to develop an understanding of their perspectives. The use of patient narratives in health interventions and service improvement initiatives has increased in popularity over recent decades (302), and hearing patients recount their experiences can be powerful, persuasive and can inspire professionals to reflect on their own practice (303, 304). However, some authors advise caution when using this method, suggesting that presentation of a range of experiences is required to prevent anecdotalism (304) and warning that the use of narratives without a clear evidence base can potentially lead to unfavourable outcomes (305). Inclusion of narratives within an intervention could be an effective strategy, but care must be taken to understand the mechanisms through

which they are effective, and to carefully select those which most closely represent the available evidence.

Finally, it is perhaps surprising that an inability to predict recovery was viewed as the least important barrier to address in an intervention aiming to improve conversations about recovery in this study. The trajectory of stroke recovery is uncertain, and while prognostic models continue to improve, meaningful application to individual patients remains challenging and uptake in clinical practice has been limited (29, 30, 306). Predictions made by stroke unit professionals therefore tend to be based on clinical judgements of patient-related factors and response to treatment; it is upon these judgements that rehabilitation, and subsequently discharge, are planned (307). Some disagreement about whether recovery can be usefully predicted was evident in the comments of professionals, both in this study and in earlier qualitative work, with some believing that having greater access to research evidence would improve their knowledge and therefore predictive ability, and others highlighting that improving communication skills to enable them to convey uncertainty was of greater importance. It is likely that both aspects have a role to play in an intervention, which could include improving knowledge of the factors influencing prognosis, alongside developing the skills required to convey uncertainty.

9.4.2.2 Methods of intervention delivery

This study has identified a wide range of possibilities for the mode of intervention delivery. Michie et al recommended using a set of criteria to narrow down possible BCTs for intervention inclusion; these are known as the APEASE criteria and involve consideration of Affordability, Practicability, Effectiveness and cost-effectiveness, Acceptability, Side effects/ safety and Equity (206). This study has invited professional stakeholders' views on these issues, to help determine the most effective mode of delivery for an intervention. The APEASE criteria require consideration of different modes of intervention delivery when targeting individuals or a population. In this study, the support of the MDT was frequently described as important in addressing a range of barriers relating to recovery conversations, with buy-in required to make changes to practice, provide support and share and delegate responsibilities. MDT involvement was also frequently mentioned in relation to barriers relating to decision-making about providing recovery information, suggesting that sharing experience and knowledge (including about individual patients) and development of understanding of each other's roles was important. As such, it is likely that at least some of the included BCTs should target the whole MDT.

The preferred mode of intervention delivery is likely to be face-to-face, however staff time was frequently mentioned by participants as the biggest barrier to the suggested strategies. Organising face-to-face training is likely to be particularly challenging for those who work shift patterns, e.g., nurses, and for those who have too few staff to prioritise training alongside their clinical work, e.g., orthoptists or dietitians. Respondents were keen to suggest ways that training and support could be more feasibly delivered. These ideas included building training or support into pre-existing practices, e.g., within formal or informal supervision sessions or ward-based in-service training. For example, learning through observation of the communication skills of more senior colleagues was felt to increase feasibility (rather than participating in a formal training session) as it could be planned into the working day and no travel would be necessary, though this does rely on colleagues demonstrating effective communication skills themselves. The use of technology, including web-based presentations and discussions, and access to written or video-based resources, were also suggested by participants to increase the feasibility of intervention delivery. A mix of these approaches is likely therefore to be useful in an intervention, which should aim to balance providing effective training opportunities with feasibility for clinical staff.

9.4.3 Impact of the COVID-19 pandemic

Participants discussed the feasibility of the proposed BCTs in light of their recent clinical experiences, of which the COVID-19 pandemic has been a key feature. It is possible that changes made to care as a result have affected professionals' views, both in relation to their current behaviour regarding conversations about recovery, and their views on training delivery. For example, several participants described how COVID-19 precautions including stroke unit visiting restrictions and social distancing had resulted in fewer conversations about recovery, and restricted attendance at family meetings (due to a lack of physical space). Although not explicitly mentioned, staffing levels may also have been affected by staff sickness and potential redeployment during this period, resulting in respondents raising greater concerns about a lack of time to participate in an intervention. Such issues have been identified as adding to the uncertainty and complicating decision-making in stroke units during this period (308). These factors may therefore require consideration in intervention development, should these changes become more permanent.

Finally, professionals in this study offered many positive comments about the possibilities regarding online training approaches, which are likely to have become more commonplace for professionals during the pandemic due to attempts to limit face-

to-face contact (309). Participants appeared keen to embrace the opportunities that technology could provide in their continuing professional development, suggesting online discussions and webinars as platforms for training delivery and websites for sharing useful resources, including videos, databases of written materials, and mobile applications. It is possible that the acceptability of online training may have recently increased and represent an opportunity when proceeding with intervention development. Professionals may also be familiar with accessing stroke-related training online, e.g., through the Stroke Training and Awareness Resources (STARs) (310).

9.4.4 Strengths and limitations

This online survey study has enabled identification of the views of UK-based stroke professionals relating to the barriers to conversations about recovery and ways that an intervention might address these barriers. Although the sample size was relatively small, a strength of the study is the large number of detailed qualitative responses received from study participants. The use of the online survey method permitted respondents to complete the questionnaire at their convenience, returning to it later if required, which may have resulted in more comprehensive responses.

A limitation of this study lies in the sampling method. The use of convenience sampling meant I was unable to control who saw the study advert and/ or completed the survey, a common difficulty in online survey research. This means no response rate could be calculated and it is unknown whether specific characteristics influenced survey completion. For example, those with a special interest in the topic tend to be more likely to respond (279). Whilst it was not the aim of the study to generate generalisable findings, but rather to gain an understanding of a wider perspective on the topic, it is important to note that study participants' views may not be representative of stroke unit professionals in general.

Some professional groups, e.g., OTs and nurses, were under-represented within the sample, despite attempts made to target participants from these backgrounds. It may be that these professionals do not identify themselves as having a substantial role in conversations about recovery on the stroke unit. Whilst my systematic review and qualitative work detailed in Sections 1 and 2 suggest this may be the case for nurses, it would be surprising if it were true for OTs, who were observed to be commonly involved in these conversations. A strength of the study is that professionals across the stroke MDT were represented, including more peripheral members, such as psychologists, orthoptists, and dietitians. This suggests there is interest in this topic

outside of the core MDT and behaviour change may be possible in these groups. Additionally, more than half of respondents also had more than ten years of experience in stroke care. This experienced group may have had more knowledge about effective strategies to improve conversations about recovery based on their past experiences, however perspectives of those with less experience (and therefore potentially more likely to benefit from an intervention) may have been missed. Additionally, although the survey was open to professionals across the UK and widely advertised, data on participants' location were not collected, and it is therefore possible that responses reflected views of professionals at only a small number of stroke units or within a specific region.

Limitations related to the use of an online survey may also have impacted the results. For example, the questionnaire could have been completed by any interested party, who may not necessarily have been eligible to participate (282). However, free-text comments did suggest that participants were knowledgeable about the topic. Using online methods of recruitment may also have limited the sample, as those without computer access and non-social media users may have missed out on the opportunity to take part.

9.5 Conclusions

Building on work in previous chapters, which identified professional-related barriers to conversations about recovery and the most effective ways that they could be addressed using the BCW, this study has identified professionals' views about the BCTs that are likely to be useful and feasible within an intervention. Potential modes of delivery for these strategies have been identified, including the possibilities of using electronic resources alongside face-to-face training delivery. Further development involving stakeholders (stroke survivors, carers and professionals) is required to design training materials and delivery processes that are acceptable and feasible to deliver in clinical practice and support the delivery of information to meet the needs of patients and carers.

Chapter 10 Discussion

10.1 Summary of main findings

This research aimed to develop an in-depth understanding of current practice in providing and receiving information about recovery on stroke units, including the experiences of those involved and the barriers and facilitators; and to use this knowledge to begin development of an intervention to improve provision of such information.

A qualitative synthesis of 28 studies across acquired neurological conditions (Chapter 1) revealed a range of challenges involved in providing and receiving information about recovery. An unmet need for such information was common across conditions, with specific challenges for professionals who experienced a lack of formal training and feared eroding patients' motivation for therapeutic engagement in the face of a potentially negative outlook and an uncertain trajectory. Honesty, positivity, and sensitivity in information delivery were valued by patients and carers.

A focused ethnographic case study of current practice in two stroke units (Chapters 2-6) revealed a complex pattern of professional reasoning about whether, when, and how the delivery of information about recovery should be tailored to each patient. However, sometimes professionals' concerns, e.g., maintaining patient motivation in therapy, resulted in the delivery of limited and vague prognostic messaging rather than individual predictions about outcome, which could leave patients' and carers' needs unmet. Factors that impacted the consistency, delivery, and quality of recovery information included: the stroke unit environment and routines, which were frequently unsuited to the delivery of confidential and sensitive information and could limit opportunities for interaction; multidisciplinary team (MDT) communication and teamworking, in which a co-ordinated approach was highlighted as important in ensuring consistency; the uncertainties of stroke recovery, which could also result in the provision of generic and vague information; and individual differences in patients' abilities and needs, of which professionals' assessments could impact whether and how information was provided.

Detailed exploration of professionals' experiences (Chapter 5) revealed that most viewed providing recovery information as an important part of their clinical practice and some perceived benefits in facilitating patients' and carers' adjustment to post-stroke disability and engagement in decision-making. However, therapists in particular

described a lack of training in specialised communication skills, which impacted their confidence. Many also worried about the potential for specific predictions to be later disproved due to the uncertainty of the stroke trajectory, and felt anxious about sharing bad news, which they worried would erode patients' motivation and hope and could result in negative reactions from patients and carers. They described an emotional cost to managing these issues, with limited formal support.

The vague and uncertain messages provided by professionals, alongside observations of others with stroke, led patients and carers to a belief that recovery could not be predicted (Chapter 6); this uncertainty could provide hope. Some received detailed information about their recovery through family meetings; those who did not felt professionals lacked proactivity. Where information was provided, this facilitated adjustment and engagement in decision-making. However patients and carers stressed the importance of information delivery, valuing sensitivity, honesty, and compassion from professionals. Patients and carers typically lacked information and understanding about the process of stroke recovery, including its likely timing and the role of, and need for, therapy, particularly across the wider stroke pathway. This typically led them to overestimate the importance of therapy and effort in their recovery, which could have negative consequences, including disappointment when therapy was withdrawn or reduced, and (self-)blame when recovery was slow or incomplete.

A second systematic review (Chapter 7) revealed no existing interventions which specifically aimed to improve provision of recovery information in neurological conditions that had been tested for their effectiveness in improving patients' and carers' outcomes. The four included studies tested interventions, which included provision of prognostic information as part of a wider intervention, and there was some weak evidence they could be effective in improving patients' satisfaction with information provided and with overall care. Three common features of these interventions were however identified: the use of evidence-based information, personalisation of information, and active provision.

The collected data facilitated intervention development, which was underpinned by behaviour change theory (the Behaviour Change Wheel (206); Chapter 8). The target behaviour for change was identified as professional provision of information about recovery to stroke unit patients and their carers, and twelve barriers were identified, alongside intervention functions and behaviour change techniques thought likely to address them.

All of the identified barriers were subsequently endorsed by >70% of a sample of 48 multidisciplinary health professionals in a UK-wide survey (Chapter 9). The most important barriers to address were identified as a lack of confidence, insufficient communication skills, lack of knowledge of the benefits of providing information, difficulties in deciding the timing and format of information, an absence of private and quiet spaces for discussions, and a lack of generic written information to support conversations. Strategies perceived to be useful and feasible in addressing these barriers were identified; future research aims to continue intervention development using co-production methods to ensure that the final product is clinically feasible and meets the needs of patients and carers.

10.2 Original contribution to knowledge

This research extends existing knowledge, through concurrent use of different methods to explore the perspectives of those involved in providing and receiving information about recovery. This approach has not previously been applied to the study of conversations about recovery in stroke units, and its employment facilitated comparison of the views of different participants, as well as understanding of how their perceptions and beliefs influenced their actions. For example, the use of observations alongside interviews with patients, carers, and professionals enabled exploration of the underlying reasons for the frequently discordant reports of professionals (who believe they have provided information about recovery) and patients and carers (who report their information needs remain unmet).

In terms of the wider literature on prognostic communication, most previous research has examined the formulation and delivery of prognoses by a single person (usually a doctor) to a patient, most frequently within cancer or palliative care settings. Conversations in stroke typically have a different focus: unlike in cancer or palliative care, a degree of recovery is nearly always possible, representing a typically upward trajectory. Whilst 'bad news' in other conditions may, for example, relate to survival, in stroke it more frequently relates to limitations to the extent of recovery or the lengthy timescales required to achieve it, with conversations taking place within the context of rehabilitation. Providing hope and engagement alongside realism is therefore a specific challenge for staff working in this field, which has seldom been explored in the stroke unit context. A related novel aspect of this research is the exploration of the contributions of members of the MDT other than doctors and the way in which

professionals work together to formulate and deliver prognostic information. This is important when considering how practice could be improved.

This is the first study to suggest that professionals' fears that 'bad news' may reduce patient motivation could be unfounded. As this is a significant barrier towards communication for professionals, this finding could have important implications for recommendations on providing information about recovery, although further research is required to explore the circumstances in which this finding is transferable. This is also the first study to highlight a need for documenting information provision in patients' notes, to increase consistency in prognostic messaging across multidisciplinary teams, and the first study to consider patients' and carers' understanding of the information provided about recovery by professionals.

Finally, the COM-B model is widely used in intervention development; it has however not previously been applied to the early development of a novel intervention to improve the provision of information about post-stroke recovery. The use of this model facilitated greater understanding of the barriers to professionals involved in providing recovery information and the identification of strategies which are likely to be effective in changing professionals' behaviour.

10.3 Comparison with existing literature, and implications for clinical practice and future research

10.3.1 The delivery of recovery information to meet patients' and carers' needs

This research adds to the well-established evidence base that many patients with stroke and their carers are dissatisfied with the information received about recovery (53, 56, 58, 64, 65), and confirms evidence from across conditions relating to preferences about the delivery of prognostic information, namely the need for honesty, compassion, sensitivity, and positivity, as well as a proactive and timely approach (95, 96, 99, 101, 109, 118). Alongside these preferences, this research also suggests that provided information should be evidence-based, personalised to the individual, and actively provided.

Positivity in the delivery of prognostic information is important for patients and carers to maintain hope (95, 96, 105, 110, 207). A perceived absence of such positivity when

delivering information may impact patients' perceptions of professionals and thus prove damaging to the therapeutic relationship (311). There is however evidence that in the early stages of recovery patients prefer information which promotes hope, but later regret not having received realistic information to help them prepare for their long-term difficulties; this has been referred to as the 'hope-information paradox' (312). The challenge for professionals is to thus find ways of promoting hope, whilst encouraging realism. Strategies such as delivering multiple scenarios to support patients to 'hope for the best, prepare for the worst' can be effective in supporting decision-making whilst not removing hope, as can highlighting potentially positive outcomes, which do not necessarily require a full recovery, alongside 'bad news' (313).

The need for information to be tailored to individual patients' needs was highlighted as important across this research, and is an important, guideline-recommended component of patient-centred care (50, 274, 275). Tailoring of information can refer to its content (i.e., personalising information according to the individual patient's case) and delivery (format, timing, amount, and environment). The complex reasoning required by professionals to achieve such individualisation has previously been reported (126), however previous research has not included observations to assess how this reasoning translates into practice. This study extends this literature by highlighting that, despite professionals' clinical reasoning, these concerns translated into practice in only a limited way, with much of the information provided about recovery comprising generic messaging rather than tailored predictions, and clinicians' infrequently involving patients and carers in conversations about their information needs and how they might best be met. Establishing a dialogue with patients and carers to identify their needs and the optimum format for information delivery represents an active approach to information provision (49). Such approaches have been demonstrated to be more successful (vs passive provision) in improving the outcomes of patients with stroke, including improving knowledge and quality of life and potentially reducing mood symptoms (49). Studies have also demonstrated that being able to select the topics and amounts of information increases patient satisfaction, in comparison with generic information provision (314). Professionals should thus be encouraged to engage in such dialogue with patients and carers to identify their information needs, and use their clinical judgement to determine how best to provide it. However, these practice changes are likely to require further training to equip professionals with the skills and confidence required.

Such tailoring of information to meet patients' needs includes consideration of format. This research identified that most information was delivered verbally, despite

expressed concerns by professionals, patients, and carers about the potential challenges, including the processing, comprehension, and retention difficulties that can occur following stroke, and can result from the shocking and lifechanging nature of the diagnosis. Challenges in retaining verbally-presented medical information are well-established in the literature (315, 316), although studies are typically limited to one-to-one information delivery. The presentation of larger amounts of information (as is the case during family meetings) generally results in poorer recall (317); the effects of team delivery (which has the potential to overwhelm information recipients) is unclear. However, provision of written information was also deemed challenging in this research, particularly where it involved personalised predictions, due to the uncertain course of recovery: patients and carers believed such information could not be provided, whilst professionals were afraid to commit their estimations to paper for fear of them being disproven. These difficulties have previously been articulated, however benefits in increasing accessibility to information, supporting recall, and reducing the possibility for misinterpretation have also been suggested (58). Further research is required to identify the best format in which to deliver prognostic information in ways which meet patients' needs and overcome the challenges. This may include, for example, providing written information detailing the generic processes of post-stroke recovery to support verbal written predictions (as was felt by survey respondents to be potentially helpful) or considering other ways to provide information such as audio-recordings of conversations (318) or visual presentation (319).

Finally, despite patients and carers frequently reporting their information needs are not met, in much of the previous literature it has been challenging to determine whether this is because information about recovery has been provided but not recalled or accepted by patients and carers, or whether this information has not been delivered. This research sheds light on this important question and three potential explanations are proposed. Firstly, in some cases, observations revealed explicit information was provided by professionals, but during later interviews, patients and carers were unable to recall this, e.g., failing to recall their attendance at a family meeting. This may be related to post-stroke difficulties, e.g., as a result of memory problems or feeling overwhelmed. It may also be the case that the prognostic messages deemed of importance have been assimilated by the patient into their understanding, although they may not recall the specific instance in which they were introduced. Both are likely possibilities. Secondly, in some cases it was identified that although professionals clearly formulated prognostic predictions, these were not always shared with patients and families, as a result of concerns about their potential negative impact.

A third potential explanation is that the challenge of conveying uncertainty in predictions about recovery faced by professionals led to the delivery of information using vague or ambiguous language. In these cases, professionals believed they had imparted specific information about recovery, but this was not received as such by patients. It may be that patients and carers focus their understanding on the uncertainty to allow them to maintain hope; alternatively it is possible that the information is heard and understood but not accepted. The latter suggests denial, which may be a coping mechanism acting to moderate emotional exposure to distressing information (320), and often features in theories of loss and adjustment, which have been applied to stroke (320-323). Hui et al. propose a five-stage conceptual framework, which aims to map the prognostic continuum, moving through stages of prognostic prediction, disclosure, awareness, acceptance and prognosis-based decision-making (324). Notably, there is a distinction made between the stages of disclosure and prognostic awareness, alluding to the idea that simply because information is provided, it is not necessarily understood; Hui et al. suggest awareness can be cultivated through the communication skills of the provider (324). The move to prognostic acceptance requires the patient's ability to cope with the information, before being able to use it to make decisions (324). Although developed in the field of cancer, this framework is likely to apply equally to stroke survivors, and difficulties within one of these stages may result in a failure to process and use information effectively; this could be a target for intervention and is thus worthy of further research.

10.3.2 The benefits of talking about post-stroke recovery

As well as a focus on *how* recovery is discussed on stroke units, this research has also shed light on *why* it is important to do so. Firstly, of greatest importance, and as has been highlighted in previous studies in stroke and other conditions as well as in this research, many patients and carers want this information (51, 53, 56, 59, 325, 326). Additionally, patient understanding of prognostic information has been associated with several benefits, including enhanced involvement in treatment decision-making and facilitating longer-term planning (63, 106, 327). Where the information constitutes 'bad news', benefits of effective communication also include supporting acceptance and emotional adjustment (328); this is particularly pertinent to stroke and other neurological conditions (83, 105, 106, 112). My qualitative work confirms some professionals' perceptions of these benefits and adds to this literature by providing observational examples from stroke unit practice. However, despite these perceptions, my second review did not identify any trials which measured the effects of providing

post-stroke recovery information on patients and carers' outcomes. This has been described across conditions, with research frequently focusing on the impact of training professionals, rather than patient outcomes, based on the assumption that improved clinician confidence and skills will be beneficial to patients (329). Further research is however required to ascertain whether this is the case. Finally, the results of my qualitative work and survey suggest that professionals may be unconvinced about the benefits to providing information about recovery; this is important for practice changes enabling patients and carers' needs to be met, and would likely be supported by further evidence.

10.3.2.1 Adjustment

Stroke can be characterised as a '*biographical disruption*' pp. 167 (196), constituting the sudden onset of often lifechanging symptoms. As in this study, research has demonstrated that many patients initially believe that recovery will be swift and they will return to their usual activities and lives once discharged from hospital (58, 330). Through the realisation that recovery is likely to take longer than many first anticipate and that they may be required to make adaptations to their lives to cope with their continuing symptoms, they must begin a dynamic process of psychosocial adjustment and development of a new post-stroke identity (330-332). This can involve acknowledging their losses, e.g., of function and of social roles. In line with the biopsychosocial model upon which rehabilitation is based (333), many argue that supporting this psychological recovery is as important as facilitating functional recovery, with acceptance resulting in improvements in mental health and quality of life (334).

Perceptions that providing information about recovery may support post-stroke adjustment have a theoretical basis. The Social Cognitive Transition model highlights the need for patients to change their core assumptions about their lives and future to accommodate the changes resulting from the stroke (320). It posits that, where a patient's current experiences, e.g., of disability, do not match their previously-held assumptions, this can result in emotional responses, including anxiety, anger, grief, and denial (320). Coping strategies are thus required to accommodate these experiences and reformulate beliefs (320). Provision of clear, timely, and realistic information about recovery may act to challenge existing beliefs about stroke and the likely extent and timescale of recovery, and could be provided alongside other interventions, such as psychological therapies and social support, to promote

adjustment (320). In this research, psychological support helped patients and carers to process the recovery information provided and discuss their emotions, although it was only available for some patients. Psychological support provided alongside realistic recovery information may thus be effective in promoting adjustment, although further research is required.

