Understanding Patient Learning in a Stroke Rehabilitation Setting: An Ethnographic Exploration

A thesis submitted in accordance with the requirements
of UCL for the degree of Doctor of Philosophy

by (Henrietta) Sally Davenport

University College London

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Abstract

Background and purpose

Learning is fundamental to recovery following stroke but little is known about how stroke survivors learn in the rehabilitation setting, how learning contexts are communicated and what impact they have on engagement with rehabilitation. This research used ethnographic methods to explore learning and being a learner in rehabilitation.

Methods

Study 1: A meta-ethnography to synthesise research on patients' perceptions of education and teaching on engagement with, and adherence to, independent therapy-based practice.

Study 2: An ethnography with observation and shared conversations to explore learning within a neurorehabilitation setting in the early to late subacute stages post stroke.

Findings

Study 1: Synthesis from 18 papers resulted in three interrelated themes focussing on the person as learner, the therapist as teacher, and the guidance received. Teaching and learning in the prescription of independent therapy-based exercises were found to be interdependent. Practice that considers one without the other may have a negative impact on outcomes.

Study 2: Observation over 53 days and serial conversations with 14 stroke survivors showed that recovery involved a complex process of new learning. Stroke survivors looked for alignment between the teaching they received and what they expected and wanted to learn. Coherence between teaching and learning positively impacted rehabilitation engagement and emotional well-being.

Conclusion

This study has improved understanding of learning from the perspective of stroke survivors and advanced the theory of learning in neurorehabilitation. Findings suggest that engagement with learning activities such as rehabilitation-based practice may be compromised when there is a mismatch between patients' learning expectations and clinicians' planned content. An openly inviting, visible and unifying rehabilitation curriculum that aligns expectations and delivery may enhance engagement. The concept of a rehabilitation curriculum is new and requires further exploration and development to determine its value within practice.

Impact statement

This clinical research has potential to impact the 120,000 people who have a stroke in the UK each year and the clinicians who work with them. Re-learning functional activities is fundamental to recovery following stroke. However, stroke survivors find it difficult to undertake prescribed exercise at sufficient intensity to optimise their recovery. Little is known about stroke survivors as learners in the rehabilitation setting, how learning contexts are communicated and what impact they have on engagement with rehabilitation. This research set out to explore these issues.

Key findings:

- Recovery post stroke is a complex process of new learning that is imposed by a sudden change to a person's health status.
- Learning theory can be applied to the stroke rehabilitation context to help make sense of how and why stroke survivors feel and act as they do.
- Learning is an inherently risky activity that involves stepping out into an unknown with no surety of the result. To help mitigate this uncertainty, stroke survivors look for a curriculum of rehabilitation that makes sense to them. This is based on their knowns and unknowns and conceptions and misconceptions of stroke, recovery, and rehabilitation.
- Stroke survivors feel confident when their experiences of rehabilitation match their expectations and make sense to them with respect to their perceived trajectory of recovery. They are distressed and saddened when there is a mismatch between expectations and delivery.
- Stroke survivors need to be actively invited into the rehabilitation learning context with a visible planned curriculum that aligns with their desired learning and which they believe, and trust, is right for them.

The impact for people post stroke is clinical practice that is better aligned between what is delivered and what the person expects and wants to receive, for example, doing exercises that feel targeted to strengthening specific muscles rather than practice of more abstract functional tasks. Rehabilitation that makes sense provides a stronger platform for desired actions to result, engagement with rehabilitation to be sustained, outcomes to be optimised and resources most effectively used.

The impact for clinicians is that it is possible to expand the theoretical underpinning of rehabilitation which, to date, is under-theorised. Understanding rehabilitation as a process of patient learning enables a rich body of research on education in general, and adult learning in particular, to be applied to the rehabilitation setting. If clinicians saw themselves as teachers and patients as learners, the application of best practice principles of education could enhance current rehabilitation.

The impact of this research is to offer a new line of understanding that can be applied to help progress the field of rehabilitation. Further exploration can be made of a wider group of people post stroke to develop typologies of different types of learner, with different learning needs and desires, and to see whether there is stability or change within individuals over time.