10.3.2.2 Shared decision-making

Provision of prognostic information has been suggested as an effective way to enhance shared decision-making across a range of conditions, including cancer (324) and neurological conditions (67), allowing patients to weigh up the potential risks and benefits of treatment and how such treatments might influence the illness trajectory, to inform their subsequent decisions. Although clinical guidelines advocate involving patients in shared decision-making after stroke, previous studies have typically related to acute interventions such as thrombolysis (335), or options for secondary prevention (336), rather than during rehabilitation. Within rehabilitation, qualitative studies have described how treatment decision-making is typically undertaken by professionals, who, following their assessments, provide therapeutic intervention according to their clinical judgement (337, 338). It is widely assumed that patients wish to engage (perhaps because no other treatment options are available), even where this is likely to convey limited benefits in function, participation and/ or quality of life. Being informed about the likely benefits of therapy (i.e., how much functional recovery can be expected) in relation to the amount of work required should inform patients' decisions about whether they choose to engage. This study has demonstrated a paucity of such conversations in stroke care, perhaps as a result of the limited evidence base for the effects of specific treatments and the frequency and intensity required to gain these effects, as well as the uncertainty in predicting outcomes for individual patients. Professionals frequently described how time is needed to assess initial response to treatment, which may prohibit patients' early involvement in decisions about whether they wish to engage, alongside stroke-related factors, such as drowsiness, cognitive difficulties, or apathy, which may limit their involvement in decision-making. Failing to provide information about recovery to inform such decisions however may represent a missed opportunity to deliver care in line with patients' wishes and values.

Where patients are engaging in therapy, the means by which they might become involved in shared decision-making is largely through goal-setting (339). This provides an opportunity for them to discuss with professionals what is most important for them;

professionals then typically negotiate (informed by their predictions of the likely speed and amount of recovery for each individual) goals that they perceive as realistic. This can be effective in managing patients' expectations, albeit without direct statements of anticipated functional recovery, which enables the professional to appear positive and encourages engagement (340). Systematic review evidence suggests however that the extent to which patients are directly involved in goal-setting is somewhat unclear (341). A reported barrier to patient involvement in goal-setting (and thus shared decision-making about their care) lies in their lack of awareness of the types of goals that may be achievable (341-343). Sharing information about the likely extent of recovery therefore has the potential to facilitate involvement. This approach is supported by the latest edition of the UK stroke guidelines, which advocate that professionals should compassionately communicate the likelihood of goal achievement to their patients (23).

The main observed benefit of the provision of recovery information on shared decision-making in this research related to stroke unit discharge, providing examples of how understanding the likely recovery trajectory enabled patients to consider their options for how they would manage post-stroke life, including meeting care needs and environmental adjustments. Although clinical guidelines recommend the involvement of patients and carers in decision-making, particularly around discharge and care provision (23, 344), there is limited literature on how this process works in practice; existing research frequently focuses on discharge decisions taken solely by professionals and reported to patients, with patients having little involvement and experiencing discharge passively (345, 346). Of course, this is to some extent expected; clinicians must balance the timeliness and safety of discharge for individual patients with service needs and availability, e.g., facilitating patient throughput (345, 347). However, patient involvement in decision-making has been linked to service satisfaction (348), and is an important component of patient-centred care. Tailored recovery information could support such involvement; current research exploring the effectiveness of a discharge decision aid incorporating such information is on-going (349).

In summary, provision of information about recovery has the potential to increase patients' and carers' involvement in decision-making and thus improve the delivery of patient-centred care; however this potential has yet to be realised.

10.3.3 Challenges specific to stroke unit practice

Despite the identified benefits, the provision of prognostic information is a challenging area of clinical practice. This is true across conditions, however this research has highlighted aspects specific to stroke, and rehabilitation more generally, which require addressing.

10.3.3.1 The challenge of communicating information about recovery whilst continuing to motivate and promote hope

As in previous studies (e.g., Wiles et al. (69)), this research has highlighted professionals' anxiety about the potential negative effects of providing information about recovery to patients with stroke and their families. In particular, concerns were raised about the impact that disclosing a potential negative outlook could have on patients' hope, which is consistently reported as troubling for clinicians (105, 350). Hope is acknowledged as important for stroke survivors and carers (351-353); it may be protective and act as a coping mechanism for patients, motivating them to continue engaging in rehabilitation, even where their expectations may not be realistic (105, 331, 354). Without it, professionals fear adverse effects on mood, including symptoms of depression, which are not uncommon after stroke and can negatively impact recovery (355), and leading to fears that unfavourable predictions can become a self-fulfilling prophecy.

Professionals' fears about destroying patients' hope and causing distress are evident in studies of breaking bad news in other conditions (123, 328); these concerns are not unique to stroke. They are however particularly salient within rehabilitation contexts, where physical effort and motivation (particularly in the face of potentially slow changes) is crucial. Increased hope and motivation have been linked with enhanced engagement in rehabilitation, and all have been associated with increased functional recovery (105, 350, 356-358). This study touches on the potential ethical issues in discussing prognosis with patients and their families. Until the not-so-recent past, it was accepted that bad news about patients' outlook could, and in some cases should, be withheld from patients, if deemed in their best interests (359). An example of this in stroke rehabilitation can be found in Becker and Kaufman's 1995 study (71). This form of paternalism has been largely replaced with a patients' right to know about the course of their illness, should they choose to (359). Despite this, some therapists in this study described a potentially overprotective attitude, describing delaying or even avoiding providing information about a pessimistic outlook, where it was felt this would affect the

patient negatively, e.g., where the patient was already low in mood. This echoes findings from ~20 years ago (69), suggesting these issues remain in clinical practice and highlighting the need for training for professionals to reduce their avoidance of delivering information in such cases and improve their understanding of the benefits, promoting strategies to communicate information in ways which can empower patients and help them to maintain hope, whilst giving them the benefits of foresight.

Despite professionals' fears however, it has been suggested that providing negative prognostic information does not necessarily degrade hope (360, 361), and that providing more general information about the process of recovery and the benefits of therapy can act to cultivate motivation (362-364). Thus it is likely that the way information is presented to patients is key. For example, this study and others have described how professionals may promote hope through encouraging a focus on what can be achieved with rehabilitation in the short-term, rather than on lost function or long-term outcomes (352), as well as communicating that predicted outcomes are not definitive (promoting hope through uncertainty) (105). Others have suggested providing information about the goals of particular exercises or treatment can also enhance motivation (364).

It is important to highlight that providing post-stroke prognostic information does not necessarily involve breaking bad news, although it is understandable that professionals frequently focus on this aspect as a challenging part of their role. It is assumed by professionals that patients and carers expect a full recovery will be possible; although some quantitative studies suggest that patients' and carers' expectations are often more optimistic than those of their therapists (365, 366), this study highlights how this is not necessarily always the case. Indeed, health expectations are formulated based on a range of factors, including previous knowledge and experiences (367). Therefore, what is perceived by a professional as 'bad news' may not be similarly recognised as such by the patient. This again demonstrates the importance of establishing an open dialogue between patients and professionals, particularly to ascertain patients' expectations for recovery. The impact of providing information about a potentially positive outlook may well be motivating and promote hope amongst patients and carers, though more research is required to ascertain this. The importance of effectively conveying understanding of the uncertainty of any tailored predictions is however clearly important, to prevent false hope and later disappointment.

10.3.3.2 Working as a multidisciplinary team

Most previous research in the area of prognosticating and breaking bad news relates to the formulation of predictions by a single professional (usually a doctor), who subsequently communicates them to a patient (and/ or their carers). Few studies have highlighted the role of the MDT in formulating or sharing such predictions with patients and families, which is particularly important in rehabilitation, where involvement from a range of professionals from different backgrounds has benefits, but also introduces increased complexity and the potential for differing opinions (83). The expertise of those with different knowledge and experiences can contribute to development of shared understanding of the likely outcomes of individual patients, which can facilitate effective patient-centred rehabilitation planning. Regular communication between stroke team members is thus particularly emphasised in clinical guidelines (23), recognising the likely contribution that such practices may have on the benefits arising from organised stroke unit care.

Identification of the wide range of professionals involved in delivering information about recovery is important so that their roles within this process can be better defined, and associated training needs met. This research has highlighted how professionals from a range of disciplines, including more peripheral MDT members such as dietitians and orthoptists, are engaged in discussing recovery with patients and families, from an early stage in their careers. Despite this, limited guidance about their roles is available to them, and many feel underprepared for this important clinical task, lacking confidence and support, as well as access to specific training, particularly in breaking bad news; as a result, these issues were reported as some of the most significant barriers to conversations about recovery in my survey study.

The literature on training professionals to break bad news consistently focuses on doctors, with techniques aiming to improve their communication skills within oncology or palliative care environments (e.g., Harnischfeger et al. (368)). Despite their reported roles in breaking bad news in rehabilitation settings, limited research has considered the effectiveness of training programmes for therapists and nurses. In line with previous qualitative research (63, 83, 126, 369), therapists in particular described how they were expected to be able to break bad news from an early point in their careers, despite acknowledging that learning occurs experientially. Although a range of models to support such learning are available, e.g., SPIKES (131) and COMFORT (370), these protocols were not mentioned in my qualitative study and only one study in my systematic review highlighted their use in professionals' training (68), suggesting their employment across neurological conditions is not widespread. Training incorporating

these models using techniques such as role play and group discussions, has been demonstrated to be effective in increasing clinicians' confidence (132, 133) and patient satisfaction (134) in other conditions, and could be beneficial for stroke MDTs. Training to support experiential learning could also include shadowing opportunities specific to recovery conversations for newly qualified therapists or those new to neurological settings, or simulation (126).

This research also draws attention to the emotional cost experienced by professionals involved in discussing recovery and breaking bad news; this has previously been reported by those working across conditions (123, 328, 369). This issue is particularly salient in neurological rehabilitation, where the result of frequently engaging in emotional conversations with patients (with potential for behavioural symptoms and interpersonal problems) and their families, has been linked to occupational stress and burnout (371-373). Clinical supervision, organisational and professional support, and strong team relationships have been suggested to ameliorate these effects (373), and were presented as potential solutions by professionals participating in this research. Promoting awareness of these issues and encouraging routine debriefing and reflective practice may help professionals manage their emotions and become more comfortable with the task of providing information about recovery (123).

In this research, the multidisciplinary nature of stroke unit care also led to concerns about inconsistencies in the prognostic information provided by different members of the team. Inconsistencies may exist in the communication of information about recovery, e.g., differing terminology, or within the actual predictions themselves (104), which may vary according to the experience of the professional providing them (83, 374). Previous interview studies of rehabilitation professionals have identified the need for clarity in the information provided to patients and families, as well as developing a shared knowledge of the patient's understanding of the information that has already been provided; both promote consistency (83, 95, 350). Receiving inconsistent information can not only be distressing and worrying for patients and carers, it can also impact their trust in the professionals treating them, potential limiting their engagement with treatment and shared decision-making (95, 97, 104). Although such inconsistencies were rarely observed within this research, findings have revealed challenges to the sharing of such information in a busy stroke unit environment, which frequently relies on access to clinical documentation and the cascade of information through uni-professional teams following regular meetings at which all team members cannot be present.

The organisation of regular family meetings may function as part of a planned approach to promote consistent information delivery from across the MDT. These meetings gave patients and carers a sense of professionals' proactivity in providing information and there is evidence that professionals view them as an effective method of information delivery (375). Limited research has however examined the conduct and benefits in stroke, there are few guidelines about how they should operate (376), and they are perceived as expensive and difficult to organise (375, 377). Despite this, existing studies in stroke and other clinical areas have indicated that family meetings can have benefits for carers, including reducing mood symptoms and improving satisfaction and knowledge; they can also serve as a forum for setting expectations and engaging in shared decision-making (376-378). Clarity about the aims of such meetings is however important to ensure such engagement, as identified in this and previous studies (378).

Ideally, the whole team, including more junior (e.g., healthcare assistants) and peripheral members (e.g., orthoptists and dieticians), should be aware of, and buy into, a consistent approach to the provision of recovery information, and contribute to this approach as appropriate to their role. Ensuring that professionals feel comfortable in refusing to provide information where they are unsure is equally important, to ensure that inconsistent messaging is not provided where staff feel under pressure.

10.3.3.3 The uncertain trajectory of post-stroke recovery

The uncertain and unpredictable trajectory of neurological recovery is a frequently highlighted barrier to providing tailored predictions about functional recovery (68, 69, 71). However, whilst these issues were raised in this research, professionals believed that predictions about recovery both could and should be developed and conveyed to patients and their families, suggesting this is not the main reason why patients' and carers' information needs are not met. Uncertainty in prognosis is not unique to stroke; it is inherent in prognostication across healthcare (379). Nonetheless it causes discomfort to professionals; they fear making inaccurate predictions, and thus creating false hope or causing distress to patients and carers (67, 69).

The uncertainty of recovery conveyed using vague and ambiguous language had an impact on the way in which information was received by patients and families in this

research. Uncertainty is a common theme across studies considering patients' and carers' experiences of stroke (331, 332) and has been defined as "*the conscious awareness of being unsure, of having doubt, of not fully knowing*" pp. 2586 (380). Mishel's theory of Uncertainty in Illness theory describes how uncertainty can arise from ambiguity, complexity, lack of information, or unpredictability of the trajectory (381). How such uncertainty is perceived and responded to by patients and carers can however be variable (382). According to Mishel (381), uncertainty can be viewed as a danger, potentially causing frustration, distress, fear, and anxiety (71, 100, 383), or as an opportunity, or source of hope (105, 383). Soundy et al. coin the latter "*hope in uncertainty*" (pp.82), describing achieving positivity through a state of not knowing (105). Kirkevold agrees, positing that such hope in uncertainty can support emotional adjustment, enabling patients to slowly realise the potential longevity of the stroke's effects rather than causing sudden psychological breakdown (330).

Although individual differences likely play a part in patients' and carers' responses to uncertainty, the way in which uncertainty is presented may affect their perceptions of their own recovery trajectory (126, 384). For example, experimental evidence suggests that the words used to denote uncertainty and the context (e.g., the salience of the outcome to the individual) can impact the recipient's interpretation of information (384). Wintle et al. demonstrated greater variation in interpretations of negative (e.g., 'unlikely') vs positive phrasing ('likely'), hypothesising this may be due to a greater focus on events that will happen, rather than those that won't (384). In stroke care (as in this research), such language is commonly used in qualitative statements of recovery potential and may contribute to patients' and carers' varying understanding. Whilst numeric estimates may be preferred by recipients to alleviate uncertainty (100), there is evidence that these are also open to interpretation (385). Whilst the implementation of prognostic models may thus facilitate the delivery of recovery information, attention should be paid to how uncertainty around their application to individual cases is conveyed and interpreted.

Although it is recommended that uncertainty in recovery trajectories is communicated (67, 386) and indeed honesty about such uncertainty is claimed to be desired by patients and families (387), limited guidance and training exists on how best to convey it and help patients to cope with it (67, 379, 388). Proposed strategies to cope with uncertainty include information seeking and psychosocial support (381). A range of illness uncertainty management-related interventions have been proven effective in reducing uncertainty in cancer; all included information provision (389). In stroke,

professionals may support patients to cope with uncertainty through providing more generic information about the process of post-stroke recovery. Even where tailored predictions are uncertain, such knowledge could help to prepare patients and families, e.g., to anticipate the slowing of recovery in the longer-term (390). Additionally, as was highlighted in my study, professionals can also help patients to cope with the uncertainty by encouraging a focus on the present (390).

Whilst patients' and carers' acceptance of the uncertainty presented to them likely helped to avoid complaints about a lack of provided information, such acceptance could also have negative effects. In this research, some patients strongly believed that the uncertainty of stroke recovery meant that it could not be predicted. This has the potential to limit the benefits of providing information about recovery described in this thesis. Where patients and carers perceive prognosis to be unpredictable, they may feel unable to make decisions based on the information provided (391). Similarly, perceptions of uncertain outcomes can limit patients' engagement in goal-setting (382). Uncertainty can also be employed by patients and families to prolong false hope; if the trajectory is unpredictable, perhaps unexpected improvements might be experienced (105). As a result, uncertainty can be used to argue for the delay of a negatively perceived process, e.g., the end of in-patient therapy (as demonstrated in my research) or provision of comfort care (392). This demonstrates the importance of the fine balance required; professionals must present sufficient uncertainty to enable hope and positivity alongside enough realism to facilitate engagement in decision-making (126, 392).

10.3.3.4 The stroke unit environment

The stroke unit environment and its conduciveness to sensitive conversations about recovery has previously received little attention in the literature. This was found to be an important factor impacting provision of information about recovery in this study, with a lack of private areas and restrictions on visiting times limiting opportunities for the exchange of sensitive information.

The need for privacy is indicated in guidance for breaking bad news, and deemed important to ensure patients' understanding and provide a safe space for them to express their emotions (393). However, the availability of quiet and private space in hospitals has been raised as a barrier to breaking bad news across conditions (394). In stroke, providing information in a quiet and private space is particularly important, due to the effects the condition can have on patients' ability to communicate and

process information (395). However, finding available private spaces on stroke units is challenging, particularly following the COVID-19 pandemic, where rehabilitation spaces were reportedly converted into overspill wards and storage; a recent survey of physiotherapists suggests these areas have not been reacquired (396).

A policy of unrestricted visiting in one site was observed to facilitate communication of information about recovery with patients' families in this research, particularly where patients were unable to relay conversations due to recall or expressive difficulties. Restrictions to visiting times are in place across many institutions, to limit disruption to professionals' work, and to enable hospitalised patients time to rest and recuperate (397). However, a range of benefits have been associated with the removal of such restrictions, including improved family satisfaction (due to being able to visit at their convenience), reduced patient anxiety, and improved opportunities for families to ask questions and receive information about the patient's condition (398). Although most research has been undertaken in critical care settings, a recent realist evaluation of the effects of implementing open visiting in older adult care identified similar benefits in communication, which also led to reduced complaints and improvements in shared decision-making (399). The sample included a high proportion of patients with dementia, who are likely to have similar cognitive and communication problems as patients with stroke, therefore the results may be transferable. Despite the identified benefits, such initiatives are often met by resistance from staff, particularly nurses (398, 399), who may require additional training to possess the confidence and skills to manage additional communication with carers (399). Further research examining the potential benefits and pitfalls of unrestricted visiting in rehabilitation settings is therefore warranted.

10.3.4 Patients and carers' expectations of recovery and the role of therapy

Findings in this study add further support to the existing literature that patients and carers view recovery differently than do professionals (346, 400, 401). Whilst for patients, recovery frequently means a return to pre-stroke life, professionals understand it as the optimisation of functional, activity, and participation levels within the context of a patient's residual disability to achieve the greatest possible independence and quality of life (346, 400). It has been suggested that patients do not know what to expect from rehabilitation (402) and survey studies have reported that they (and their carers) hold higher expectations about the outcomes than do their treating therapists (365, 366). My qualitative work adds to evidence that such health

expectations, which impact patients' satisfaction with care (403), are formed from a variety of sources (367), rather than simply the information provided by professionals involved in their care. Effective management of these expectations, e.g., through provision of information about the likely extent and timing of recovery and the process through which it occurs, therefore has the potential to improve patient satisfaction.

The physiological processes through which post-stroke recovery occurs were frequently highlighted as an omission in information provision in my qualitative work, with only vague and ambiguous messages about the long-term nature and requirement for effort observed, and reflected in patients' understanding. This may be due to the complex nature of such processes, however it is likely that sharing simplified information could be both possible, and beneficial for patients. Without such knowledge, this study, alongside others, suggests that patients and carers associate therapy with recovery; believing that greater frequency will result in increased function, with no upper limit (69). Beliefs that anticipated outcomes have not been achieved due to insufficient amounts of therapy can result in complaints, and disappointment following discharge (72, 312). However, the best 'dose' of therapy required to optimise recovery is still a matter for debate (404), and is likely individual to each patient. Access to national guidelines advocating minimum amounts of therapy (23) (which many units still do not achieve (10)), alongside absent communication about the contribution of therapy to recovery, is likely to fuel such complaints, particularly in a society where expectations for effective healthcare are high.

Patients' understanding of the role of therapy in their recovery likely impacts their experiences, and views of the services providing it. It is becoming increasingly accepted that post-stroke recovery can continue for years after the acute event, and in the context of this wider journey, time spent receiving professionally-delivered therapy is relatively short. As in previous qualitative studies (58, 69), this research highlighted patients' lack of awareness about the likely length of time that therapy would continue (and indeed, be beneficial) and they typically assumed it would continue until they perceived a full recovery had been achieved. As Wiles et al. argue, this information could be easily provided (58), however, it is possible to go further. For example, patients' expectations could be managed through helping them to understand how the process of neurological recovery lends itself to the intensive targeting of in-patient therapy within the early weeks post-stroke (targeting restoration of function during the critical window), before transitioning to less intensive home-based therapy in their own environment (and moving to compensatory strategies) and subsequent self-management of their symptoms. This could aid understanding that recovery is likely to

be incomplete at the point of discharge, and thus increase satisfaction with services as well as supporting adjustment. It may involve communicating easily understood and evidence-based statistics with patients early in their admission, e.g., that around a third of patients will leave hospital requiring some help with daily activities (3).

10.4 Strengths and limitations

Potential strengths and limitations of the methods and approaches have been addressed in detail throughout this thesis. The strengths of the work include the exploration of a clinical problem using multiple methods (systematic review, qualitative study and survey research), as well as detailed ethnographic work, which facilitated triangulation of the contemporaneous viewpoints of stroke survivors, carers, and stroke unit professionals and explored their perspectives and experiences using observation, interview, and documentary methods. This work has facilitated the development of evidence-based recommendations for intervention, underpinned by behaviour change theory.

The generalisability of the findings presented in this thesis may be limited. The reported qualitative research was conducted in one UK county in the National Health Service, therefore the extent to which findings apply to other countries and health systems is unknown. However, detailing of the context in which the research took place supports transferability. Additionally, the views of professionals from across the UK were subsequently sought, the results of which added validity to the barriers identified within the localised qualitative work, as well as progressing intervention development. Finally, the systematic reviews undertaken explored the delivery of prognostic information across a range of countries; it is reassuring that many of the findings were similar, both in stroke and across other neurological conditions.

The timing of this research is also pertinent. The qualitative data reported in this thesis were collected in 2019, prior to the start of the COVID-19 pandemic; survey data were subsequently collected in 2022 following its impact. The NHS in 2023 is under significant pressure, with staffing shortages remaining a big issue, and the pandemic has altered clinical practice in a range of ways: in 2020, communication with patients' families significantly changed, due to visiting restrictions in hospitals. This meant that prognostic information was provided by telephone or using online platforms, including the delivery of family meetings (376). The extent to which these changes have been maintained following the relaxation of visiting restrictions, and their impact on provision and receipt of information about recovery, is yet to be determined. However, despite

these practice variations, it is likely that the main issues in providing and receiving information about recovery remain unchanged.

The focus of this research was the in-patient stroke unit; this setting was selected as a mandatory component of UK-based stroke care. I did not observe the delivery of prognostic information at earlier or later stages of the stroke pathway (i.e., in hyper-acute or community-based services) to identify the types of information provided by these services and the impact this might have on patients' and carers' expectations about recovery; further research is required to shed light on how information is provided and received in these settings and the impact on patients' expectations. Additionally, a proportion of patients leave hospital directly following hyper-acute care, either with Early Supported Discharge, or without follow-up. The information needs of these patients and their families are unclear; their symptoms are likely to be mild or have resolved, but they may continue to have questions about future recovery or stroke recurrence. This research cannot provide insights as to the type of information provided to, or required by, these patients, and further study is required to ensure a joined-up and consistent approach to the provision of information about recovery across the pathway.

Finally, it has been recommended that stakeholders are involved in intervention development throughout the process (204). In this research, I had intended to use coproduction methods, engaging stroke survivors, carers, and professionals to develop the intervention. This plan proved unviable, with challenges in recruiting stroke survivors and carers to participate in face-to-face meetings in 2021, when social distancing and masking recommendations remained in place. However, the time spent developing a theoretical underpinning for the intervention is likely to have been a beneficial step, presenting a clear starting point for the intended coproduction work, which, following receipt of further funding, will now begin in 2023. This work will involve stakeholders in decision-making around the content and delivery of the intervention (204), including the materials.

10.5 Dissemination

I intend to disseminate my research findings as widely as possible to facilitate impact. This will include publishing peer-reviewed journal articles in Open Access formats. My first systematic review (Chapter 1) was published in 2021 in *BMJ Open*; a second paper based on findings from my qualitative study (presented in Chapter 4) is currently under review. I plan to publish separate papers based on staff perspectives (Chapter

5) and patient and carer views and experiences (Chapter 6), as well as a methods paper on intervention development. I will consider using a theoretical lens, e.g., biographical disruption (196) to further explain my qualitative data. I aim to publish in journals widely accessed by stroke clinicians and to also share findings via professional bulletins. For example, the results of my survey study were shared with practising OTs in the Royal College of Occupational Therapy's Specialist Section on Neurological Practice newsletter in April 2023.

I have also presented the findings of my systematic review and qualitative work to researchers and clinicians at national and international stroke conferences, including an invited presentation at the UK Stroke Forum in 2022, and posters at the UK Stroke Forum (2019, 2020, 2022) and the European Stroke Organisation Conference (2021). I also presented my research and ran an associated workshop at the Stroke Association North Zone event in 2018, attended by the charity's staff, to raise awareness of the importance of talking about recovery with stroke survivors and their families.

Findings from my qualitative work have been shared locally with stroke survivors and carers attending organised stroke groups (e.g., the Roundhay stroke club and Different Strokes in Leeds) and awareness of my research has been raised through a feature ("The Power of Talking") in the Stroke Association's monthly newsletter in March 2021, which reaches stroke survivors and carers nationally.

10.6 Implications for intervention development

This research suggests that professionals working in stroke units both require and desire greater support and training in the provision of information about recovery, to enable them to meet patients' and carers' information needs. A range of barriers which require addressing within an intervention have been identified in this research; it is likely to be particularly important to improve professionals' confidence and communication skills. This could be supported through the use of existing techniques and strategies, e.g., models of breaking bad news such as SPIKES (131)) and approaches such as Communication Coaching (405). Additionally, interventions should aim to improve professionals' knowledge and understanding of the benefits of providing recovery information and the effects on not providing such information on patients' and carers' experiences. This research has contributed to that evidence

base, and presentation of these findings alongside those from other relevant research and stroke survivor and carer perspectives may be effective in persuading professionals of the importance of talking about recovery.

The importance of tailoring information according to patients' and carers' needs should be emphasised; interventions should thus avoid prescribed timing of provision and promote flexibility to meet patients' needs, including encouragement to engage in dialogue to ascertain these needs and how information can best be delivered to ensure they are met. This may include developing standardised or modifiable written resources, and support for professionals to make decisions about how and when to deliver these resources and how they can be appropriately individualised.

Finally, the findings of this research indicate that interventions to improve delivery of recovery information are likely to require delivery using combined methods, with face-to-face training (encompassing observations, practice and feedback) supported by remote technological solutions, such as online video demonstrations and webinars, and provision of forums for online discussion and support. The importance of targeting the whole stroke unit MDT (including peripheral members) has been highlighted, to facilitate a consistent approach for patients and families, with improved organisation, planning and focus on provision of recovery information likely to lead to benefits.

10.7 Conclusions

In conclusion, the findings of this research indicate that patients and carers' needs for information about recovery continue to remain unmet, negatively impacting their experiences of post-stroke care; they also highlight the considerable challenges faced by professionals in providing this information.

These findings have key implications for the ways in which information about recovery should be shared with patients and their carers on the stroke unit. Firstly, patients and carers desire information to be provided with empathy and compassion, allowing them to retain hope for the future. Training for professionals is likely to be required to facilitate development of the confidence and communication skills required to achieve this, as well as to improve the clarity of information, particularly in the face of uncertainty. An awareness of the roles of MDT members is critical, and professionals across the MDT should work together to formulate predictions and communicate how

these predictions have and will be shared with patients and carers to ensure consistency, as well as to support each other to manage the psychological impact of engaging in challenging conversations.

This research particularly highlights patients' and carers' dissatisfaction with the lack of opportunities provided to discuss recovery, which appeared to result in inequity, with some patients afforded more opportunities to ask questions and receive information than others. Focusing professionals' minds on how such conversations can be built into routine practice and how their work can be organised to facilitate them could improve equity. This should include processes for ensuring proactive engagement in dialogue about patients' and carers' information needs and how best they might be met. Inclusion in professional guidelines as part of the ongoing policy drive for patient-centred care would facilitate this.

Concrete examples have been provided relating to how sharing information about post-stroke recovery can facilitate engagement in shared decision-making and adjustment to the potential for on-going symptoms and disability. Improving patients' and carers' knowledge of the process of stroke recovery, and how services are organised to support it, could improve satisfaction with care through instilling realistic expectations.

These findings highlight the need for further research in a range of areas. Firstly, although this research has developed an understanding of the roles of most MDT members in providing information about recovery, the roles of some professionals remains unclear, including nurses, and more peripheral allied health professionals, including dieticians and orthoptists. The role of clinical psychologists in supporting professionals to compassionately provide information and also patients and families to come to terms with the potential for any ongoing disability is worthy of further investigation, particularly with the drive to improve psychological care post-stroke.

Despite attempts to recruit a diverse sample of stroke survivors and carers in this research, the voices of those from ethnic minorities were underrepresented. Further research is required to understand how cultural factors can impact interpretations and expectations of post-stroke recovery, and how information can best be shared with those whose first language is not English. Finally, although clinical guidelines recommend the use of standardised tools to predict recovery, such measures are

seldom employed in stroke unit practice. Research to understand how best these tools could be implemented and their findings shared with patients and families to support conversations about recovery is in its infancy; more work is required to understand the acceptability to professionals, patients and families, and any associated benefits.

References

1. Feigin VL, Stark BA, Johnson CO, Roth GA, Bisignano C, Abady GG, et al. Global, regional, and national burden of stroke and its risk factors, 1990–2019: a systematic analysis for the Global Burden of Disease Study 2019. *The Lancet Neurology*. 2021;20(10):795-820.
2. World Stroke Organisation. Global Stroke Fact Sheet: World Stroke Organization; 2022. Available from: https://www.world-stroke.org/assets/downloads/WSO_Global_Stroke_Fact_Sheet.pdf [accessed June 2023].
3. The Stroke Association. State of the nation: Stroke statistics 2017. Available from: <https://www.mynewsdesk.com/uk/stroke-association/documents/state-of-the-nation-2017-68765> [accessed March 2023].
4. Aho K, Harmsen P, Hatano S, Marquardsen J, Smirnov VE, Strasser T. Cerebrovascular disease in the community: results of a WHO collaborative study. *Bull World Health Organ*. 1980;58(1):113-30.
5. Rathore SS, Hinn AR, Cooper LS, Tyroler HA, Rosamond WD. Characterization of incident stroke signs and symptoms: findings from the atherosclerosis risk in communities study. *Stroke*. 2002;33(11):2718-21.
6. Naess H, Lunde L, Brogger J. The effects of fatigue, pain, and depression on quality of life in ischemic stroke patients: the Bergen Stroke Study. *Vascular Health and Risk Management*. 2012:407-13.
7. De Wit L, Theuns P, Dejaeger E, Devos S, Gantenbein AR, Kerckhofs E, et al. Long-term impact of stroke on patients' health-related quality of life. *Disabil Rehabil*. 2017;39(14):1435-40.
8. Low JT, Payne S, Roderick P. The impact of stroke on informal carers: a literature review. *Soc Sci Med*. 1999;49(6):711-25.
9. Pucciarelli G, Vellone E, Savini S, Simeone S, Ausili D, Alvaro R, et al. Roles of changing physical function and caregiver burden on quality of life in stroke: A longitudinal dyadic analysis. *Stroke*. 2017;48(3):733-9.
10. Sentinel Stroke National Audit Programme. The road to recovery: The ninth annual SSNAP report. London: Healthcare Quality Improvement Partnership; 2022. Available from: <https://www.strokeaudit.org/Documents/National/Clinical/Apr2021Mar2022/Apr2021Mar2022-AnnualReport.aspx> [accessed June 2023].
11. Seminog OO, Scarborough P, Wright FL, Rayner M, Goldacre MJ. Determinants of the decline in mortality from acute stroke in England: linked national database study of 795 869 adults. *BMJ*. 2019;365(11778):1-10.

12. DeJong G, Horn SD, Conroy B, Nichols D, Heulton EB. Opening the black box of poststroke rehabilitation: stroke rehabilitation patients, processes, and outcomes. *Arch Phys Med Rehabil.* 2005;86(12):1-7.
13. Krakauer JW, Carmichael ST, Corbett D, Wittenberg GF. Getting neurorehabilitation right: what can be learned from animal models? *Neurorehabilitation and Neural Repair.* 2012;26(8):923-31.
14. Kalra L, Harris R. Stroke rehabilitation. In: Kalra L, Wolfe C, Rudd A, editors. *Practical Guide To Comprehensive Stroke Care, A: Meeting Population Needs.* Singapore: World Scientific Publishing Co; 2010. p. 253-82.
15. Langhorne P, Bernhardt J, Kwakkel G. Stroke rehabilitation. *Lancet.* 2011;377(9778):1693-702.
16. Plowman E, Hentz B, Ellis C. Post-stroke aphasia prognosis: A review of patient-related and stroke-related factors. *J Eval Clin Pract.* 2012;18(3):689-94.
17. Watila MM, Balarabe SA. Factors predicting post-stroke aphasia recovery. *J Neurol Sci.* 2015;352(1-2):12-8.
18. Kwakkel G, Kollen BJ. Predicting Activities after Stroke: What is Clinically Relevant? *International Journal of Stroke.* 2013;8(1):25-32.
19. Zeiler SR, Krakauer JW. The interaction between training and plasticity in the post-stroke brain. *Curr Opin Neurol.* 2013;26(6):609.
20. Lohse KR, Lang CE, Boyd LA. Is more better? Using metadata to explore dose–response relationships in stroke rehabilitation. *Stroke.* 2014;45(7):2053-8.
21. Kwakkel G, van Peppen R, Wagenaar RC, Wood Dauphinee S, Richards C, Ashburn A, et al. Effects of augmented exercise therapy time after stroke: a meta-analysis. *Stroke.* 2004;35(11):2529-39.
22. Veerbeek JM, Koolstra M, Ket JC, van Wegen EE, Kwakkel G. Effects of augmented exercise therapy on outcome of gait and gait-related activities in the first 6 months after stroke: a meta-analysis. *Stroke.* 2011;42(11):3311-5.
23. Intercollegiate Stroke Working Party. National Clinical Guideline for Stroke for the UK and Ireland. London: Royal College of Physicians; 2023. Available from: <https://www.strokeguideline.org/> [accessed April 2023].
24. Sun Y, Boots J, Zehr EP. The lingering effects of a busted myth—false time limits in stroke rehabilitation. *Applied Physiology, Nutrition, and Metabolism.* 2015;40(8):858-61.
25. Ward NS, Brander F, Kelly K. Intensive upper limb neurorehabilitation in chronic stroke: outcomes from the Queen Square programme. *J Neurol Neurosurg Psychiatry.* 2019;90(5):498-506.
26. Ingwersen T, Wolf S, Birke G, Schlemm E, Bartling C, Bender G, et al. Long-term recovery of upper limb motor function and self-reported health: results from a

- multicenter observational study 1 year after discharge from rehabilitation. *Neurological Research and Practice*. 2021;3(1):1-10.
27. Holland A, Fromm D, Forbes M, MacWhinney B. Long-term recovery in stroke accompanied by aphasia: A reconsideration. *Aphasiology*. 2017;31(2):152-65.
28. Kim S, Cho S. The effect of cognitive rehabilitation program combined with physical exercise on cognitive function, depression, and sleep in chronic stroke patients. *Physical Therapy Rehabilitation Science*. 2022;11(1):32-42.
29. Stinear CM, Smith M-C, Byblow WD. Prediction tools for stroke rehabilitation. *Stroke*. 2019;50(11):3314-22.
30. Kiær C, Lundquist CB, Brunner I. Knowledge and application of upper limb prediction models and attitude toward prognosis among physiotherapists and occupational therapists in the clinical stroke setting. *Topics in Stroke Rehabilitation*. 2021;28(2):135-41.
31. Stinear CM, Ward NS. How useful is imaging in predicting outcomes in stroke rehabilitation? *International Journal of Stroke*. 2013;8(1):33-7.
32. Hoffmann JE. "Nothing Can Be Done": Social Dimensions of the Treatment of Stroke Patients in a General Hospital. *Urban Life and Culture*. 1974;3(1):50-70.
33. Wardlaw JM, Murray V, Berge E, Del Zoppo GJ. Thrombolysis for acute ischaemic stroke. *Cochrane database of systematic reviews*. 2014(7).
34. Morris S, Hunter RM, Ramsay AI, Boaden R, McKeivitt C, Perry C, et al. Impact of centralising acute stroke services in English metropolitan areas on mortality and length of hospital stay: difference-in-differences analysis. *BMJ*. 2014;349(g4757).
35. Hunter RM, Davie C, Rudd A, Thompson A, Walker H, Thomson N, et al. Impact on clinical and cost outcomes of a centralized approach to acute stroke care in London: a comparative effectiveness before and after model. *PloS One*. 2013;8(8):e70420.
36. Goyal M, Menon BK, Van Zwam WH, Dippel DW, Mitchell PJ, Demchuk AM, et al. Endovascular thrombectomy after large-vessel ischaemic stroke: a meta-analysis of individual patient data from five randomised trials. *Lancet*. 2016;387(10029):1723-31.
37. Stroke Unit Trialists' Collaboration. Collaborative systematic review of the randomised trials of organised inpatient (stroke unit) care after stroke. *BMJ*. 1997;314:1151-9.
38. Langhorne P, Ramachandra S, Stroke Unit Trialists' Collaboration. Organised inpatient (stroke unit) care for stroke: network meta-analysis. *Cochrane Database of Systematic Reviews*. 2020(4).
39. Rudd A, Hoffman A, Irwin P, Pearson M, Lowe D. Stroke units: research and reality. Results from the National Sentinel Audit of Stroke. *BMJ Quality & Safety*. 2005;14(1):7-12.

40. Langhorne P. The Stroke Unit Story: Where Have We Been and Where Are We Going? *Cerebrovascular Diseases*. 2021;1-8.
41. Rodgers H, Price C. Stroke unit care, inpatient rehabilitation and early supported discharge. *Clinical Medicine*. 2017;17(2):173.
42. Dewey HM, Sherry LJ, Collier JM. Stroke rehabilitation 2007: what should it be? *International Journal of Stroke*. 2007;2(3):191-200.
43. National Stroke Programme. National service model for an integrated community stroke service. London: NHS England and NHS Improvement; 2022. Available from: <https://www.england.nhs.uk/wp-content/uploads/2022/02/stroke-integrated-community-service-february-2022.pdf> [accessed June 2023].
44. Clery A, Bhalla A, Bisquera A, Skolarus LE, Marshall I, McKeivitt C, et al. Long-term trends in stroke survivors discharged to care homes: The South London Stroke Register. *Stroke*. 2020;51(1):179-85.
45. Intercollegiate Stroke Working Party. National Clinical Guideline for Stroke (5th Ed). UK: Royal College of Physicians; 2016.
46. Fisher RJ, Chouliara N, Byrne A, Cameron T, Lewis S, Langhorne P, et al. Large-scale implementation of stroke early supported discharge: the WISE realist mixed-methods study. *Health Services and Delivery Research*. 2021;9(22).
47. Langhorne P, Pollock A. What are the components of effective stroke unit care? *Age Ageing*. 2002;31(5):365-71.
48. Department of Health. Better information, better choices, better health: Putting information at the centre of healthcare. London: Department of Health; 2004. Available from: https://webarchive.nationalarchives.gov.uk/ukgwa/20121011072939/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4098576 [accessed June 2023].
49. Crocker TF, Brown L, Lam N, Wray F, Knapp P, Forster A. Information provision for stroke survivors and their carers. *Cochrane Database of Systematic Reviews*. 2021(11).
50. Department of Health. National Stroke Strategy. London: Department of Health; 2007. Available from: https://nsnf.org.uk/assets/documents/dh_081059.pdf [accessed June 2023].
51. Prick J, Zonjee V, Van Schaik S, Dahmen R, Garvelink M, Brouwers P, et al. Experiences with information provision and preferences for decision making of patients with acute stroke. *Patient Education and Counseling*. 2022;105(5):1123-9.
52. Lin B-l, Mei Y-x, Wang W-n, Wang S-s, Li Y-s, Xu M-y, et al. Unmet care needs of community-dwelling stroke survivors: a systematic review of quantitative studies. *BMJ Open*. 2021;11(4):e045560.

53. Zawawi NSM, Aziz NA, Fisher R, Ahmad K, Walker MF. The Unmet Needs of Stroke Survivors and Stroke Caregivers: A Systematic Narrative Review. *Journal of Stroke and Cerebrovascular Diseases*. 2020;29(8):104875.
54. Denham AM, Wynne O, Baker AL, Spratt NJ, Loh M, Turner A, et al. The long-term unmet needs of informal carers of stroke survivors at home: a systematic review of qualitative and quantitative studies. *Disabil Rehabil*. 2022;44(1):1-12.
55. Pindus DM, Mullis R, Lim L, Wellwood I, Rundell AV, Abd Aziz NA, et al. Stroke survivors' and informal caregivers' experiences of primary care and community healthcare services—a systematic review and meta-ethnography. *PloS One*. 2018;13(2):e0192533.
56. Hafsteinsdóttir TB, Vergunst M, Lindeman E, Schuurmans M. Educational needs of patients with a stroke and their caregivers: a systematic review of the literature. *Patient education and counseling*. 2011;85(1):14-25.
57. Garrett D, Cowdell F. Information needs of patients and carers following stroke. *Nursing older people*. 2005;17(6):14-6.
58. Wiles R, Pain H, Buckland S, McLellan L. Providing appropriate information to patients and carers following a stroke. *J Adv Nurs*. 1998;28(4):794-801.
59. Cameron JI, Gignac MA. “Timing It Right”: A conceptual framework for addressing the support needs of family caregivers to stroke survivors from the hospital to the home. *Patient education and counseling*. 2008;70(3):305-14.
60. Luker J, Murray C, Lynch E, Bernhardsson S, Shannon M, Bernhardt J. Carers' experiences, needs, and preferences during inpatient stroke rehabilitation: a systematic review of qualitative studies. *Arch Phys Med Rehab*. 2017;98:1852-62.
61. Connell LA, Chesworth B, Ackerley S, Smith M-C, Stinear CM. Implementing the PREP2 algorithm to predict upper limb recovery potential after stroke in clinical practice: a qualitative study. *Phys Ther*. 2021;101(5):pzab040.
62. Grainger KP, Masterson S, Jennings M. ‘Things aren't the same, are they?': The management of bad news delivery in the discourse of stroke care. *Communication and Medicine*. 2005;2(1):35-44.
63. Sexton D. ‘As Good as it's Going to Get'. Bad News Conversations in Neurology: Challenges for Occupational Therapists. *Br J Occup Ther*. 2013;76(6):270-9.
64. Hanger H, Walker G, Paterson L, McBride S, Sainsbury R. What do patients and their carers want to know about stroke? A two-year follow-up study. *Clin Rehabil*. 1998;12(1):45-52.
65. The Stroke Association. Stroke Patient Reported Experience Measures (PREMs) Survey 2022/23: National Report. UK: IQVIA UK&I Healthcare; 2023. Available from:

https://www.stroke.org.uk/sites/default/files/professionals/stroke_premis_22_23_national_report.pdf [accessed September 2023].

66. Christakis NA. *Death foretold: prophecy and prognosis in medical care*: University of Chicago Press; 2001.
67. Holloway RG, Gramling R, Kelly AG. Estimating and communicating prognosis in advanced neurologic disease. *Neurology*. 2013;80(8):764-72.
68. Phillips J, Kneebone II, Taverner B. Breaking bad news in stroke rehabilitation: a consultation with a community stroke team. *Disabil Rehabil*. 2013;35(8):694-701.
69. Wiles R, Ashburn A, Payne S, Murphy C. Patients' expectations of recovery following stroke: a qualitative study. *Disabil Rehabil*. 2002;24(16):841-50.
70. Maclean N, Pound P, Wolfe C, Rudd A. A critical review of the concept of patient motivation in the literature on physical rehabilitation. *Soc Sci Med*. 2000;50(4):495-506.
71. Becker G, Kaufman SR. Managing an uncertain illness trajectory in old age: patients' and physicians' views of stroke. *Med Anthropol Q*. 1995;9(2):165-87.
72. Wiles R, Ashburn A, Payne S, Murphy C. Discharge from physiotherapy following stroke: the management of disappointment. *Soc Sci Med*. 2004;59(6):1263-73.
73. Higgins J, Thomas J, Chandler J, Cumpston M, Li T, Page M, et al. *Cochrane Handbook for Systematic Reviews of Interventions version 6.3 (updated February 2022)*. UK: Cochrane; 2022. Available from: <http://www.training.cochrane.org/handbook> [Accessed July 2022].
74. Aromataris E, Munn Z. Chapter 1: JBI Systematic Reviews. 2020. In: *JBI Manual for Evidence Synthesis* [Internet]. JBI. Available from: <https://synthesismanual.jbi.global> [accessed August 2023].
75. Sackett DL, Rosenberg WM, Gray JM, Haynes RB, Richardson WS. Evidence based medicine: what it is and what it isn't. *BMJ*; 1996. p. 71-2.
76. Green S. Systematic reviews and meta-analysis. *Singapore Med J*. 2005;46(6):270-4.
77. Munn Z, Stern C, Aromataris E, Lockwood C, Jordan Z. What kind of systematic review should I conduct? A proposed typology and guidance for systematic reviewers in the medical and health sciences. *BMC Medical Research Methodology*. 2018;18(1):1-9.
78. Thomas J, Harden A, Oakley A, Oliver S, Sutcliffe K, Rees R, et al. Integrating qualitative research with trials in systematic reviews. *BMJ*. 2004;328(7446):1010-2.
79. Green J, Thorogood N. *Qualitative methods for health research (4th Ed)*. UK: SAGE; 2018.