Although it would need exploration, the findings do not seem to be so specific to stroke that they would not have transferability to other patient groups.

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Abbreviations	Definition
AF	Atrial fibrillation
ABI	Acquired brain injury
CASP	Critical Appraisal Skills Programme
GP	General practitioner
ICF	International Classification of Functioning, Disability and Health
HCA	Healthcare assistant
NHS	National health Service
OECD	Organisation for Economic Co-operation and Development
UK	United Kingdom

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Chapter 1 Introduction

1.1 Phenomena of interest and purpose of the research

The phenomena of interest in this research are learning and recovery in the context of neurorehabilitation, particularly post stroke, as understood by the patients who experience these. Learning to accomplish everyday activities is fundamental to neurorehabilitation and recovery (Wade, 2015a). As this research will demonstrate, learning is a complex evolving concept that lacks a significant theoretical or empirical foundation in the context of neurorehabilitation. The focus of this research was to develop greater understanding of the learning and sense making undertaken by patients during the early to late subacute recovery period post stroke (Bernhardt et al., 2017) and to offer new insights for rehabilitation professionals.

1.2 Stroke

Globally, there are more than 12 million first event strokes each year and approximately 101 million stroke survivors (Feigin et al., 2021). Stroke is the second most common cause of death and third most common cause of death and disability combined (Feigin et al., 2021). Improved medical management (Lackland et al., 2014) and the wider introduction of organised stroke care (Crichton et al., 2016) have led to the rate of stroke deaths falling. However, the change in population profile with both population growth and aging, and greater exposure of people to key risk factors, has resulted in the absolute numbers of people living with the effects of stroke increasing (Feigin et al., 2021).

In the UK, there are currently over 100,000 new incident strokes each year, adding to the more than 1.3 million stroke survivors (Stroke Association, 2022). Although varying across studies, estimates have shown that the number of strokes could increase by 60% by 2035, with the number of people living with stroke doubling (King et al., 2020). The indicative cost of stroke within the UK is estimated to be £26 billion per year, which includes formal and informal care costs, lost income and benefits (Patel et al., 2020). From formal care costs, rehabilitation has been shown to be the main contributor to the overall cost of post stroke care (Rajsic et al., 2019). It has been suggested that investment in rehabilitation could lead to substantial benefits and savings (Patel et al., 2020).

Approximately 85% of people post-stroke survive their hospital stay and approximately 66% return home (Royal College of Physicians Sentinel Stroke National Audit Programme, 2015). Of these, almost 70% feel that stroke has impacted on their independence (Stroke Association, 2019) and 45% report feeling abandoned (Stroke Association, 2016). The wide range of difficulties experienced by people post stroke persist, with stroke survivors often living with poor outcomes that are similar in type and number to those shown shortly after the stroke itself (Crichton et al., 2016). The implications of this are broad, with impacts on health-related quality of life generally (De Wit et al., 2017; Schindel et al., 2021), as well as more specifically on relationships and family (Northcott et al., 2016; Stroke Association, 2019), and income and employment (Maaijwee et al., 2014; Stroke Association, 2019). These long-term impacts have reinforced the thinking of stroke being a long-term chronic condition (Crichton et al., 2016).

1.3 Recovery Following Stroke and Neurorehabilitation

Recovery of function post stroke is underpinned by non-learning dependent spontaneous biological recovery; learning dependent mechanisms of restorative change and substitution; and the use of compensations, adaptive interventions, and modifications of the environment (Buma et al., 2013). The degree of recovery depends on both internal and external factors, including those that are person related such as age, genetics, and associated comorbidities; those that are lesion location and severity dependent; and those that relate to opportunity for behavioural training (Alawieh et al., 2018). Key to this training is both the learning environment in which the training is situated and the sensorimotor exposure afforded to, and thus experienced by, the individual.