80. Lockwood C, Porritt K, Munn Z, Rittenmeyer L, Salmond S, Bjerrum M, et al. Chapter 2: Systematic reviews of qualitative evidence. 2020. In: JBI Manual for Evidence Synthesis [Internet]. JBI. Available from: <https://synthesismanual.jbi.global> [Accessed August 2023].
81. Bousquet G, Orri M, Winterman S, Brugière C, Verneuil L, Revah-Levy A. Breaking bad news in oncology: a metasynthesis. *J Clin Oncol*. 2015;33(22):2437-43.
82. Stinear C. Prediction of recovery of motor function after stroke. *The Lancet Neurology*. 2010;9(12):1228-32.
83. Peel R, Jones S, Miller C, Gibson J. Great expectations? A qualitative study of health professionals' perspectives on breaking bad news about rehabilitation potential after traumatic brain injury or spinal injury. *Disabil Rehabil*. 2019;42(22):3209-14.
84. Yates J, Stanyon M, Samra R, Clare L. Challenges in disclosing and receiving a diagnosis of dementia: a systematic review of practice from the perspectives of people with dementia, carers, and healthcare professionals. *Int Psychogeriatr*. 2021;33(11):1161-92.
85. Walsh RA, Girgis A, Sanson-Fisher RW. Breaking bad news 2: What evidence is available to guide clinicians? *Behav Med*. 1998;24(2):61-72.
86. Kühne F, Hermann M, Preisler M, Rohrmoser A, Letsch A, Goerling U. Prognostic awareness in advanced disease: a review update and concept analysis. *Frontiers in Psychology*. 2021;12:629050.
87. Lemmon ME, Gamaldo C, Salas RME, Saxena A, Cruz TE, Boss RD, et al. Education Research: difficult conversations in neurology: lessons learned from medical students. *Neurology*. 2018;90(2):93-7.
88. Ritchie J, Lewis J, Nicholls CM, Ormston R. *Qualitative research practice: A guide for social science students and researchers (2nd Ed)*. London: SAGE Publications Ltd; 2013.
89. De Jong Y, van der Willik E, Milders J, Voorend C, Morton RL, Dekker F, et al. A meta-review demonstrates improved reporting quality of qualitative reviews following the publication of COREQ-and ENTREQ-checklists, regardless of modest uptake. *BMC medical research methodology*. 2021;21:1-11.
90. Pope C, Mays N. *Qualitative research in health care (3rd Ed)*. Oxford: Blackwell Publishing Ltd; 2006.
91. Garside R. Should we appraise the quality of qualitative research reports for systematic reviews, and if so, how? *Innovation: The European Journal of Social Science Research*. 2014;27(1):67-79.
92. National Institute for Health and Care Excellence. *Methods for the development of NICE public health guidance (third edition)*. UK: NICE; 2012. Available from:

<https://www.nice.org.uk/process/pmg4/chapter/15-appendix-h-quality-appraisal-checklist-qualitative-studies> [accessed January 2020].

93. Thomas J, Harden A. Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Med Res Methodol*. 2008;8(1):45.
94. Barnett-Page E, Thomas J. Methods for the synthesis of qualitative research: a critical review. *BMC Med Res Methodol*. 2009;9(1):1-11.
95. Lefebvre H, Levert M-J. The close relatives of people who have had a traumatic brain injury and their special needs. *Brain Inj*. 2012;26(9):1084-97.
96. Lefebvre H, Levert MJ. The needs experienced by individuals and their loved ones following a traumatic brain injury. *J Trauma Nurs*. 2012;19(4):197-207.
97. Bond AE, Draeger CRL, Mandlco B, Donnelly M. Needs of family members of patients with severe traumatic brain injury: Implications for evidence-based practice. *Crit Care Nurse*. 2003;23(4):63-72.
98. Danzl MM, Harrison A, Hunter EG, Kuperstein J, Sylvia V, Maddy K, et al. "A lot of things passed me by": Rural stroke survivors' and caregivers' experience of receiving education from health care providers. *The Journal of Rural Health*. 2016;32(1):13-24.
99. Kirshblum SC, Botticello AL, DeSipio GB, Fichtenbaum J, Shah A, Scelza W. Breaking the news: A pilot study on patient perspectives of discussing prognosis after traumatic spinal cord injury. *J Spinal Cord Med*. 2016;39(2):155-61.
100. Quinn T, Moskowitz J, Khan MW, Shutter L, Goldberg R, Col N, et al. What families need and physicians deliver: contrasting communication preferences between surrogate decision-makers and physicians during outcome prognostication in critically ill TBI patients. *Neurocrit Care*. 2017;27(2):154-62.
101. Schutz RE, Coats HL, Engelberg RA, Curtis JR, Creutzfeldt CJ. Is there hope? Is she there? How families and clinicians experience severe acute brain injury. *J Palliat Med*. 2017;20(2):170-6.
102. Applebaum A, Buda K, Kryza-Lacombe M, Buthorn J, Walker R, Shaffer K, et al. Prognostic awareness and communication preferences among caregivers of patients with malignant glioma. *Psychooncology*. 2018;27(3):817-23.
103. Dams-O'Connor K, Landau A, Hoffman J, St De Lore J. Patient perspectives on quality and access to healthcare after brain injury. *Brain Inj*. 2018;32(4):431-41.
104. Zahuranec DB, Anspach RR, Roney ME, Fuhrel-Forbis A, Connochie DM, Chen EP, et al. Surrogate decision makers' perspectives on family members' prognosis after intracerebral hemorrhage. *Journal of palliative medicine*. 2018;21(7):956-62.
105. Soundy A, Smith B, Butler M, Lowe CM, Helen D, Winward CHJPT, et al. A qualitative study in neurological physiotherapy and hope: beyond physical improvement. *Physiother Theory Pract*. 2010;26(2):79-88.

106. Hersh D. "Weaning" clients from aphasia therapy: Speech pathologists' strategies for discharge. *Aphasiology*. 2003;17(11):1007-29.
107. Ch'Ng AM, French D, Mclean N. Coping with the challenges of recovery from stroke: long term perspectives of stroke support group members. *Journal of Health Psychology*. 2008;13(8):1136-46.
108. Lobb EA, Halkett G, Nowak A. Patient and caregiver perceptions of communication of prognosis in high grade glioma. *J Neurooncol*. 2011;104(1):315-22.
109. El Masry Y, Mullan B, Hackett M. Psychosocial experiences and needs of Australian caregivers of people with stroke: prognosis messages, caregiver resilience, and relationships. *Topics in Stroke Rehabilitation*. 2013;20(4):356-68.
110. Maddern R, Kneebone II. Receiving bad news: a thematic analysis of stroke survivor experiences. *Journal of Patient Experience*. 2019;6(4):271-7.
111. Dewar A. Nurses' experiences in giving bad news to patients with spinal cord injuries. *J Neurosci Nurs*. 2000;32(6):324.
112. Lefebvre H, Levert MJ. Breaking the news of traumatic brain injury and incapacities. *Brain Inj*. 2006;20(7):711-8.
113. Gofton T, Chum M, Schulz V, Gofton B, Sarpal A, Watling C. Challenges facing palliative neurology practice: a qualitative analysis. *J Neurol Sci*. 2018;385:225-31.
114. Garrino L, Curto N, Decorte R, Felisi N, Matta E, Gregorino S, et al. Towards personalized care for persons with spinal cord injury: a study on patients' perceptions. *J Spinal Cord Med*. 2011;34(1):67-75.
115. Conti A, Garrino L, Montanari P, Dimonte V. Informal caregivers' needs on discharge from the spinal cord unit: analysis of perceptions and lived experiences. *Disabil Rehabil*. 2016;38(2):159-67.
116. Rejnö Å, Silfverberg G, Ternstedt B-M. Reasoning about truth-telling in end-of-life care of patients with acute stroke. *Nursing ethics*. 2017;24(1):100-10.
117. Ozyemisci-Taskiran O, Coskun O, Budakoglu II, Demirsoy N. Breaking bad news in spinal cord injury; a qualitative study assessing the perspective of spinal cord injury survivors in Turkey. *J Spinal Cord Med*. 2018;41(3):347-54.
118. Matthews T, Baken D, Ross K, Ogilvie E, Kent L. The experiences of patients and their family members when receiving bad news about cancer: A qualitative meta-synthesis. *Psychooncology*. 2019;28(12):2286-94.
119. Hagerty R, Butow PN, Ellis P, Dimitry S, Tattersall M. Communicating prognosis in cancer care: a systematic review of the literature. *Ann Oncol*. 2005;16(7):1005-53.
120. Fujimori M, Uchitomi Y. Preferences of cancer patients regarding communication of bad news: a systematic literature review. *Jpn J Clin Oncol*. 2009;39(4):201-16.

121. Ptacek JT, Eberhardt TL. Breaking bad news: a review of the literature. *JAMA*. 1996;276(6):496-502.
122. Warriar V, Pradhan A. A narrative review of interventions to teach medical students how to break bad news. *Medical science educator*. 2020;30:1299-312.
123. Francis L, Robertson N. Healthcare practitioners' experiences of breaking bad news: a critical interpretative meta synthesis. *Patient Education and Counseling*. 2022:107574.
124. Nye E, Melendez-Torres G, Bonell C. Origins, methods and advances in qualitative meta-synthesis. *Review of Education*. 2016;4(1):57-79.
125. Mays N, Pope C. Assessing quality in qualitative research. *BMJ*. 2000;320(7226):50-2.
126. Cheng BB, Ryan B, Copland DA, Wallace SJ. Prognostication in post-stroke aphasia: Speech pathologists' clinical insights on formulating and delivering information about recovery. *Disabil Rehabil*. 2022;44(18):5046-59.
127. Cheng BB, Ryan BJ, Copland DA, Wallace SJ. Prognostication in post-stroke aphasia: Perspectives of people with aphasia on receiving information about recovery. *Neuropsychological Rehabilitation*. 2022;33(5):871-902.
128. Cheng BB, Ryan BJ, Copland DA, Wallace SJ. Prognostication in Poststroke Aphasia: Perspectives of Significant Others of People With Aphasia on Receiving Information About Recovery. *American Journal of Speech-Language Pathology*. 2022;31(2):896-911.
129. Kersten P, George S, McLellan L, Smith JA, Mullee MA. Met and unmet needs reported by severely disabled people in southern England. *Disabil Rehabil*. 2000;22(16):737-44.
130. Cox RJ, Amsters DI, Pershouse KJ. The need for a multidisciplinary outreach service for people with spinal cord injury living in the community. *Clin Rehabil*. 2001;15(6):600-6.
131. Buckman RA. Breaking bad news: the SPIKES strategy. *Community Oncol*. 2005;2(2):138-42.
132. Baile WF, Kudelka AP, Beale EA, Globler GA, Myers EG, Greisinger AJ, et al. Communication skills training in oncology: description and preliminary outcomes of workshops on breaking bad news and managing patient reactions to illness. *Cancer*. 1999;86(5):887-97.
133. Park I, Gupta A, Mandani K, Haubner L, Peckler B. Breaking bad news education for emergency medicine residents: A novel training module using simulation with the SPIKES protocol. *J Emerg Trauma Shock*. 2010;3(4):385-8.

134. McCluskey L, Casarett D, Siderowf A. Breaking the news: a survey of ALS patients and their caregivers. *Amyotroph Lateral Scler Other Motor Neuron Disord.* 2004;5(3):131-5.
135. Feigin VL, Norrving B, Mensah GA. Global Burden of Stroke. *Circ Res.* 2017;120(3):439-48.
136. Donkor ES. Stroke in the century: a snapshot of the burden, epidemiology, and quality of life. *Stroke research and treatment.* 2018;2018:3238165.
137. Bryman A. The end of the paradigm wars. In: Alasuutari P, Bickman L, Brannen J, editors. *The SAGE handbook of social research methods.* London: SAGE Publications Ltd; 2008. p. 13-25.
138. Chamberlain K. Methodolatry and qualitative health research. *Journal of Health Psychology.* 2000;5(3):285-96.
139. Avis M. Do we need methodological theory to do qualitative research? *Qualitative health research.* 2003;13(7):995-1004.
140. Bryman A. Paradigm peace and the implications for quality. *International journal of social research methodology.* 2006;9(2):111-26.
141. Giacomini M. Theory matters in qualitative health research. In: Bourgeault I, Dingwall R, De Vries R, editors. *The SAGE handbook of qualitative methods in health research.* London: SAGE Publications Ltd; 2010. p. 125-56.
142. Savage J. Ethnography and health care. *BMJ.* 2000;321(7273):1400-2.
143. Hammersley M, Atkinson P. *Ethnography: Principles in Practice (3rd Ed).* UK: Routledge; 2007.
144. Atkinson P, Hammersley M. Ethnography and Participant Observation. In: Denzin NKE, Lincoln YS, editors. *Strategies of qualitative inquiry.* Thousand Oaks, CA: SAGE Publications Ltd; 1998. p. 110-36.
145. Finlay L. Negotiating the swamp: the opportunity and challenge of reflexivity in research practice. *Qualitative research.* 2002;2(2):209-30.
146. Finlay L, Gough B. *Reflexivity: A practical guide for researchers in health and social sciences.* Oxford, UK: Blackwell Science Ltd; 2003.
147. Côté-Boileau É, Gaboury I, Breton M, Denis J-L. Organizational ethnographic case studies: toward a new generative in-depth qualitative methodology for health care research? *International Journal of Qualitative Methods.* 2020;19:1609406920926904.
148. Simons H. *Case study research in practice.* London: SAGE publications; 2009.
149. Yin RK. *Case study research and applications: Design and method (6th Ed).* Thousand Oaks, CA: SAGE Publications 2018.
150. Higginbottom GM, Boadu N, Pillay J. Guidance on performing focused ethnographies with an emphasis on healthcare research. *The Qualitative Report.* 2013;18(17):1-16.

151. Bikker AP, Atherton H, Brant H, Porqueddu T, Campbell JL, Gibson A, et al. Conducting a team-based multi-sited focused ethnography in primary care. *BMC Medical Research Methodology*. 2017;17:1-9.
152. Reigada C, Arantzamendi M, Centeno C. Palliative care in its own discourse: a focused ethnography of professional messaging in palliative care. *BMC Palliative Care*. 2020;19(1):1-10.
153. Atherton H, Brant H, Ziebland S, Bikker A, Campbell J, Gibson A, et al. Alternatives to the face-to-face consultation in general practice: focused ethnographic case study. *Br J Gen Pract*. 2018;68(669):e293-e300.
154. Hales C, Coombs M, de Vries K. The challenges in caring for morbidly obese patients in Intensive Care: A focused ethnographic study. *Australian Critical Care*. 2018;31(1):37-41.
155. Andreassen P, Christensen MK, Møller JE. Focused ethnography as an approach in medical education research. *Med Educ*. 2020;54(4):296-302.
156. Mays N, Pope C. Qualitative research: observational methods in health care settings. *BMJ*. 1995;311(6998):182-4.
157. Gold R. Roles in Sociological Field Observations. *Social Forces*. 1958;36:217-23.
158. Wind G. Negotiated interactive observation: Doing fieldwork in hospital settings. *Anthropology & medicine*. 2008;15(2):79-89.
159. Roethlisberger FJ, Dickson WJ. *Management and the Worker*. Cambridge, MA: Harvard University Press; 2003.
160. Sedgwick P, Greenwood N. Understanding the Hawthorne effect. *BMJ*. 2015;351:h4672.
161. Roper J, Shapira J. *Ethnography in nursing research*. Thousand Oaks, CA: SAGE Publications; 2000.
162. Prior L. Documents. In: Seale C, Silverman D, Gubrium JF, Gobo G, editors. *Qualitative Research Practice*. London: SAGE Publications Ltd; 2003. p. 1-640.
163. Dalglis SL, Khalid H, McMahon SA. Document analysis in health policy research: the READ approach. *Health policy and planning*. 2020;35(10):1424-31.
164. Bateman BT, Meyers PM, Schumacher HC, Mangla S, Pile-Spellman J. Conducting stroke research with an exception from the requirement for informed consent. *Stroke*. 2003;34(5):1317-23.
165. Shiggins C, Ryan B, O'Halloran R, Power E, Bernhardt J, Lindley RI, et al. Towards the consistent inclusion of people with aphasia in stroke research irrespective of discipline. *Arch Phys Med Rehabil*. 2022;103(11):2256-63.

166. Townend E, Brady M, McLaughlan K. Exclusion and inclusion criteria for people with aphasia in studies of depression after stroke: a systematic review and future recommendations. *Neuroepidemiology*. 2007;29(1-2):1-17.
167. Janssen PM, Chalos V, van den Berg SA, Kompanje EJ, Nederkoorn PJ, van der Worp BH, et al. Neurological deficits in stroke patients that may impede the capacity to provide informed consent for endovascular treatment trials. *Journal of Stroke and Cerebrovascular Diseases*. 2019;28(12):104447.
168. Vaughan E, Manning MX. Are People with Aphasia Included in Stroke Trials? A Systematic Review and Narrative Synthesis. *Clin Rehabil*. 2023;37(10):1375-85.
169. Shepherd V. Research involving adults lacking capacity to consent: the impact of research regulation on 'evidence biased' medicine. *BMC Medical Ethics*. 2016;17(1):1-8.
170. Flowers HL, Skoretz SA, Silver FL, Rochon E, Fang J, Flaman-Roze C, et al. Poststroke aphasia frequency, recovery, and outcomes: a systematic review and meta-analysis. *Arch Phys Med Rehabil*. 2016;97(12):2188-201. e8.
171. Mellon L, Brewer L, Hall P, Horgan F, Williams D, Hickey A. Cognitive impairment six months after ischaemic stroke: a profile from the ASPIRE-S study. *BMC Neurology*. 2015;15(1):1-9.
172. Mental Capacity Act [Internet]. The Stationary Office. 2005. Available from: <https://www.legislation.gov.uk/ukpga/2005/9/contents> [accessed March 2023].
173. Holloway I, Wheeler S. *Qualitative research in nursing*. Oxford: Wiley-Blackwell; 2002.
174. Data Protection Act [Internet]. 2018. Available from: <https://www.legislation.gov.uk/ukpga/2018/12/contents/enacted> [accessed March 2023].
175. Saunders B, Sim J, Kingstone T, Baker S, Waterfield J, Bartlam B, et al. Saturation in qualitative research: exploring its conceptualization and operationalization. *Quality & Quantity*. 2018;52(4):1893-907.
176. Glaser BG, Strauss AL. *The discovery of grounded theory: Strategies for qualitative research*. New York: Aldine Publishing; 1967.
177. Guest G, Bunce A, Johnson L. How many interviews are enough? An experiment with data saturation and variability. *Field methods*. 2006;18(1):59-82.
178. Hennink M, Kaiser BN. Sample sizes for saturation in qualitative research: A systematic review of empirical tests. *Social Sci Med*. 2022;292:114523.
179. National Institute of Neurological Disorders and Stroke. NIH Stroke Scale. USA: Dept. of Health and Human Services; 2011.
180. Mahoney FI, Barthel D. Functional evaluation: the Barthel index. *Maryland State Medical Journal*. 1965;14(2):61-5.

181. Spradley JP. Participant observation. USA: Thompson Learning, Inc.; 1980.
182. Kendall M, Murray SA, Carduff E, Worth A, Harris F, Lloyd A, et al. Use of multiperspective qualitative interviews to understand patients' and carers' beliefs, experiences, and needs. *BMJ*. 2009;339:b4122.
183. Herzog H. On home turf: Interview location and its social meaning. *Qualitative Sociology*. 2005;28:25-47.
184. Srivastava A, Thomson SB. Framework analysis: a qualitative methodology for applied policy research. *JOAGG*. 2009;4:2.
185. Seale C. *The Quality of Qualitative Research*. UK: SAGE Publications; 1999. 1-224 p.
186. Lincoln Y, Guba E. *Naturalistic Inquiry*. California: SAGE Publications; 1985.
187. Stahl NA, King JR. Expanding approaches for research: Understanding and using trustworthiness in qualitative research. *Journal of Developmental Education*. 2020;44(1):26-8.
188. Tobin GA, Begley CM. Methodological rigour within a qualitative framework. *J Adv Nurs*. 2004;48(4):388-96.
189. Younas A, Fàbregues S, Durante A, Escalante EL, Inayat S, Ali P. Proposing the "MIRACLE" narrative framework for providing thick description in qualitative research. *International Journal of Qualitative Methods*. 2023;22:16094069221147162.
190. Mays N, Pope C. Qualitative research: rigour and qualitative research. *BMJ*. 1995;311(6997):109-12.
191. Altheide DL, Johnson JM. Criteria for assessing interpretive validity in qualitative research. In: Denzin N, Lincoln Y, editors. *Handbook of qualitative research*. CA: SAGE Publications; 1994.
192. Creswell JW, Miller DL. Determining validity in qualitative inquiry. *Theory into practice*. 2000;39(3):124-30.
193. Payne G, Payne J. Reflexivity. 2011. In: *Key concepts in social research* [Internet]. London: SAGE Publications, Ltd; [191-5]. Available from: <https://dx.doi.org/10.4135/9781849209397> [accessed May 2021].
194. Miles MB, Huberman AM. *An expanded sourcebook: Qualitative data analysis* (2nd edition). USA: Sage Publications; 1994.
195. Sentinel Stroke National Audit Programme. Site-specific portfolio, Acute Organisational Audit 2019. Available from: <https://www.strokeaudit.org/Results2/Organisational/Site.aspx> [accessed May 2021].
196. Bury M. Chronic illness as biographical disruption. *Sociology of Health & Illness*. 1982;4(2):167-82.

197. Green TL, King KM. The trajectory of minor stroke recovery for men and their female spousal caregivers: literature review. *Journal of advanced nursing*. 2007;58(6):517-31.
198. Bowen A, Hesketh A, Patchick E, Young A, Davies L, Vail A, et al. Effectiveness of enhanced communication therapy in the first four months after stroke for aphasia and dysarthria: a randomised controlled trial. *BMJ*. 2012;345:e4407.
199. Campbell NC, Murray E, Darbyshire J, Emery J, Farmer A, Griffiths F, et al. Designing and evaluating complex interventions to improve health care. *BMJ*. 2007;334:455-9.
200. Hawe P. Lessons from complex interventions to improve health. *Annu Rev Public Health*. 2015;36:307-23.
201. Campbell M, Fitzpatrick R, Haines A, Kinmonth AL, Sandercock P, Spiegelhalter D, et al. Framework for design and evaluation of complex interventions to improve health. *BMJ*. 2000;321:694-6.
202. Corry M, Clarke M, While AE, Lalor J. Developing complex interventions for nursing: a critical review of key guidelines. *Journal of Clinical Nursing*. 2013;22(17-18):2366-86.
203. Craig P, Dieppe P, Macintyre S, Michie S, Nazareth I, Petticrew M. Developing and evaluating complex interventions: the new Medical Research Council guidance. *BMJ*. 2008;337:a1655.
204. O'Cathain A, Croot L, Duncan E, Rousseau N, Sworn K, Turner KM, et al. Guidance on how to develop complex interventions to improve health and healthcare. *BMJ Open*. 2019;9(8):e029954.
205. Skivington K, Matthews L, Simpson SA, Craig P, Baird J, Blazeby JM, et al. A new framework for developing and evaluating complex interventions: update of Medical Research Council guidance. *BMJ*. 2021;374:n2061.
206. Michie S, Atkins L, West R. *The behaviour change wheel: A guide to designing interventions*. UK: Silverback Publishing; 2014.
207. van der Velden NC, Meijers MC, Han PK, van Laarhoven HW, Smets E, Henselmans I. The effect of prognostic communication on patient outcomes in palliative cancer care: a systematic review. *Current Treatment Options in Oncology*. 2020;21(5):1-38.
208. Richardson WS, Wilson MC, Nishikawa J, Hayward RS. The well-built clinical question: a key to evidence-based decisions. *ACP J Club*. 1995;123(3):A12-A3.
209. Thomas J, Kneale D, McKenzie J, Brennan S, Bhaumik S. Chapter 2: Determining the scope of the review and the questions it will address. 2022. In: *Cochrane Handbook for Systematic Reviews of Interventions version 63 (updated*

- February 2022) [Internet]. Cochrane. Available from: <http://www.training.cochrane.org/handbook> [accessed March 2022].
210. Seale C, Davies P. Outcome measurement in stroke rehabilitation research. *International Disability Studies*. 1987;9(4):155-60.
211. Woolley FR, Kane RL, Hughes CC, Wright DD. The effects of doctor-patient communication on satisfaction and outcome of care. *Social Science & Medicine Part A: Medical Psychology & Medical Sociology*. 1978;12:123-8.
212. Köpke S, Solari A, Rahn A, Khan F, Heesen C, Giordano A. Information provision for people with multiple sclerosis. *Cochrane Database of Systematic Reviews*. 2018(10).
213. Cummings S, Browner W, Hulley S. Conceiving the research question and developing the study plan. In: Hulley S, Cummings S, Browner W, editors. *Designing Clinical Research: An Epidemiological Approach* (4th ed). Philadelphia: Lippincott Williams & Wilkins; 2007. p. 14–22.
214. Stoll CR, Izadi S, Fowler S, Green P, Suls J, Colditz GA. The value of a second reviewer for study selection in systematic reviews. *Research Synthesis Methods*. 2019;10(4):539-45.
215. Boutron I, Page M, Higgins J, Altman D, Lundh A, Hróbjartsson A. Chapter 7: Considering bias and conflicts of interest among the included studies. 2022. In: *Cochrane Handbook for Systematic Reviews of Interventions version 63* (updated February 2022) [Internet]. Cochrane. Available from: www.training.cochrane.org/handbook [accessed July 2022].
216. Higgins JP, Altman DG, Gøtzsche PC, Jüni P, Moher D, Oxman AD, et al. The Cochrane Collaboration's tool for assessing risk of bias in randomised trials. *BMJ*. 2011;343.
217. Cochrane Effective Practice and Organisation of Care. Suggested risk of bias criteria for EPOC reviews [online] 2017 [Available from: https://epoc.cochrane.org/sites/epoc.cochrane.org/files/public/uploads/Resources-for-authors2017/suggested_risk_of_bias_criteria_for_epoc_reviews.pdf] [Accessed July 2022].
218. Deeks J, Higgins J, Altman D. Chapter 10: Analysing data and undertaking meta-analyses. In: *Cochrane Handbook for Systematic Reviews of Interventions version 63* (updated February 2022) [Internet]. Cochrane. Available from: www.training.cochrane.org/handbook [Accessed July 2022].
219. Popay J, Roberts H, Sowden A, Petticrew M, Arai L, Rodgers M, et al. *Guidance on the conduct of narrative synthesis in systematic reviews* 2006. Available from:

<https://citeseerx.ist.psu.edu/document?repid=rep1&type=pdf&doi=ed8b23836338f6dea0cc55e161b0fc5805f9e27> [Accessed Oct 2023].

220. Hoffmann TC, Glasziou PP, Boutron I, Milne R, Perera R, Moher D, et al. Better reporting of interventions: template for intervention description and replication (TIDieR) checklist and guide. *BMJ*. 2014;348:g1687.

221. Jin Z, Guo F, Li Y. Effects of systemic rehabilitation nursing combined with WeChat publicity and education on the early cognitive function and living quality of the patients with cerebral arterial thrombosis. *Journal of Healthcare Engineering*. 2022;2022:7396950.

222. Pegg Jr PO, Auerbach SM, Seel RT, Buenaver LF, Kiesler DJ, Plybon LE. The Impact of Patient-Centered Information on Patients' Treatment Satisfaction and Outcomes in Traumatic Brain Injury Rehabilitation. *Rehabilitation Psychology*. 2005;50(4):366.

223. Muehlschlegel S, Goostrey K, Flahive J, Zhang Q, Pach JJ, Hwang DY. A Pilot Randomized Clinical Trial of a Goals-of-Care Decision Aid for Surrogates of Severe Acute Brain Injury Patients. *Neurology*. 2022;99(14):e1446-e55.

224. Muehlschlegel S, Hwang DY, Flahive J, Quinn T, Lee C, Moskowitz J, et al. Goals-of-care decision aid for critically ill patients with TBI: Development and feasibility testing. *Neurology*. 2020;95(2):e179-e93.

225. Köpke S, Kern S, Ziemssen T, Berghoff M, Kleiter I, Marziniak M, et al. Evidence-based patient information programme in early multiple sclerosis: a randomised controlled trial. *J Neurol Neurosurg Psychiatry*. 2014;85(4):411-8.

226. Rahn A, Köpke S, Backhus I, Kasper J, Anger K, Untiedt B, et al. Nurse-led immunotreatment DEcision Coaching In people with Multiple Sclerosis (DECIMS)– Feasibility testing, pilot randomised controlled trial and mixed methods process evaluation. *Int J Nurs Stud*. 2018;78:26-36.

227. Rahn AC, Köpke S, Kasper J, Vettorazzi E, Mühlhauser I, Heesen C. Evaluator-blinded trial evaluating nurse-led immunotherapy DEcision Coaching In persons with relapsing-remitting Multiple Sclerosis (DECIMS) and accompanying process evaluation: study protocol for a cluster randomised controlled trial. *Trials*. 2015;16(1):1-20.

228. Ajzen I. The theory of planned behavior. *Organizational behavior and human decision processes*. 1991;50(2):179-211.

229. O'Connor AM, Tugwell P, Wells GA, Elmslie T, Jolly E, Hollingworth G, et al. A decision aid for women considering hormone therapy after menopause: decision support framework and evaluation. *Patient Education and Counseling*. 1998;33(3):267-79.

230. O'Connor AM. Validation of a decisional conflict scale. *Med Decis Making*. 1995;15(1):25-30.
231. Pegg P, Seel R, Auerbach S. *Treatment Satisfaction Questionnaire*. Richmond: Virginia Commonwealth University; 2001.
232. Seel R, Pegg P. *Rehabilitation Intensity of Therapy Scale*. Richmond, VA: McGuire Veterans Administration Medical Center; 2001.
233. Tavakol M, Dennick R. Making sense of Cronbach's alpha. *Int J Med Educ*. 2011;2:53-5.
234. Elwyn G, O'Connor A, Stacey D, Volk R, Edwards A, Coulter A, et al. Developing a quality criteria framework for patient decision aids: online international Delphi consensus process. *BMJ*. 2006;333(7565):417.
235. Kasper J, van de Roemer A, Pöttgen J, Rahn A, Backhus I, Bay Y, et al. A new graphical format to communicate treatment effects to patients—A web-based randomized controlled trial. *Health Expectations*. 2017;20(4):797-804.
236. Gold S, Heesen C, Schulz H, Guder U, Mönch A, Gbadamosi J, et al. Disease specific quality of life instruments in multiple sclerosis: validation of the Hamburg Quality of Life Questionnaire in Multiple Sclerosis (HAQUAMS). *Multiple Sclerosis Journal*. 2001;7(2):119-30.
237. Zigmond AS, Snaith RP. The hospital anxiety and depression scale. *Acta Psychiatr Scand*. 1983;67(6):361-70.
238. Marrie RA, Zhang L, Lix LM, Graff LA, Walker JR, Fisk JD, et al. The validity and reliability of screening measures for depression and anxiety disorders in multiple sclerosis. *Multiple sclerosis and related disorders*. 2018;20:9-15.
239. Whelan-Goodinson R, Ponsford J, Schönberger M. Validity of the Hospital Anxiety and Depression Scale to assess depression and anxiety following traumatic brain injury as compared with the Structured Clinical Interview for DSM-IV. *J Affect Disord*. 2009;114(1-3):94-102.
240. Keith RA. The functional independence measure: a new tool for rehabilitation. *Advances in clinical rehabilitation*. 1987;2:6-18.
241. Selim S, Kunkel E, Wegier P, Tanuseputro P, Downar J, Isenberg SR, et al. A systematic review of interventions aiming to improve communication of prognosis to adult patients. *Patient Education and Counseling*. 2020;103(8):1467-97.
242. Parry R. Are interventions to enhance communication performance in allied health professionals effective, and how should they be delivered? Direct and indirect evidence. *Patient Education and Counseling*. 2008;73(2):186-95.
243. Lonsdale C, Hall AM, Murray A, Williams GC, McDonough SM, Ntoumanis N, et al. Communication skills training for practitioners to increase patient adherence to

- home-based rehabilitation for chronic low back pain: results of a cluster randomized controlled trial. *Arch Phys Med Rehabil.* 2017;98(9):1732-43. e7.
244. Hoffmann TC, Eructi C, Glasziou PP. Poor description of non-pharmacological interventions: analysis of consecutive sample of randomised trials. *BMJ.* 2013;347:f3755.
245. Selman LE, Brighton LJ, Hawkins A, McDonald C, O'Brien S, Robinson V, et al. The effect of communication skills training for generalist palliative care providers on patient-reported outcomes and clinician behaviors: a systematic review and meta-analysis. *J Pain Symptom Manage.* 2017;54(3):404-16. e5.
246. Michie S, Abraham C. Interventions to change health behaviours: evidence-based or evidence-inspired? *Psychology & Health.* 2004;19(1):29-49.
247. Michie S, Prestwich A. Are interventions theory-based? Development of a theory coding scheme. *Health psychology.* 2010;29(1):1-8.
248. Davis R, Campbell R, Hildon Z, Hobbs L, Michie S. Theories of behaviour and behaviour change across the social and behavioural sciences: a scoping review. *Health Psychology Review.* 2015;9(3):323-44.
249. Taylor N, Conner M, Lawton R. The impact of theory on the effectiveness of worksite physical activity interventions: a meta-analysis and meta-regression. *Health Psychology Review.* 2012;6(1):33-73.
250. Webb T, Joseph J, Yardley L, Michie S. Using the internet to promote health behavior change: a systematic review and meta-analysis of the impact of theoretical basis, use of behavior change techniques, and mode of delivery on efficacy. *Journal of Medical Internet Research.* 2010;12(1):e1376.
251. Gardner B, Wardle J, Poston L, Croker H. Changing diet and physical activity to reduce gestational weight gain: a meta-analysis. *Obesity reviews.* 2011;12(7):e602-e20.
252. Dalgetty R, Miller CB, Dombrowski SU. Examining the theory-effectiveness hypothesis: A systematic review of systematic reviews. *British Journal of Health Psychology.* 2019;24(2):334-56.
253. Prestwich A, Sniehotta FF, Whittington C, Dombrowski SU, Rogers L, Michie S. Does theory influence the effectiveness of health behavior interventions? Meta-analysis. *Health psychology.* 2014;33(5):465-74.
254. Prestwich A, Webb TL, Conner M. Using theory to develop and test interventions to promote changes in health behaviour: evidence, issues, and recommendations. *Current Opinion in Psychology.* 2015;5:1-5.
255. Michie S, Abraham C, Whittington C, McAteer J, Gupta S. Effective techniques in healthy eating and physical activity interventions: a meta-regression. *Health psychology.* 2009;28(6):690-701.

256. Bandura A. Health promotion from the perspective of social cognitive theory. *Psychology and Health*. 1998;13(4):623-49.
257. Rogers RW. Cognitive and psychological processes in fear appeals and attitude change: A revised theory of protection motivation. *Social psychophysiology: A sourcebook*. 1983:153-76.
258. Bronfenbrenner U. Toward an experimental ecology of human development. *American Psychologist*. 1977;32(7):513-31.
259. Fishbein M, Ajzen I. Belief, attitude, intention, and behavior: An introduction to theory and research. *Contemporary Sociology*. 1977;6(2):244-5.
260. Sniehotta FF, Penseau J, Araújo-Soares V. Time to retire the theory of planned behaviour. *Health Psychology Review*. 2014;8(1):1-7.
261. Hardeman W, Johnston M, Johnston D, Bonetti D, Wareham N, Kinmonth AL. Application of the theory of planned behaviour in behaviour change interventions: A systematic review. *Psychology and Health*. 2002;17(2):123-58.
262. Michie S, Van Stralen MM, West R. The behaviour change wheel: a new method for characterising and designing behaviour change interventions. *Implementation Science*. 2011;6(1):1-12.
263. Michie S, Johnston M, Abraham C, Lawton R, Parker D, Walker A. Making psychological theory useful for implementing evidence based practice: a consensus approach. *BMJ Quality & Safety*. 2005;14(1):26-33.
264. Michie S, Abraham C, Eccles MP, Francis JJ, Hardeman W, Johnston M. Strengthening evaluation and implementation by specifying components of behaviour change interventions: a study protocol. *Implementation Science*. 2011;6(1):1-8.
265. Michie S, Richardson M, Johnston M, Abraham C, Francis J, Hardeman W, et al. The behavior change technique taxonomy (v1) of 93 hierarchically clustered techniques: building an international consensus for the reporting of behavior change interventions. *Ann Behav Med*. 2013;46(1):81-95.
266. Hall J, Morton S, Hall J, Clarke DJ, Fitzsimons CF, English C, et al. A co-production approach guided by the behaviour change wheel to develop an intervention for reducing sedentary behaviour after stroke. *Pilot and Feasibility Studies*. 2020;6(1):1-13.
267. Connell LA, McMahon NE, Redfern J, Watkins CL, Eng JJ. Development of a behaviour change intervention to increase upper limb exercise in stroke rehabilitation. *Implementation Science*. 2015;10(1):1-9.
268. Stewart C, Power E, McCluskey A, Kuys S. Development of a participatory, tailored behaviour change intervention to increase active practice during inpatient stroke rehabilitation. *Disabil Rehabil*. 2020;42(24):3516-24.

269. Loft MI, Martinsen B, Esbensen BA, Mathiesen LL, Iversen HK, Poulsen I. Strengthening the role and functions of nursing staff in inpatient stroke rehabilitation: developing a complex intervention using the Behaviour Change Wheel. *International Journal of Qualitative Studies on Health and Well-being*. 2017;12(1):1392218.
270. Fulton EA, Brown KE, Kwah KL, Wild S. StopApp: using the behaviour change wheel to develop an app to increase uptake and attendance at NHS Stop Smoking Services. *Healthcare*. 2016;4(2):31.
271. Webster R, Michie S, Estcourt C, Gerressu M, Bailey JV, Group MT. Increasing condom use in heterosexual men: development of a theory-based interactive digital intervention. *Translational Behavioral Medicine*. 2016;6(3):418-27.
272. Ekberg K, Timmer B, Schuetz S, Hickson L. Use of the Behaviour Change Wheel to design an intervention to improve the implementation of family-centred care in adult audiology services. *International Journal of Audiology*. 2021;60(sup2):20-9.
273. Cane J, O'Connor D, Michie S. Validation of the theoretical domains framework for use in behaviour change and implementation research. *Implementation science*. 2012;7(1):1-17.
274. National Institute for Health and Care Excellence. Stroke Rehabilitation in Adults. UK: NICE; 2013. Available from: <https://www.nice.org.uk/guidance/cg162/resources/stroke-rehabilitation-in-adults-pdf-35109688408261> [Accessed October 2022].
275. National Institute for Health and Care Excellence. Patient experience in adult NHS services: improving the experience of care for people using adult NHS services. UK: NICE; 2012. Available from: <https://www.nice.org.uk/guidance/cg138/chapter/1-Guidance#enabling-patients-to-actively-participate-in-their-care> [Accessed October 2022].
276. Atkins L, Michie S. Designing interventions to change eating behaviours. *Proc Nutr Soc*. 2015;74(2):164-70.
277. Sinnott C, Mercer SW, Payne RA, Duerden M, Bradley CP, Byrne M. Improving medication management in multimorbidity: development of the Multimorbidity COllaborative Medication Review And DEcision making (MY COMRADE) intervention using the Behaviour Change Wheel. *Implementation Science*. 2015;10(1):1-11.
278. Robson C. *Real World Research* (3rd Ed). UK: John Wiley & Sons; 2011.
279. Sue V, Ritter L. *Conducting Online Surveys*. 2 ed. Thousand Oaks, California: Sage Publications, Inc.; 2012 2022/08/14.
280. Kalton G. *Introduction to survey sampling*. UK: Sage Publications; 2020.
281. De Man J, Campbell L, Tabana H, Wouters E. The pandemic of online research in times of COVID-19. *BMJ Open*. 2021;11(2):e043866.

282. O'Connor A, Jackson L, Goldsmith L, Skirton H. Can I get a retweet please? Health research recruitment and the Twittersphere. *J Adv Nurs*. 2014;70(3):599-609.
283. Kelley K, Clark B, Brown V, Sitzia J. Good practice in the conduct and reporting of survey research. *Int J Qual Health Care*. 2003;15(3):261-6.
284. Hsieh H-F, Shannon SE. Three approaches to qualitative content analysis. *Qualitative Health Research*. 2005;15(9):1277-88.
285. Jones F, Mandy A, Partridge C. Changing self-efficacy in individuals following a first time stroke: preliminary study of a novel self-management intervention. *Clin Rehabil*. 2009;23(6):522-33.
286. Royal College of Speech & Language Therapists. Speech and Language Therapy Competency Framework to Guide Transition to Certified RCSLT Membership. UK: RCSLT; 2007. Available from: <https://www.rcslt.org/wp-content/uploads/media/docs/delivering-quality-services/supervision-nqp-compentency-framework-2007-updated-jan-2013.pdf> [Accessed October 2022].
287. Chartered Society of Physiotherapy. CSP Accreditation of Qualifying Programmes in Physiotherapy: Quality assurance processes. UK: Chartered Society of Physiotherapy; 2022. Available from: <https://www.csp.org.uk/system/files/documents/2022-04/QA%20processes%20April%202022.pdf> [Accessed October 2022].
288. General Medical Council. Outcomes for graduates 2018. UK: GMC; 2018. Available from: https://www.gmc-uk.org/-/media/documents/outcomes-for-graduates-2020_pdf-84622587.pdf?la=en&hash=35E569DEB208E71D666BA91CE58E5337CD569945 [Accessed October 2022].
289. Nursing & Midwifery Council. Standards for pre-registration nursing education. UK: NMC; 2010. Available from: <https://www.nmc.org.uk/globalassets/sitedocuments/standards/nmc-standards-for-pre-registration-nursing-education.pdf> [Accessed October 2022].
290. Brown RF, Bylund CL. Communication skills training: describing a new conceptual model. *Acad Med*. 2008;83(1):37-44.
291. Moore PM, Rivera S, Bravo-Soto GA, Olivares C, Lawrie TA. Communication skills training for healthcare professionals working with people who have cancer. *Cochrane Database of Systematic Reviews*. 2018(7).
292. Parry RH, Brown K. Teaching and learning communication skills in physiotherapy: what is done and how should it be done? *Physiotherapy*. 2009;95(4):294-301.

293. Berg MN, Ngune I, Schofield P, Grech L, Juraskova I, Strasser M, et al. Effectiveness of online communication skills training for cancer and palliative care health professionals: a systematic review. *Psychooncology*. 2021;30(9):1405-19.
294. Barth J, Lannen P. Efficacy of communication skills training courses in oncology: a systematic review and meta-analysis. *Ann Oncol*. 2011;22(5):1030-40.
295. Berthier ML. Poststroke aphasia. *Drugs & Aging*. 2005;22(2):163-82.
296. Mauk KL. Nursing interventions within the Mauk Model of Poststroke Recovery. *Rehabilitation Nursing*. 2006;31(6):257-64.
297. Lutz BJ, Ellen Young M, Cox KJ, Martz C, Rae Creasy K. The crisis of stroke: experiences of patients and their family caregivers. *Topics in Stroke Rehabilitation*. 2011;18(6):786-97.
298. Kurtz S, Silverman J, Draper J, van Dalen J, Platt FW. Teaching and learning communication skills in medicine: CRC press; 2017.
299. Gysels M, Richardson A, Higginson IJ. Communication training for health professionals who care for patients with cancer: a systematic review of training methods. *Support Care Cancer*. 2005;13(6):356-66.
300. Nestel D, Tierney T. Role-play for medical students learning about communication: guidelines for maximising benefits. *BMC Medical Education*. 2007;7(1):1-9.
301. Gelis A, Cervello S, Rey R, Llorca G, Lambert P, Franck N, et al. Peer role-play for training communication skills in medical students: a systematic review. *Simulation in Healthcare*. 2020;15(2):106-11.
302. Winterbottom A, Bekker HL, Conner M, Mooney A. Does narrative information bias individual's decision making? A systematic review. *Soc Sci Med*. 2008;67(12):2079-88.
303. Greenhalgh T, Russell J, Swinglehurst D. Narrative methods in quality improvement research. *BMJ Quality & Safety*. 2005;14(6):443-9.
304. Locock L, Robert G, Boaz A, Vougioukalou S, Shuldham C, Fielden J, et al. Testing accelerated experience-based co-design: a qualitative study of using a national archive of patient experience narrative interviews to promote rapid patient-centred service improvement. *Health Services and Delivery Research*. 2014;2(4).
305. Fadlallah R, El-Jardali F, Nomier M, Hemadi N, Arif K, Langlois EV, et al. Using narratives to impact health policy-making: a systematic review. *Health Research Policy and Systems*. 2019;17(1):1-22.
306. Drozdowska BA, Singh S, Quinn TJ. Thinking about the future: a review of prognostic scales used in acute stroke. *Frontiers in Neurology*. 2019;10:274.
307. Burton CR, Horne M, Woodward-Nutt K, Bowen A, Tyrrell P. What is rehabilitation potential? Development of a theoretical model through the accounts of

- healthcare professionals working in stroke rehabilitation services. *Disabil Rehabil.* 2015;37(21):1955-60.
308. Ganesh A, Ospel JM, Kromm J, Goyal M. Ignorance is not bliss: managing uncertainty in acute stroke treatment in the COVID-19 era. *Neuroradiology.* 2021;63(1):3-6.
309. Windrim RC, Gan E, Kingdom JC. The Impact of COVID-19 on Continuing Professional Development: Go Green and Go Home? *J Obstet Gynaecol Can.* 2022;44(3):231-3.
310. Chest Heart & Stroke Scotland & The University of Edinburgh. *Stroke Training and Awareness Resources.* Scotland: Chest Heart & Stroke Scotland; 2020.
311. Tanco K, Rhondali W, Perez-Cruz P, Tanzi S, Chisholm GB, Baile W, et al. Patient perception of physician compassion after a more optimistic vs a less optimistic message: a randomized clinical trial. *JAMA Oncology.* 2015;1(2):176-83.
312. Visvanathan A, Mead G, Dennis M, Whiteley W, Doubal F, Lawton J. Maintaining hope after a disabling stroke: A longitudinal qualitative study of patients' experiences, views, information needs and approaches towards making treatment decisions. *PLoS One.* 2019;14(9):e0222500.
313. Evans WG, Tulskey JA, Back AL, Arnold RM. Communication at times of transitions: how to help patients cope with loss and re-define hope. *The Cancer Journal.* 2006;12(5):417-24.
314. Hoffmann T, McKenna K, Worrall L, Read SJ. Randomised trial of a computer-generated tailored written education package for patients following stroke. *Age Ageing.* 2007;36(3):280-6.
315. Sandberg EH, Sharma R, Sandberg WS. Deficits in retention for verbally presented medical information. *The Journal of the American Society of Anesthesiologists.* 2012;117(4):772-9.
316. McCarthy DM, Waite KR, Curtis LM, Engel KG, Baker DW, Wolf MS. What did the doctor say? Health literacy and recall of medical instructions. *Med Care.* 2012;50(4):277-82.
317. Mcguire LC. Remembering what the doctor said: organization and adults' memory for medical information. *Exp Aging Res.* 1996;22(4):403-28.
318. Tattersall MH. Consultation audio-tapes: an information aid, and a quality assurance and research tool. *Support Care Cancer.* 2002;10:217-21.
319. Abukmail E, Bakhit M, Del Mar C, Hoffmann T. Effect of different visual presentations on the comprehension of prognostic information: a systematic review. *BMC Medical Informatics and Decision Making.* 2021;21(1):1-10.

320. Taylor GH, Todman J, Broomfield NM. Post-stroke emotional adjustment: A modified social cognitive transition model. *Neuropsychological rehabilitation*. 2011;21(6):808-24.
321. Hughes AK, Cummings CE. Grief and loss associated with stroke recovery: a qualitative study of stroke survivors and their spousal caregivers. *Journal of Patient Experience*. 2020;7(6):1219-26.
322. Holbrook M. Stroke: social and emotional outcome. *J R Coll Physicians Lond*. 1982;16(2):100-4.
323. Brennan J. Adjustment to cancer—coping or personal transition? *Psychooncology*. 2001;10(1):1-18.
324. Hui D, Mo L, Paiva CE. The importance of prognostication: impact of prognostic predictions, disclosures, awareness, and acceptance on patient outcomes. *Current Treatment Options in Oncology*. 2021;22:1-14.
325. Lim YZ, Chou L, Au RT, Seneviwickrama KMD, Cicuttini FM, Briggs AM, et al. People with low back pain want clear, consistent and personalised information on prognosis, treatment options and self-management strategies: a systematic review. *Journal of Physiotherapy*. 2019;65(3):124-35.
326. Sisk BA, Fasciano K, Block SD, Mack JW. Longitudinal prognostic communication needs of adolescents and young adults with cancer. *Cancer*. 2020;126(2):400-7.
327. Moré JM, Lang-Brown S, Romo RD, Lee SJ, Sudore R, Smith AK. "Planting the Seed": Perceived Benefits of and Strategies for Discussing Long-Term Prognosis with Older Adults. *J Am Geriatr Soc*. 2018;66(12):2367-71.
328. Fallowfield L, Jenkins V. Communicating sad, bad, and difficult news in medicine. *Lancet*. 2004;363(9405):312-9.
329. Paul C, Clinton-McHarg T, Sanson-Fisher R, Douglas H, Webb G. Are we there yet? The state of the evidence base for guidelines on breaking bad news to cancer patients. *Eur J Cancer*. 2009;45(17):2960-6.
330. Kirkevold M. The unfolding illness trajectory of stroke. *Disabil Rehabil*. 2002;24(17):887-98.
331. Lou S, Carstensen K, Jørgensen CR, Nielsen CP. Stroke patients' and informal carers' experiences with life after stroke: an overview of qualitative systematic reviews. *Disabil Rehabil*. 2017;39(3):301-13.
332. Salter KL, Hellings C, Foley NC, Teasell RW. The experience of living with stroke: a qualitative meta-synthesis. *Journal of rehabilitation medicine*. 2008;40(8):595-602.
333. Bolton D. Looking forward to a decade of the biopsychosocial model. *BJPsych Bulletin*. 2022;46(4):228-32.

334. Sarre S, Redlich C, Tinker A, Sadler E, Bhalla A, McKeivitt C. A systematic review of qualitative studies on adjusting after stroke: lessons for the study of resilience. *Disabil Rehabil.* 2014;36(9):716-26.
335. Flynn D, Nesbitt DJ, Ford GA, McMeekin P, Rodgers H, Price C, et al. Development of a computerised decision aid for thrombolysis in acute stroke care. *BMC Medical Informatics and Decision Making.* 2015;15(1):1-15.
336. Baers JH, Adekanye J, Hazlewood G, Davies JM, Caird JK, Wilton SB. Systematic Review of Patient Decision Aids for Stroke Prevention Therapy in Atrial Fibrillation Management. *Reviews in Cardiovascular Medicine.* 2022;23(10):353.
337. Clark B, BurrIDGE J, Whittall J, Turk R, Hughes A-M, Truman J. Why do some people with stroke not receive the recommended 45 minutes of Occupational Therapy and Physiotherapy after stroke? A qualitative study using focus groups. *BMJ Open* (in press). 2023.
338. McGlinchey MP, Faulkner-Gurstein R, Sackley CM, McKeivitt C. Factors guiding therapist decision making in the rehabilitation of physical function after severely disabling stroke—an ethnographic study. *Disabil Rehabil.* 2023:1-13.
339. McGlinchey MP, Davenport S. Exploring the decision-making process in the delivery of physiotherapy in a stroke unit. *Disabil Rehabil.* 2015;37(14):1277-84.
340. Parsons JG, Plant SE, Slark J, Tyson SF. How active are patients in setting goals during rehabilitation after stroke? A qualitative study of clinician perceptions. *Disabil Rehabil.* 2018;40(3):309-16.
341. Sugavanam T, Mead G, Bulley C, Donaghy M, Van Wijck F. The effects and experiences of goal setting in stroke rehabilitation—a systematic review. *Disabil Rehabil.* 2013;35(3):177-90.
342. Plant SE, Tyson SF, Kirk S, Parsons J. What are the barriers and facilitators to goal-setting during rehabilitation for stroke and other acquired brain injuries? A systematic review and meta-synthesis. *Clin Rehabil.* 2016;30(9):921-30.
343. Young CA, Manmathan GP, Ward JC. Perceptions of goal setting in a neurological rehabilitation unit: a qualitative study of patients, carers and staff. *Journal of Rehabilitation Medicine.* 2008;40(3):190-4.
344. Mountain A, Patrice Lindsay M, Teasell R, Salbach NM, de Jong A, Foley N, et al. Canadian stroke best practice recommendations: rehabilitation, recovery, and community participation following stroke. Part two: transitions and community participation following stroke. *International Journal of Stroke.* 2020;15(7):789-806.
345. Marnane K, Gustafsson L, Bennett S, Rosbergen I, Grimley R. “Everyone needs rehab, but...”: Exploring post-stroke rehabilitation referral and acceptance decisions. *Disabil Rehabil.* 2022;44(17):4717-28.
346. Bendz M. Rules of relevance after a stroke. *Soc Sci Med.* 2000;51(5):713-23.

347. Ellis-Hill C, Robison J, Wiles R, McPherson K, Hyndman D, Ashburn A, et al. Going home to get on with life: patients and carers experiences of being discharged from hospital following a stroke. *Disabil Rehabil.* 2009;31(2):61-72.
348. Kristensen HK, Tistad M, Koch Lv, Ytterberg C. The importance of patient involvement in stroke rehabilitation. *PLoS One.* 2016;11(6):e0157149.
349. Prick J, van Schaik S, Deijle I, Dahmen R, Brouwers P, Hilkens P, et al. Development of a patient decision aid for discharge planning of hospitalized patients with stroke. *BMC Neurology.* 2022;22(1):1-9.
350. Amati M, Grignoli N, Rubinelli S, Amann J, Zanini C. The role of hope for health professionals in rehabilitation: a qualitative study on unfavorable prognosis communication. *PLoS One.* 2019;14(10):e0224394.
351. Barker R, Brauer S. Upper limb recovery after stroke: the stroke survivors' perspective. *Disabil Rehabil.* 2005;27(20):1213-23.
352. Tutton E, Seers K, Langstaff D, Westwood M. Staff and patient views of the concept of hope on a stroke unit: a qualitative study. *J Adv Nurs.* 2012;68(9):2061-9.
353. Cross A, Schneider M. A preliminary qualitative analysis of the impact of hope on stroke recovery in women. *Topics in Stroke Rehabilitation.* 2010;17(6):484-95.
354. Levy T, J. Christie L, Killington M, Laver K, Crotty M, Lannin NA. "Just that four letter word, hope": Stroke survivors' perspectives of participation in an intensive upper limb exercise program; A qualitative exploration. *Physiotherapy Theory and Practice.* 2022;38(11):1624-38.
355. Robinson RG, Jorge RE. Post-stroke depression: a review. *Am J Psychiatry.* 2016;173(3):221-31.
356. Kortte KB, Stevenson JE, Hosey MM, Castillo R, Wegener ST. Hope predicts positive functional role outcomes in acute rehabilitation populations. *Rehabilitation Psychology.* 2012;57(3):248-55.
357. Lenze EJ, Munin MC, Quear T, Dew MA, Rogers JC, Begley AE, et al. Significance of poor patient participation in physical and occupational therapy for functional outcome and length of stay. *Arch Phys Med Rehabil.* 2004;85(10):1599-601.
358. Ru X, Dai H, Jiang B, Li N, Zhao X, Hong Z, et al. Community-based rehabilitation to improve stroke survivors' rehabilitation participation and functional recovery. *Am J Phys Med Rehabil.* 2017;96(7):e123-e9.
359. Watson M, Campbell R, Vallath N, Ward S, Wells J. *Oxford handbook of palliative care*: Oxford University Press, USA; 2019.
360. Mack JW, Wolfe J, Cook EF, Grier HE, Cleary PD, Weeks JC. Hope and prognostic disclosure. *J Clin Oncol.* 2007;25(35):5636-42.
361. Smith TJ, Dow LA, Khatcheressian J, Lyckholm LJ. Giving honest information to patients with advanced cancer maintains hope. *Oncology.* 2010;24(6):521-5.

362. Maclean N, Pound P, Wolfe C, Rudd A. Qualitative analysis of stroke patients' motivation for rehabilitation. *BMJ*. 2000;321(7268):1051-4.
363. Oyake K, Sue K, Sumiya M, Tanaka S. Physical therapists use different motivational strategies for stroke rehabilitation tailored to an individual's condition: a qualitative study. *Phys Ther*. 2023:pzad034.
364. Maclean N, Pound P, Wolfe C, Rudd A. The concept of patient motivation: a qualitative analysis of stroke professionals' attitudes. *Stroke*. 2002;33(2):444-8.
365. Stein J, Shafqat S, Doherty D, Frates EP, Furie KL. Family member knowledge and expectations for functional recovery after stroke. *Am J Phys Med Rehabil*. 2003;82(3):169-74.
366. Stein J, Shafqat S, Doherty D, Frates EP, Furie KL. Patient knowledge and expectations for functional recovery after stroke. *Am J Phys Med Rehabil*. 2003;82(8):591-6.
367. Carroll LJ, Lis A, Weiser S, Torti J. How well do you expect to recover, and what does recovery mean, anyway? Qualitative study of expectations after a musculoskeletal injury. *Phys Ther*. 2016;96(6):797-807.
368. Harnischfeger N, Rath HM, Oechsle K, Bergelt C. Addressing palliative care and end-of-life issues in patients with advanced cancer: a systematic review of communication interventions for physicians not specialised in palliative care. *BMJ Open*. 2022;12(6):e059652.
369. Gold R, Gold A. The experience of speech–language therapists and audiologists when delivering bad news: A qualitative analysis. *International Journal of Language & Communication Disorders*. 2021;56(2):402-14.
370. Villagran M, Goldsmith J, Wittenberg-Lyles E, Baldwin P. Creating COMFORT: A communication-based model for breaking bad news. *Commun Educ*. 2010;59(3):220-34.
371. Schlenz KC, Guthrie MR, Dudgeon B. Burnout in occupational therapists and physical therapists working in head injury rehabilitation. *Am J Occup Ther*. 1995;49(10):986-93.
372. Broom JP, Williams J. Occupational stress and neurological rehabilitation physiotherapists. *Physiotherapy*. 1996;82(11):606606-14614.
373. Wittig P, Tilton-Weaver L, Patry B, Mateer C. Variables related to job satisfaction among professional care providers working in brain injury rehabilitation. *Disabil Rehabil*. 2003;25(2):97-106.
374. Christakis NA, Smith JL, Parkes CM, Lamont EB. Extent and determinants of error in doctors' prognoses in terminally ill patients: prospective cohort studyCommentary: Why do doctors overestimate? Commentary: Prognoses should be based on proved indices not intuition. *BMJ*. 2000;320(7233):469-73.

375. Roy D, Gasquoine S, Caldwell S, Nash D. Health professional and family perceptions of post-stroke information. *Nursing Praxis in New Zealand*. 2015;31(2):7-24.
376. Ritsma BR, Gariscsak PJ, Vyas A, Chan-Nguyen S, Appireddy R. The virtual family conference in stroke rehabilitation: Education, preparation, and transition planning. *Clin Rehabil*. 2023;37(8):1099-110.
377. Loupis YM, Faux SG. Family conferences in stroke rehabilitation: a literature review. *Journal of Stroke and Cerebrovascular Diseases*. 2013;22(6):883-93.
378. Hansen P, Cornish P, Kayser K. Family conferences as forums for decision making in hospital settings. *Soc Work Health Care*. 1998;27(3):57-74.
379. Han PK, Klein WM, Arora NK. Varieties of uncertainty in health care: a conceptual taxonomy. *Med Decis Making*. 2011;31(6):828-38.
380. Simpkin AL, Armstrong KA. Communicating uncertainty: a narrative review and framework for future research. *J Gen Intern Med*. 2019;34:2586-91.
381. Mishel MH. Uncertainty in illness. *Image J Nurs Sch*. 1988;20(4):225-32.
382. Brown M, Levack W, McPherson KM, Dean SG, Reed K, Weatherall M, et al. Survival, momentum, and things that make me "me": patients' perceptions of goal setting after stroke. *Disabil Rehabil*. 2014;36(12):1020-6.
383. Bright FA, Kayes NM, McCann CM, McPherson K. Hope in people with aphasia. *Aphasiology*. 2013;27(1):41-58.
384. Wintle BC, Fraser H, Wills BC, Nicholson AE, Fidler F. Verbal probabilities: Very likely to be somewhat more confusing than numbers. *PLoS One*. 2019;14(4):e0213522.
385. Lee Char SJ, Evans LR, Malvar GL, White DB. A randomized trial of two methods to disclose prognosis to surrogate decision makers in intensive care units. *Am J Respir Crit Care Med*. 2010;182(7):905-9.
386. Creutzfeldt CJ, Holloway RG. Treatment decisions after severe stroke: uncertainty and biases. *Stroke*. 2012;43(12):3405-8.
387. Hannah D, Lindholm B, Maisch L. Certain uncertainty: life after stroke from the patient's perspective. *Circulation: Cardiovascular Quality and Outcomes*. 2014;7(6):968-9.
388. Harrison M, Han PK, Rabin B, Bell M, Kay H, Spooner L, et al. Communicating uncertainty in cancer prognosis: a review of web-based prognostic tools. *Patient Education and Counseling*. 2019;102(5):842-9.
389. Guan T, Qan'ir Y, Song L. Systematic review of illness uncertainty management interventions for cancer patients and their family caregivers. *Support Care Cancer*. 2021;29:4623-40.

390. White CL, Barrientos R, Dunn K. Dimensions of uncertainty after stroke: perspectives of the stroke survivor and family caregiver. *J Neurosci Nurs*. 2014;46(4):233-40.
391. Jones K, Quinn T, Mazor KM, Muehlschlegel S. Prognostic uncertainty in critically ill patients with traumatic brain injury: a multicenter qualitative study. *Neurocritical Care*. 2021;35(2):311-21.
392. Peoples HA, Boone B, Blumenthal-Barby JS, Bruce CR. How clinician–family interactions potentially impact clinicians’ conceptualization and discussions regarding prognostic uncertainties. *J Palliat Care*. 2020;35(1):29-33.
393. Buckman R. *Bad News: A Guide for Health Care Professionals*. Baltimore, MD: Johns Hopkins University Press; 1992.
394. Warnock C, Tod A, Foster J, Soreny C. Breaking bad news in inpatient clinical settings: role of the nurse. *J Adv Nurs*. 2010;66(7):1543-55.
395. O'Halloran R, Grohn B, Worrall L. Environmental factors that influence communication for patients with a communication disability in acute hospital stroke units: a qualitative metasynthesis. *Arch Phys Med Rehabil*. 2012;93(1):S77-S85.
396. Chartered Society of Physiotherapy. Government 'backsliding' on rehab space promises, says CSP. UK: Chartered Society of Physiotherapy; 2023. Available from: <https://www.csp.org.uk/news/2023-05-25-government-backsliding-rehab-space-promises-says-csp#results> [Accessed October 2023].
397. Shulkin D, O'Keefe T, Visconi D, Robinson A, Rooke AS, Neigher W. Eliminating visiting hour restrictions in hospitals. *Journal for Healthcare Quality*. 2014;36(6):54-7.
398. Sims JM, Miracle VA. A look at critical care visitation: the case for flexible visitation. *Dimensions of Critical Care Nursing*. 2006;25(4):175-80.
399. Hurst H, Griffiths J, Hunt C, Martinez E. A realist evaluation of the implementation of open visiting in an acute care setting for older people. *BMC Health Services Research*. 2019;19:1-11.
400. Demir YP, Balci NÇ, Ünlüer NÖ, Uluğ N, Dogru E, Kiliç M, et al. Three different points of view in stroke rehabilitation: patient, caregiver, and physiotherapist. *Topics in Stroke Rehabilitation*. 2015;22(5):377-85.
401. Wottrich AW, Åström K, Löfgren M. On parallel tracks: newly home from hospital—people with stroke describe their expectations. *Disabil Rehabil*. 2012;34(14):1218-24.
402. Wade DT. What is rehabilitation? An empirical investigation leading to an evidence-based description. *Clin Rehabil*. 2020;34(5):571-83.

403. Groeneveld I, Van der Pas S, Meesters J, Schuurman J, van Meijeren-Pont W, Jagersma E, et al. Illness perceptions of stroke survivors: Predictors and changes over time—A 1 year follow-up study. *J Psychosom Res.* 2019;116:54-61.
404. Kwakkel G. Impact of intensity of practice after stroke: issues for consideration. *Disabil Rehabil.* 2006;28(13-14):823-30.
405. Pollak KI. Teaching effective communication by modeling effective communication: experiences of a communication coach for clinicians. *Patient Education and Counseling.* 2020;103(2):423-7.

Appendices

Appendix A

Example search strategy (Medline) for qualitative review and RCT review

- 1 (break* adj3 news).tw.
- 2 ((difficult or bad or traumatic) adj3 news).tw.
- 3 ((communicat* or tell* or convey* or disclos* or giv*) adj2 (diagnos* or prognos*)).tw.
- 4 ((inform or news) adj2 patient*).tw.
- 5 (information provision or information exchange* or receiving the news).tw.
- 6 (recovery adj2 (expect* or conversation*)).tw.
- 7 (truth-telling or truth disclosure).tw.
- 8 Truth Disclosure/
- 9 or/1-8 [breaking bad news]
- 10 (brain injur* or head injur* or spinal cord injur* or spinal injur* or multiple sclerosis or demyelinating disease* or Parkinson* or dementia or Alzheimer* or vascular cognitive impair* or lewy bod* or huntington* or korsako* or motor neuron* disease or Gehrig syndrome or amyotrophic lateral sclerosis or brain tumo?r or stroke* or hemiplegia).tw.
- 11 (neurological adj2 (impair* or disease* or disorder* or condition*)).tw.
- 12 Brain Injuries/
- 13 Spinal Injuries/
- 14 Multiple Sclerosis/
- 15 Parkinson Disease/
- 16 Dementia/ or Dementia, Multi-Infarct/ or Dementia, Vascular/ or Frontotemporal Dementia/
- 17 Alzheimer Disease/
- 18 Amyotrophic Lateral Sclerosis/
- 19 Brain Neoplasms/
- 20 Stroke/
- 21 Hemiplegia/
- 22 or/10-21 [neurological conditions]
- 23 9 and 22
- 24 limit 23 to english language
- 25 exp animals/ not humans.sh.
- 26 24 not 25 [human only filter]

27 (exp Child/ or Adolescent/ or exp Infant/) not exp Adult/

28 26 not 27 [adult only filter]

29 remove duplicates from 28

Appendix B

NHS ethical approval letter*



Dr David Clarke
Academic Unit of Elderly Care and Rehabilitation
Bradford Royal Infirmary, Duckworth Lane
Bradford
Duckworth Lane
BD9 6RJ

Email: hra.approval@nhs.net
Research-permissions@wales.nhs.uk

12 February 2019

Dear Dr Clarke

**HRA and Health and Care
Research Wales (HCRW)
Approval Letter**

Study title: Talking about recovery after stroke: A qualitative study of current practice and exploration of the views of stroke survivors, caregivers and staff

IRAS project ID: 255197

REC reference: 19/YH/0009

Sponsor The University of Leeds

I am pleased to confirm that [HRA and Health and Care Research Wales \(HCRW\) Approval](#) has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

How should I continue to work with participating NHS organisations in England and Wales?
You should now provide a copy of this letter to all participating NHS organisations in England and Wales, as well as any documentation that has been updated as a result of the assessment.

Following the arranging of capacity and capability, participating NHS organisations should **formally confirm** their capacity and capability to undertake the study. How this will be confirmed is detailed in the "*summary of assessment*" section towards the end of this letter.

You should provide, if you have not already done so, detailed instructions to each organisation as to how you will notify them that research activities may commence at site following their confirmation of capacity and capability (e.g. provision by you of a 'green light' email, formal notification following a site initiation visit, activities may commence immediately following confirmation by participating organisation, etc.).

*Application details are in my supervisor's name, as the HRA rejected the initial application in my name as I was a student

| | |
|-----------------|--------|
| IRAS project ID | 255197 |
|-----------------|--------|

It is important 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 of the research management function for each organisation can be accessed [here](#).

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within the devolved administrations of Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) has been sent to the coordinating centre of each participating nation. You should work with the relevant national coordinating functions to ensure any nation specific checks are complete, and with each site so that they are able to give management permission for the study to begin.

Please see [IRAS Help](#) for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?

HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to [obtain local agreement](#) in accordance with their procedures.

What are my notification responsibilities during the study?

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.

I am a participating NHS organisation in England or Wales. What should I do once I receive this letter?

You should work with the applicant and sponsor to complete any outstanding arrangements so you are able to confirm capacity and capability in line with the information provided in this letter.

The sponsor contact for this application is as follows:

Tel: 01133437587

Email: governance-ethics@leeds.ac.uk

| | |
|-----------------|--------|
| IRAS project ID | 255197 |
|-----------------|--------|

Who should I contact for further information?

Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is 255197. Please quote this on all correspondence.

Yours sincerely

Kevin Ahmed
Assessor

Telephone: 0207 104 8171
Email: hra.approval@nhs.net

Copy to: *Mrs Jane Dennison, R&D Contact, Bradford Teaching Hospitals NHS Foundation Trust*

| | |
|-----------------|--------|
| IRAS project ID | 255197 |
|-----------------|--------|

List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

| <i>Document</i> | <i>Version</i> | <i>Date</i> |
|---|----------------|-------------------|
| Copies of advertisement materials for research participants [Poster - staff areas] | v1.0 | 11 December 2018 |
| Copies of advertisement materials for research participants [Poster - patient areas] | v1.0 | 11 December 2018 |
| Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [UoL insurance document] | | 17 September 2018 |
| HRA Schedule of Events | 1.0 | 12 February 2019 |
| HRA Statement of Activities | 1.0 | 12 February 2019 |
| Interview schedules or topic guides for participants [Interview topic guides] | v1.0 | 11 December 2018 |
| IRAS Application Form [IRAS_Form_20122018] | | 20 December 2018 |
| Letter from funder [Letter from The Stroke Association confirming funding] | | 02 May 2017 |
| Letter from sponsor [Letter from Sponsor] | | 20 December 2018 |
| Other [Observational framework] | v1.0 | 11 December 2018 |
| Participant consent form [Stroke Survivor Consent Form] | v1.2 | 05 February 2019 |
| Participant consent form [Consultee Declaration Form] | v1.2 | 05 February 2019 |
| Participant consent form [Accessible Consent Form (Stroke Survivors)] | v1.2 | 05 February 2019 |
| Participant consent form [Caregiver Consent Form] | v1.2 | 05 February 2019 |
| Participant consent form [Staff Consent Form] | v1.2 | 05 February 2019 |
| Participant consent form [Consent to contact form] | v1.0 | 11 December 2018 |
| Participant information sheet (PIS) [Stroke Survivor Participant Information Sheet] | v1.2 | 05 February 2019 |
| Participant information sheet (PIS) [Consultee Information Sheet] | v1.2 | 05 February 2019 |
| Participant information sheet (PIS) [Accessible Stroke Survivor Information Sheet] | v1.2 | 05 February 2019 |
| Participant information sheet (PIS) [Caregiver Information Sheet] | v1.2 | 05 February 2019 |
| Participant information sheet (PIS) [Staff Participant Information Sheet] | v1.2 | 05 February 2019 |
| Research protocol or project proposal [Study Protocol] | v1.1 | 20 December 2018 |
| Summary CV for Chief Investigator (CI) [Summary CV David Clarke] | | 15 October 2018 |
| Summary CV for student [Short CV L Burton] | | 11 December 2018 |
| Summary CV for supervisor (student research) [Summary CV Anne Forster] | | 20 December 2018 |
| Summary CV for supervisor (student research) [Summary CV Judith Johnson] | | 07 September 2018 |

Appendix C

Participant information sheet (stroke survivors/ carers)



Information Sheet for Stroke Survivors (version 1.2 05.02.19)
Study title: Talking about recovery after a stroke
Observations and interviews

You are being invited to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. This information sheet tells you about the study, what we would like to do in the study and how we would manage the information collected. Please read this carefully and ask us if anything is not clear or if you would like more information. Talk to other people about the study if you wish.

Why me?

We are inviting you to take part because you have had a stroke and you are being cared for in a stroke unit.

Who is organising and funding this study?

The Chief Investigator of this research is David Clarke, who is responsible for the study. Louisa Burton (PhD student) is running the study on his behalf from the Academic Unit of Elderly Care and Rehabilitation in Bradford. The research is funded by The Stroke Association, as part of the Postgraduate Fellowship Programme.

What is the purpose of the study?

We are interested in how recovery from stroke is discussed in hospitals. We hope to gain a better understanding of the ways that stroke unit team members talk with stroke survivors and their families about what has happened to them and their recovery. We also wish to understand the views of stroke survivors, their relatives and stroke unit team members about recovery from stroke. We will review the information we collect and use this to think about whether talking about recovery after stroke could be improved for future stroke survivors and their families.

Stroke survivor information sheet, Observations and interviews Version 1.2, 05.02.2019

Study title: Talking about recovery after stroke: A qualitative study of current practice and exploration of the views of stroke survivors, caregivers and staff.
 IRAS Project ID: 255197



What will I have to do?

If you agree, we will ask you to do two things. First, we would like to observe some of the care you receive. With your permission, a researcher will sit in on some of the care and treatment sessions you have with staff at [the NHS Trust]. This may include planning meetings you have with staff. The researcher would make notes during the session, but would not take part in the care you receive or any discussions. With your agreement, the researcher may also audio record some of these sessions. The researcher will not observe any intimate personal care. They may speak to you informally for a few minutes after you have been seen by the stroke unit staff, if you agree. The researcher would also review the records made by stroke unit staff about the care you have received, and information about the type of stroke you have had and its impact.

Secondly, after you leave the hospital, we would contact you (4 to 6 weeks later) to invite you to take part in an interview about your views about the way your recovery was discussed with you while you were in hospital. This would involve being interviewed by a trained researcher at a time and in a location that is convenient for you (probably your own home) and would take about one hour. We would like to record the interview so that we can accurately recollect what you say. With your agreement, we would also invite a relative or friend to take part in the interview, either alongside you, or separately if you wish.

We may also ask if we can contact you again to see if you want to take part in a future study, which will aim to help stroke unit staff talk to stroke survivors and their families about recovery.

Do I have to take part?

No, it is up to you. You do not have to give a reason if you decide not to take part. The standard of care that you receive will not be affected in any way, whether you decide to take part in this study or not.

Stroke survivor information sheet, Observations and interviews Version 1.2, 05.02.2019

Study title: Talking about recovery after stroke: A qualitative study of current practice and exploration of the views of stroke survivors, caregivers and staff.

IRAS Project ID: 255197



Will my information be kept confidential?

The Academic Unit of Elderly Care and Rehabilitation, a department of the University of Leeds, which is based at Bradford Teaching Hospitals NHS Foundation Trust will securely store your name, date of birth, gender, time since stroke, stroke severity, your address, telephone number and consent form. The AUECR will keep your information confidential.

We will ask a company called Typing Works to type up a copy of your interview. Typing Works have signed a confidentiality agreement with the Academic Unit of Elderly Care and Rehabilitation. Typing Works will not include any identifiable information about you, or about organisations or places in the typed copy of your interview.

The researcher will not use your real name in any reports they write about what they observe or what you tell us in your interview. To keep your involvement confidential, you will be given a pseudonym (false name) in our reports and only researchers involved in the study will be able to identify you from your pseudonym. We will not share identifiable information about you with anyone outside of the research team. However, if we have concerns that you, or someone else is at risk of harm then we may break confidentiality and tell the relevant healthcare services.

The University of Leeds is the sponsor for this study based in the United Kingdom. We will be using information from you and your medical records in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. The University of Leeds will keep identifiable information about you for 3 years after the study has finished.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

Stroke survivor information sheet, Observations and interviews Version 1.2, 05.02.2019

Study title: Talking about recovery after stroke: A qualitative study of current practice and exploration of the views of stroke survivors, caregivers and staff.

IRAS Project ID: 255197



You can find out more about how we use your information by contacting the University Data Protection Officer on dpo@leeds.ac.uk.

[The NHS Trust] will collect information from you and your medical records for this research study in accordance with our instructions.

[The NHS Trust] will use your name, date of birth, NHS number and contact details to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Individuals from The University of Leeds and regulatory organisations may look at your medical and research records to check the accuracy of the research study. [The NHS Trust] will pass these details to The University of Leeds along with the information collected from you and your medical records. The only people in The University of Leeds who will have access to information that identifies you will be people who need to contact you to arrange your interview or audit the data collection process. The people who analyse the information will not be able to identify you and will not be able to find out your name, date of birth, NHS number or contact details.

[The NHS Trust] will keep identifiable information about you from this study for 3 years after the study has finished.

The data collected from you may be used to inform the development of future research within the Academic Unit of Elderly Care and Rehabilitation. This information will not identify you and will not be combined with other information in a way that could identify you. The information will only be used for the development of health and care research, and cannot be used to contact you.

What are the possible benefits of taking part?

Being involved is unlikely to benefit you directly. However, it may help improve future services and support for people who have had a stroke. You might also enjoy taking part and talking to someone about your stroke

Stroke survivor information sheet, Observations and interviews Version 1.2, 05.02.2019
 Study title: Talking about recovery after stroke: A qualitative study of current practice and exploration of the views of stroke survivors, caregivers and staff.
 IRAS Project ID: 255197



Are there any risks from taking part?

We do not anticipate that there will be any disadvantages or risks if you agree to be involved. You may pause or stop the observations at any time. Some people may find answering questions about their stroke upsetting. You do not have to answer any questions you do not wish to and you may pause or stop the interview at any time.

What will happen if I do not want to carry on with the study?

If you change your mind about taking part you can stop at any time. You don't have to give a reason. If you decide to stop taking part, we will use the information already collected from you unless you ask us not to.

What will happen to the results of the study?

We hope to publish the results of this study in an academic journal. If you would like a copy of the report, you can request one from the Chief Investigator at the address below or visit our website using the following address:

https://medhealth.leeds.ac.uk/info/646/elderly_care_and_rehabilitation. We will share the results with other researchers at conferences and meetings, and through newsletters and academic journals. We may use ~~anonymised~~ quotations from the interviews but you will not be identified in any report/ publication.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee. A favourable ethical opinion has been obtained from Yorkshire & The Humber – Bradford-Leeds Research Ethics Committee. **The ethics committee will check that the research is done properly and that you are kept safe.**

When do I need to decide?

You don't need to decide now. We will contact you and answer any questions. You can read the information again. You can talk to your family to help you decide.

If you decide to take part you will need to sign a consent form. It says that you understand the research and have decided to take part.

Stroke survivor information sheet, Observations and interviews Version 1.2, 05.02.2019

Study title: Talking about recovery after stroke: A qualitative study of current practice and exploration of the views of stroke survivors, caregivers and staff.

IRAS Project ID: 255197



What if there is a problem?

If you would like to discuss this study with someone independent of the study team please contact: Clare Skinner, Faculty Research Office, Room 9.29, Level 9 Worsley Building, Clarendon Way, Leeds, LS2 9NL. Tel: 0113 343 4897 or email: governance-ethics@leeds.ac.uk. Please quote study title: Talking about recovery after stroke.

Sources of support:

In England the Patient Advice and Liaison Service (PALS) provides a confidential service, helping you to sort out any concerns you may have about the care provide in an NHS service and advising you of support agencies and other organisations that can help, for example the Stroke Association. PALS can be contacted on [telephone number] or by e-mail: [\[e-mail address\]](#).

Claims/insurance

In the unlikely event that something goes wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against [the NHS Trust] but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you (if appropriate).

For more information please contact:

Louisa Burton – PhD Student
 Academic Unit of Elderly Care and Rehabilitation
 Temple Bank House, Bradford Royal Infirmary
 Duckworth Lane
 Bradford
 BD9 6RJ

Tel: 01274 383xxx

E-mail: [\[e-mail address\]](#)

Stroke survivor information sheet, Observations and interviews Version 1.2, 05.02.2019
 Study title: Talking about recovery after stroke: A qualitative study of current practice and exploration of the views of stroke survivors, caregivers and staff.
 IRAS Project ID: 255197



Supervisor: *Dr David Clarke* (Chief Investigator) – Associate Professor in Stroke Care (address as above)

Tel: 01274 383xxx

E-mail: [\[e-mail address\]](#)

Thank you for taking the time to read this information.

This study is organized and run by the Academic Unit of Elderly Care and Rehabilitation, a department of the University of Leeds, based at Bradford Teaching Hospitals NHS Foundation Trust. This study is funded by The Stroke Association. The Sponsor for the research is The University of Leeds. The study has been approved by a NHS Research Ethics Committee, ref 19/YH/0009.

Stroke survivor information sheet, Observations and interviews Version 1.2, 05.02.2019

Study title: Talking about recovery after stroke: A qualitative study of current practice and exploration of the views of stroke survivors, caregivers and staff.

IRAS Project ID: 255197

Appendix D

Consent form for stroke survivors



| | |
|-----------------|---|
| Participant ID: | Initials: |
| Date of Birth: | Participant's carer/significant other ID: |

Study Title: **Talking about recovery after a stroke**

Observations and interviews

A large-print version of this sheet is available on request

STROKE SURVIVOR CONSENT FORM

Version 1.2 05/02/2019

Please
initial the
boxes

| | | |
|----|---|--|
| 1. | I confirm that I have read and understood the Information Sheet dated 05.02.2019 (Version 1.2) for the above study. I have had the opportunity to ask questions. | |
| 2. | I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason and without my medical care or legal rights being affected. | |
| 3. | I agree to be observed when taking part in routine care and therapy activities, including meetings with staff. I understand that some of these sessions may be audio-recorded. | |
| 4. | I agree for the researcher to access my medical notes to review the records made by stroke unit staff about the care I have received. | |
| 5. | I agree to take part in an interview and for my interview to be audio recorded. | |
| 6. | I understand that anonymised quotations from my interview may be used in study reports but I will not be identified. | |
| 7. | I understand that my data will be collected for this study and may be used to help develop new research. I understand that Data Protection regulations will be observed. | |
| 8. | I understand that confidentiality will be maintained unless there are concerns that I, or someone else, is at risk of harm. | |
| 9. | If I become unwell for any reason after providing consent to participate in the study and am no longer able to make decisions, I understand that the researcher will consult with someone close to me about whether I carry on with the research. | |



| | | |
|-----|--|--|
| 10. | I understand that even if I withdraw consent to take part in the study, the data already collected will contribute to the study unless I specifically withdraw consent for this. | |
| 11. | I give permission for my details, which will include name, address, date of birth, telephone number, NHS number and consent form, to be passed to the Academic Unit for Elderly Care and Rehabilitation for the administration of the study. | |
| 12. | I understand that a copy of this Consent Form will be stored at the Academic Unit for Elderly Care and Rehabilitation. | |
| 13. | I agree to take part in the above study. | |

PARTICIPANT:

NAME (CAPITALS)

DATE

SIGNATURE

WITNESS (if required):

NAME (CAPITALS)

DATE

SIGNATURE

RESEARCHER:

NAME (CAPITALS)

DATE

SIGNATURE

(1 copy for the participant and 1 copy for the AUECR)

Appendix E

Example poster – patient areas



UNIVERSITY OF LEEDS

TRUST LOGO HERE

This stroke unit is taking part in a research study which aims to understand the ways that stroke unit team members talk with stroke survivors and their families about what has happened to them and their recovery.

The study involves researchers being present on the unit on some weekdays and weekend days, so you may see someone walking around the ward, making notes and talking to staff. They may also observe activity in different areas of the unit, for example the therapy rooms, the bays, the dining room and day room.

Unless you have agreed to participate in the research project, the researcher will not record any personal information relating to you or your care. For example they will not record your name.

When the researchers are on the unit they will introduce themselves and ask if their presence is acceptable to you. Please let them or the unit staff know if you have any concerns.

The lead researcher would be happy to provide more information if you wish.

Thank you

For more information, please contact Louisa Burton, telephone: 01274 383426 or 07503727990 or write to: Academic Unit of Elderly Care, Temple Bank House, Bradford Royal Infirmary, Duckworth Lane, Bradford, BD9 6RJ

The research is funded by The Stroke Association's Postgraduate Fellowship programme

Appendix F

Extract from observational framework

Date, unit identifier, visit number, case identifier (patient-specific observations only)

Duration of non-participant observation

Locations for observations (including time spent): To include: therapy rooms, shared workspaces or areas where stroke unit professionals routinely congregate to discuss patient activity or meet with patients/ carers; staff meeting rooms (including attending board round/ MDT meetings); therapy areas (gyms, therapy kitchens); patient dining areas, day rooms or other communal areas; bed areas.

Focus of general non-participant observation: To include description of:

- General activities routinely involving interaction between professionals, patients and carers (where appropriate)
- What appears to be important and meaningful for professionals and patients in discussing recovery, e.g., beliefs, feelings, and worries where verbalised
- Specific activities focusing on discussing recovery, including planning or feeding back information to colleagues
- The conditions under which patients, carers and professionals interact, including perceived barriers and facilitators
- Staff interactions
- Informal, unplanned activity, which appears to contribute to or reinforce information about recovery, e.g., corridor conversations.

Record summaries of dialogue where appropriate; verbatim recording will require written informed consent.

Focus of patient-specific observations (therapy sessions, ward rounds, family meetings, informal interactions between professionals, patients, and carers):

Includes the above, but with increased detail to facilitate description and explanation and understanding. To include description of:

- The context of the interaction
- Who is participating
- The nature and purpose of the interaction as articulated by professionals
- How the participants appear to respond to, participate in, feel about, describe, explain and make sense of the interaction

- The researcher's perceptions of the relationship of the interaction to the study aims

Documents reviewed (aims to capture any textual information to facilitate understanding of how, when and why recovery information is provided): To include:

- Individual patient records in which professionals may record discussions about or predictions for recovery (e.g., individual therapy sessions records and meeting records) – patient-specific with written informed consent only
- Written information, e.g., leaflets, provided to patients and carers about recovery
- Policies or guidance for professionals (e.g., local, national) to guide conversations about recovery

Expanded fieldnote record: To be completed as soon after observation as possible.

Linked memo number: Memos will include ideas (and links between them), hypotheses, recurring themes, reflections, and key quotations upon which to base formulation and revisions of explanations and understanding.

Appendix G

Topic guide for stroke survivor interviews

Personal context

- Tell me a little about your home life.
- How long is it since you had your stroke? How is your general health?
- How has your life changed since your stroke?

Stroke unit experiences

- Could you tell me about when you had your stroke?
- How did you find out you had had a stroke?

- Did any of the staff members in the stroke unit give you information about your stroke?
 - If so, who? (*Prompt: doctors, nursing staff, therapy staff, psychologist*)
 - How was this information provided? (*Prompt: spoken, written, once only or repeated*)

- Did anyone speak to you about how long it might take for you to recover or what how much recovery you might expect to make?
 - If so, who? (*Prompt: doctors, nursing staff, therapy staff, psychologist*)
 - How was this information provided? (*Prompt: spoken, written, once only or repeated*)
 - Were your family members/ friends given information? (*Prompt: at the same time, separately*)
 - How did you feel about the information you received and the way it was communicated to you?
 - Can you think of any ways this could have been better?

- Did you ask any questions about whether or how you might improve after your stroke?
 - If so, who did you ask?
 - Were you satisfied with the answers to these questions? If no, how could these have been improved?

- Did you have any meetings with staff on the stroke unit, to talk about your recovery and progress or your plans for discharge?
 - If so, can you tell me about these meetings? (*Prompts: how many, who attended, what types of information were provided?*)
 - How did you find these experiences?

- Is there anything you wanted to know about your recovery when you were in hospital that you weren't told?

Coming home

- Has your progress continued since leaving hospital? Have you continued to have therapy?
 - If so, has anyone spoken to you about your recovery since you've been at home?

- Is there anything you know now that you would have wanted to know about your recovery when you were in hospital?

- Is there anything else you'd like to tell me about your experiences of receiving information about your recovery from your stroke?

Appendix H

Topic guide for interviews with professionals

Personal context/ role

- Tell me about your role on the stroke unit ... (Profession, banding, hours worked)
- How long have you worked in stroke/ on this stroke unit?
- What does recovery after stroke mean to you? (Prompt: What does good patient recovery after stroke look like? How do you know when a patient has had a good recovery, what things change?)
- What do you think stroke survivors and their families want to know about their recovery? (Prompt: *initial diagnosis, how the stroke has affected them, how long they might be in hospital for, how long their recovery might take, how much recovery they might make (in hospital/ longer-term), general vs personalised information*)
- Could you tell me about your role in providing information about recovery to stroke survivors and their families?

Identifying current practice

- Is information about recovery is routinely provided to stroke survivors and their families in this stroke service?
 - If so, what kinds of information are provided? (Prompt: *general or individualised*)
- Who provides information about recovery to stroke survivors and their families in this stroke service? In what format is it provided? (Prompt: *verbal, written, repeated, family meetings*)
- When is information about recovery provided to stroke survivors and their caregivers in this stroke service?

Predicting recovery

- Do you get a hunch or gut feeling about how much recovery a stroke survivor might make?
- What information do you use to predict how much recovery a stroke survivor might make and how long this could take? (Prompt: *professional guidelines, research literature (evidence surrounding optimum time periods for recovery), previous experience, advice from other staff, assessment results, lesion location*)
- Are these predictions communicated to patients/ families? How?
- Are these predictions communicated between staff members/ staff groups? How? (Prompt: *MDT meetings, family meeting, patient records*)
- Do you feel you have enough information/ expertise to predict recovery?

Effects of providing information, including benefits and barriers

- Do you think there are any benefits to providing information about recovery to stroke survivors and their families? What do you think they are? (Prompt: *Impact on patients, families, staff*)
- Do you think there are any negative effects of providing information to stroke survivors and their families? What do you think they are? (Prompt: *Impact on patients, families, staff*)
- What facilitates provision of information about recovery?
- What do you think are the barriers to providing information about recovery to stroke survivors and their families? (Prompt: *Environmental (e.g., quiet room space), patient factors (e.g., patient impairments, shock, don't want to know), staff-related factors (e.g., time, staffing levels, insufficient training/ support, organisation of who will provide information, inability to predict recovery)*)

Support and training for staff

- Have you received any training about providing information about recovery to stroke survivors and their families? This might include general training in breaking bad news.
 - If yes, who provided training and what did it entail?
 - If no, would training be helpful?
- What support (if any) do you receive to provide information about recovery to stroke survivors and their families? (*Prompt: psychological, peer support, managerial support?*)
- How do you feel about the amount of support provided?

Improving practice

- Is there anything you think could be improved about the way that information about recovery is provided to stroke survivors and their families?
- Can you identify any opportunities for provision of information about recovery in this stroke service?
- Who do you think is best placed to provide information about recovery to stroke survivors and their families? (*Prompt: consultant, nurses, therapists, other staff, families*)
- In what format should it be provided? (*Prompt: verbal, written, repeated*)
- In relation to the stroke survivor's experience of the stroke care pathway, when do you think is the optimal time for provision of information about recovery? (*Prompt: on admission, in acute care, during rehabilitation, at discharge, in the community*)
- Is there anything else you'd like to tell me about your experiences of providing information about recovery after a stroke?

Appendix I

Extract from Framework matrix

| | HCPs try to manage patient and carer expectations about recovery | Summary |
|---|---|--|
| <p>1 : S15 22.10.19</p> <p>Age range = 18-30 years Banding = Band 5 Profession = Physiotherapist Site = Brownside</p> | <p>I think patients expect to return to normal. And I think a lot of patients, a lot of challenges and difficult conversations that I have with patients is around where their expectations, the expectations of family. I think a lot of people think that a stroke is something that can be reversed and they don't necessarily always recognise the amount of damage that's been done. A lot of my patients say "I'm only going to leave hospital when I can walk again" and actually we might be looking at they might potentially never walk again and it's how do you have, how do you set that expectation with them as well?</p> <p>Unless I know that they're completely cognitively intact I will normally always try and have a conversation with them but their family being there because sometimes you have to be really careful what you say, there's certain words just get picked out and you have to be, I sort of explain to the rotational Band 5s that you want to be positive, as a therapist you really want to say that somebody's getting, you really want to tell someone they're getting better, you want to tell them it's all going to be alright but actually you have to be really realistic and if we're not seeing that they're making potential we need to be really honest with them and the family because if not it just makes the conversation that we're going to have in a couple of weeks or in a month's time even harder.</p> <p>I think you can, there are definitely signs and especially when a lot of our patients, if somebody's impaired from a speech and language point of view, an occupational therapy and a physiotherapy point of view we're kind of getting no signs that they're actually probably likely going to be long-term disabled or heavily reliant on others, and that's something that's really difficult to come to terms with and a lot of times you want someone to carry on getting better but coming to that realisation is probably the best because then you can be really realistic with the patient but more so with patient's family. Because patients who are probably impaired from all those point of views, they might be non-verbal, they might not actually have, might be expressive or receptive dysphasic, and so we don't, we can't necessarily have those conversations with that patient. So it's more about how do we handle that information with the family and how do we sort of, sometimes those conversations can be quite easy because patient's relatives recognise that they are quite impaired but it usually takes sort of a week, couple of weeks for us to notice that someone is, we're not really achieving goals or potentially they are, we're just achieving things that are so slow it's probably not going to make any functional difference overall.</p> <p>Usually around, I will try and have a conversation with the patient with the family before the first time we meet them but the first time we're meeting I'm just trying to be as realistic as possible.</p> | <p>S15 describes how she thinks pts expect to return to normal - she has lots of difficult conversations with pts and families around managing expectations. Lots of ppl expect damage can be reversed - need to set expectation, e.g., that they might not walk again. Describes how its important to be realistic and honest with pts and families if not seeing progress, even though its hard and would be easier to tell them they're getting better - if don't set expectations early, makes later conversations more difficult. Tries to be as realistic as possible in the first FM - try to speak with pt and family first.</p> |
| <p>2 : S08 22.08.19</p> <p>Age range = 18-30 years Banding = Band 6 Profession = Speech & Language Therapist Site = Summerfield</p> | <p>I think probably being open and honest from the get-go is definitely a benefit because you get these families with high and unrealistic expectations and it's about setting their expectations of recovery so I think having those discussions, it is better, it's much better.</p> <p>Well, if families are thinking that the patient's going to make a full recovery and they're going to walk out of the hospital the person that they walked in then you have to set expectations because it just, it impacts on their life so much that it's not fair is it for them to be under a false illusion.</p> | <p>S08 describes how it's important to be open and honest from the start as some families have unrealistically high expectations about recovery. Isn't fair to let families maintain high hopes for recovery if not possible - have to manage expectations.</p> |

Appendix J

Screenshot from coded NVivo file (Patient/ carer data)

The screenshot displays the NVivo 12 Plus software interface. The main window shows a text document with several paragraphs of text, each preceded by a label (P16 or Int). The text is color-coded with vertical bars on the right side, indicating the application of specific codes. The coding pane on the right lists various codes, such as 'Experiences of the process of adjustment to disability', 'Role of hopes in recovery', and 'Confidence information provided about recovery by different professionals'. The left-hand navigation pane shows a project structure with folders for 'Quick Access', 'Data', 'Codes', 'Cases', 'Notes', 'Search', 'Maps', and 'Output'. The 'Data' folder is expanded, showing a list of files and folders, including 'Summerfield'. The 'Codes' folder is also expanded, showing a list of codes. The 'Cases' folder is expanded, showing a list of cases, including 'David'. The 'Notes' folder is expanded, showing a list of notes, including 'David'. The 'Search' folder is expanded, showing a list of search results, including 'David'. The 'Maps' folder is expanded, showing a list of maps, including 'David'. The 'Output' folder is expanded, showing a list of outputs, including 'David'. The bottom status bar shows the current project name 'A702 / Morning... Construction' and the date '14/06/2023'.

Table 1: Project Structure (Left Pane)

| Folder | Item | Codes | References | |
|--------|----------------------|----------------------|------------|--|
| Data | Files | | | |
| | Case studies | | | |
| | Brownside | | | |
| | Summerfield | | | |
| | Documentary analysis | | | |
| | Brownside | | | |
| | Summerfield | | | |
| | Field notes | | | |
| | Brownside | | | |
| | Summerfield | | | |
| Codes | Nodes | | | |
| | Sentiment | | | |
| | Relationships | | | |
| | Relationship Types | | | |
| | Cases | Cases | | |
| | | Case Classifications | | |
| | Notes | Notes | | |
| | | Search | | |
| | Maps | Maps | | |
| | | Output | | |

Table 2: Case Data (Left Pane)

| Name | Codes | References |
|-----------------|-------|------------|
| Ajey | 22 | 28 |
| Anne and Stacey | 34 | 67 |
| Bob | 15 | 22 |
| David | 38 | 59 |
| Ethel and Karen | 22 | 26 |
| Janet | 25 | 40 |
| Marie | 27 | 52 |
| Peter | 22 | 37 |
| Peter and Jean | 41 | 77 |
| Ruth and Adam | 29 | 44 |

Table 3: Text Editor Content (Center Pane)

David

P16: It might have been, but I suspect getting them all together at the same time might have been difficult.

Int: How would it have benefited you if they had been able to do that?

P16: I think sometimes if you heard other, several people's opinion on something, you get a more balanced view. Because, in a sense, if there are more than one possible outcome of a situation, different people looking at it from a different perspective might come to different conclusions.

Int: Did you feel that you would kind of trust the information given to you by the consultant more than the physiotherapist, or did you see all that information kind of at the same level?

P16: I was getting, in a sense, different information. The consultant told me what had happened, and I've no reason not to believe that his interpretation of the scans he saw were anything but professional. The physios were talking mainly about what could be done to alleviate the position, and they were coming from their particular speciality. I mean, if I was having a house rebuilt, you might get a different story from the plumber than the electrician, but you'd expect both to know what they were doing in their own particular trade or profession.

Int: You could kind of understand that as a whole picture, it didn't feel like one person was saying it might take a couple of weeks to recover, and someone else was saying it might take six months?

P16: No, no, I think they were all talking about the same timescale. [Pause] I must admit, on the first couple of days I didn't think I would be at this point in time, where I am now. I think I'm possibly doing better than I thought I would.

Int: What was that based on?

P16: What was that based on? I think where I physically was, and the fact that I knew other people that had had strokes and it had taken ages for them to recover. I must admit that while, when you get to your middle 70s, you might half at the back of your mind, be thinking that something is going to catch up with you, having a stroke was something which had never occurred to me. If I'd gone to see a doctor and been told, "Well, you're showing early signs of some form of cancer, we need to investigate that", I'd have believed it. If they'd done some heart, routine heart tests and said that I'd have believed it, because my late mother did have a bit of a heart problem, she lived to be about 82, by the way. But I could have, I think a stroke was something which was not on my horizon of things that could happen.

Table 4: Coding Pane (Right Pane)

| Code | Color |
|---|--------|
| Experiences of the process of adjustment to disability | Yellow |
| Role of hopes in recovery | Yellow |
| Staff try to manage expectations | Yellow |
| Who provides information about recovery | Yellow |
| Different MDT members contribute different information about recovery based on their knowledge and skills | Yellow |
| Confidence information provided about recovery by different professionals | Red |
| Staff lack proactivity in providing information about recovery | Red |
| Confidence is required to ask questions of professionals | Red |
| Values honesty in communication | Blue |
| Understanding of acute care and treatment | Blue |
| Understanding of uncertainty | Blue |
| Professionals are the experts who have the knowledge | Blue |
| Not enough information provided | Blue |
| David | Blue |
| Coding Density | Blue |
| Uncertainty about recovery conveyed to patients and families | Green |
| Perceptions of progress | Green |
| Own judgements about recovery | Green |
| Knowledge of others who have had stroke impacts expectations | Green |

Appendix K

University ethical approval e-mail

MREC 21-013 - Study Approval Confirmation

Medicine and Health Univ Ethics Review <FMHUniEthics@leeds.ac.uk>

Wed 09/02/2022 09:33

To: Louisa-Jane Burton <umljb@leeds.ac.uk>

Cc: Anne Forster <A.Forster@leeds.ac.uk>

Dear Louisa-Jane

MREC 21-013 - Developing strategies to improve talking about recovery on the stroke unit

NB: All approvals/comments are subject to compliance with current University of Leeds and UK Government advice regarding the Covid-19 pandemic.

I am pleased to inform you that the above research ethics application has been reviewed by the School of Medicine Ethics Committee and I can confirm a favourable ethical opinion based on the documentation received at date of this email.

Please retain this email as evidence of approval in your study file.

Please notify the committee if you intend to make any amendments to the research as submitted and approved to date. This includes recruitment methodology; all changes must receive ethical approval prior to implementation. Please see <https://ris.leeds.ac.uk/research-ethics-and-integrity/applying-for-an-amendment/> or contact the Research Ethics & Governance Administrator for further information fmhuniethics@leeds.ac.uk if required.

Ethics approval does not infer you have the right of access to any member of staff or student or documents and the premises of the University of Leeds. Nor does it imply any right of access to the premises of any other organisation, including clinical areas. The committee takes no responsibility for you gaining access to staff, students and/or premises prior to, during or following your research activities.

Please note: You are expected to keep a record of all your approved documentation, as well as documents such as sample consent forms, risk assessments and other documents relating to the study. This should be kept in your study file, which should be readily available for audit purposes. You will be given a two week notice period if your project is to be audited.

It is our policy to remind everyone that it is your responsibility to comply with Health and Safety, Data Protection and any other legal and/or professional guidelines there may be.

I hope the study continues to go well.

Best wishes

Sou Chung

On behalf of Dr Naomi Quinton, CHAIR, SoMREC

Sou Sit Chung, Research Ethics Administrator, The Secretariat, University of Leeds, LS2 9NL, s.chung@leeds.ac.uk
Please note my working hours are Monday to Friday 9am – 12.30pm

Appendix L

Survey study Participant Information Sheet



Information Sheet for Survey Participants (version 1.1 30/12/2021)

Study title: Developing strategies to improve talking about recovery on the stroke unit

You are being invited to take part in a research study. Participation is entirely voluntary. Before you decide whether to take part, it is important for you to understand why the research is being done and what it will involve. This information sheet tells you about the study, what we would like to do and how we would manage the information. Please read this carefully and ask us if anything is not clear or if you would like more information. Talk to other people about the study if you wish.

Why me?

We are inviting you to take part because you are a professional providing care and/ or therapy for stroke survivors in a stroke unit. We are interested in your views about some strategies we have developed for inclusion in an intervention to improve conversations about recovery between healthcare professionals and stroke survivors and families in stroke units.

Who is organising and funding this study?

The Chief Investigator of this research is Louisa Burton from the Academic Unit for Ageing and Stroke Research in Bradford, who is responsible for the study. The research is funded by The Stroke Association, as part of the Postgraduate Fellowship Programme. The study Sponsor is the University of Leeds.

Why are we doing the research?

Research has shown that stroke survivors and their family members would like more information about their recovery when they are on a stroke unit, including how much recovery will take place, how long it might take and what they can do to help. Our research aims to develop an intervention to help stroke professionals discuss recovery more effectively, and we would like your feedback on some of the approaches we are considering.

What will I have to do?

If you agree, we will ask you to complete an online survey. In the survey, we will present some barriers to discussing recovery with stroke survivors and their families, which have been reported by healthcare professionals in our previous research. We will ask you:

- How important you feel it is to address each barrier in an intervention designed to help stroke professionals discuss recovery more effectively.

Survey participant information sheet, Version 1.1, 30.12.2021
 Study title: Developing strategies to improve talking about recovery on the stroke unit
 Ethical approval ref number: MREC 21-013





- Whether you think it would be feasible to deliver the proposed approaches to address these barriers in a stroke unit.
- Whether you think the proposed approaches would be useful in addressing the identified barriers.

The questionnaire will take up to 20 minutes to complete.

Do I have to take part?

No, it is up to you. You do not have to give a reason if you decide not to take part.

How will we use information about you?

We will ask for information about you for this research project. This information will include your age group, gender identity, profession and years of experience in stroke care. We will not however ask for information, which could directly identify you, e.g., your name or date of birth. When completing the survey, we ask that you do not provide personal information, e.g., names or contact details, from which you could be identified. We will keep all information about you safe and secure. We will write our reports in a way that no-one can work out that you took part in the study. The supplementary information sheet tells you more about this.

What are the possible benefits of taking part?

Being involved is unlikely to benefit you directly. However, it may help improve future services and support for people who have had a stroke and their families.

Are there any risks from taking part?

We do not anticipate that there will be any disadvantages or risks if you agree to be involved.

What are my choices about how my information is used?

- You can stop being part of the study at any time, without giving a reason.
- If you wish to withdraw your survey responses after you have submitted them, you may do this by contacting the research team within 14 days of submission and quoting the number on your completion receipt.
- We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

Survey participant information sheet, Version 1.1, 30.12.2021
 Study title: Developing strategies to improve talking about recovery on the stroke unit
 Ethical approval ref number: MREC 21-013





Where can I find out more about how my data is used?

You can find out more about how we use your information:

- from our leaflet available from https://dataprotection.leeds.ac.uk/wp-content/uploads/sites/48/2020/08/My_data_and_research.pdf
- by asking one of the research team (see contact details below)
- by sending an email to the University data protection officer at dpo@leeds.ac.uk
- University of Leeds Privacy Notice is available to read at <https://dataprotection.leeds.ac.uk/wp-content/uploads/sites/48/2019/02/Research-Privacy-Notice.pdf>

What will happen to the results of the study?

The results of the study will be written up as part of a PhD. We hope to publish the results of this study in an academic journal. If you would like a copy of the report, you can request one from the Research Team at the address below or visit our website using the following address:

<https://www.bradfordresearch.nhs.uk/our-research-teams/academic-unit-for-ageing-and-stroke-research/>. We will share the results with other researchers at conferences and meetings, and through academic journals. We may use anonymised quotations from the questionnaire, but it will not be possible to identify you from them.

Who has reviewed the study?

All research is looked at by an independent group of people, called a Research Ethics Committee. A favourable ethical opinion has been obtained from the University of Leeds Medicine & Health Research Ethics Committee. **The ethics committee will check that the research is done properly and that you are kept safe.**

For more information please contact:

Louisa Burton – Chief Investigator/ PhD Student

Academic Unit for Ageing and Stroke Research

Temple Bank House, Bradford Royal Infirmary

Duckworth Lane

Bradford

BD9 6RJ

Tel: 07436 020 488

E-mail: louisa.burton@bthft.nhs.uk

Survey participant information sheet, Version 1.1, 30.12.2021

Study title: Developing strategies to improve talking about recovery on the stroke unit

Ethical approval ref number: MREC 21-013



UNIVERSITY OF LEEDS



Lead Supervisor: Professor Anne Forster (Professor of Stroke Rehabilitation and Head of the Academic Unit for Ageing and Stroke Research) - address as above

Tel: 01274 383446

E-mail: a.forster@leeds.ac.uk

Supervisor: Dr Tom Crocker (Senior Research Fellow, Academic Unit for Ageing and Stroke Research)

Tel: 01274 366 615

E-mail: tom.crocker@bthft.nhs.uk

Supervisor: Dr Judith Johnson (Lecturer, School of Psychology, University of Leeds)

Tel: 0113 343 0510

E-mail: j.johnson@leeds.ac.uk

Thank you for taking the time to read this information

This study is organised and run by the Academic Unit for Ageing and Stroke Research, a department of the University of Leeds, based at Bradford Teaching Hospitals NHS Foundation Trust. This study is funded by The Stroke Association's Postgraduate Fellowship programme. The Sponsor for the research is The University of Leeds. The study has been approved by a University Research Ethics Committee.

Survey participant information sheet, Version 1.1, 30.12.2021

Study title: Developing strategies to improve talking about recovery on the stroke unit

Ethical approval ref number: MREC 21-013



UNIVERSITY OF LEEDS

Appendix M

Survey front page and consent form



Developing strategies to improve talking about recovery on the stroke unit

Page 1: Participant Information

Are you a healthcare professional working in a stroke unit? If so, please read on:

Many thanks for your interest in this research study. This study aims to identify strategies, which could be included in an intervention designed to help stroke unit professionals discuss recovery with patients and their families more effectively.

In brief, the study involves completion of a one-off online survey, which will take **up to 20 minutes** to complete.

Please read the participant information sheet below, which provides more information about the study. You may download a copy for your records if you wish. If you would **like more information or have any questions**, please contact Louisa Burton (e-mail: louisa.burton@bthft.nhs.uk, or telephone: 07436 020 488). Supervisors: Prof Anne Forster (Professor of Stroke Rehabilitation and Head of the Academic Unit for Ageing and Stroke Research), e-mail: a.forster@leeds.ac.uk, telephone: 01274 383446; Dr Tom Crocker (Senior research fellow, Academic Unit for Ageing & Stroke Research), e-mail: tom.crocker@bthft.nhs.uk, telephone: 01274 366 615; Dr Judith Johnson (Lecturer, School of Psychology, University of Leeds), e-mail: j.johnson@leeds.ac.uk, telephone: 0113 343 0510.

Participant Information Sheet

(v1.1 30/12/21): https://static.onlinesurveys.ac.uk/media/account/133/survey/796989/question/survey_participant_information.pdf

Our Privacy Notice for Research is available

here: <https://static.onlinesurveys.ac.uk/media/account/133/survey/778675/question/research-privacy-notice.pdf>

This survey has been granted ethical approval from the University of Leeds (MREC 21-013). If you decide to participate, please answer the questions as honestly as possible as all responses are confidential. To further guarantee confidentiality please do not provide any personal information from which you could be identified.

If you wish to participate, please continue to the next page, where we will ask for your consent.

Page 2: Consent form

Please tick to indicate that you agree with each of the following statements:

Please select at least 6 answer(s).

- I confirm that I have read and understood the Information Sheet dated 30/12/2021 (Version 1.1) for this study.
- I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason and without my legal rights being affected.
- I understand that my data will be collected for this study and may be used to help develop new research. I understand that Data Protection regulations will be observed.
- I understand that I may withdraw my submitted survey responses by contacting the researcher within 14 days of submission
- I understand that anonymised quotations from the survey I complete may be used in study reports, but I will not be identified.
- I agree to take part in the above study.

If you do not agree with all of the above statements, you will be unable to proceed with the survey. Thank you very much for your time and consideration.

Appendix N

Example question from survey study

Barrier 3: Some professionals describe feeling unable to predict recovery

How **important** do you feel it is to address this barrier in an intervention?

- Not (at all) important
- Slightly important
- Moderately important
- Very important
- Extremely important

How **feasible** do you think the following approach would be to address this barrier?

Please don't select more than 1 answer(s) per row.

Please select at least 1 answer(s).

| | Very unlikely to be feasible | Unlikely to be feasible | Likely to be feasible | Very likely to be feasible |
|---|------------------------------|--------------------------|--------------------------|----------------------------|
| Receive information on (evidence-based) factors to consider, which may impact recovery after stroke | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

How **useful** do you think the following approach would be to address this barrier?

Please don't select more than 1 answer(s) per row.

Please select at least 1 answer(s).

| | Very unlikely to be useful | Unlikely to be useful | Likely to be useful | Very likely to be useful |
|---|----------------------------|--------------------------|--------------------------|--------------------------|
| Receive information on (evidence-based) factors to consider, which may impact recovery after stroke | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Please tell us why you think using this approach to address this barrier would be: - Feasible/ unlikely to be feasible - Useful/ unlikely to be useful.

Do you have any other ideas about how this barrier might be addressed?