Rehabilitation aims to enable individuals to reach their optimal functional level so as, where possible, to attain independence and self-determination (World Health Organization, 2011). To achieve these goals, people with neurological conditions, such as stroke, typically engage in personalised one-to-one treatment programmes provided by neurorehabilitation professionals, such as physiotherapists and occupational therapists (Wade, 2015b). Motor learning and dosage, adherence to prescribed exercise, and therapeutic patient education are critical components of these programmes, with a positive dose-response relationship shown (Lohse et al., 2014).

1.3.1 Motor Learning and Dosage

Neuroplastic change underpins the learning dependent processes of recovery. The brain is maximally responsive to learning-dependent neuroplasticity in the first three months after stroke (Dromerick et al., 2021; Hordacre et al., 2021; Zeiler and Krakauer, 2013). For rehabilitation to be effective, it must harness this potential through the provision of sufficient training and opportunities for practice (Kitago and Krakauer, 2013; Krakauer et al., 2019; Lohse et al., 2014). Although dosage and intensity have been much discussed, to date there is no clarity in respect to exactly what constitutes an intense programme. Trials of both standard care and novel therapies involving 30-40 extra hours of practice have failed to show consistent benefit (Lang et al., 2016; Pomeroy et al., 2018; Winstein et al., 2016). In contrast, clinically and statistically significant change at impairment level was shown following 300 extra hours over 12 weeks in chronic stroke survivors (McCabe et al., 2015). These findings were supported in a systematic review by Schneider et al (2016) which concluded that a 240% increase in rehabilitation time over usual care would be needed to confer benefit.

Despite the lack of certainty about optimal dosage, the reality is that levels within standard care often fall far below what could be considered even the lower limit of an intense programme (Hargroves and Lowe, 2022). Observational studies from stroke units have consistently shown that people post stroke spend much of their days alone and inactive, with only relatively small amounts of time engaged in therapeutic activities (Bernhardt et al., 2004; Hokstad et al., 2015; King et al., 2011; Sjoholm et al., 2014; Wellwood et al., 2009). In their seminal work, Bernhardt et al (2004) demonstrated that on a stroke ward, patients spent 60% of their day alone, 28% sitting out of bed and only 13% in therapeutic activity. Despite the awareness of low levels of activity, later work by this group showed that 50% of patients' days were still spent alone, that therapists were infrequently on the ward, family were rarely present in therapy, and little was in place to enable independent practice (West and Bernhardt, 2013). This lack of meaningful activity has also been reflected in qualitative explorations of time on inpatient stroke units, with people post stroke reporting feeling bored and alone, that free time is depressing and unstimulating, and that they want to do more (Eng et al., 2014; Luker et al., 2015). Overall, although the concept of a 'dose' in neurorehabilitation is complex and multidimensional (Hayward et al., 2021), most stroke survivors do not do enough or at a sufficient intensity to optimise learning and motor function (Hayward and Brauer, 2015).

1.3.2 Adherence

As highlighted, stroke survivors and their relatives have consistently indicated that they would like more therapy (Bennett et al., 2016; Galvin et al., 2009; Lewinter and Mikkelsen, 1995; Wiles et al., 2002;). To build intensity of practice, however, rehabilitation cannot be restricted to just temporally and spatially isolated therapy sessions and face-to-face involvement should not be considered to constitute the most important aspect of the process (Taylor et al., 2015; Wade, 2016). As discussed by both Wade (2016) and Dobkin (2016), although face-to-face therapy contact is important, rehabilitation should not be synonymous with therapy. Going beyond the recommended 45 minutes of therapy instead involves patients practising either with other patients, carers/family members, or alone. Despite the potential benefits of independent practice, currently little occurs outside therapy (Taylor et al., 2015), and when it does it is mostly structured and with full supervision by a qualified therapist (Stewart et al., 2017).

The reasons why many people fail to follow recommendations for independent exercise are multifactorial. Adherence is a complex phenomenon. It is defined as 'the extent to which a person's behaviour – taking medications, following a diet and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider' (World Health Organization, 2003, p3). The multidimensional nature of the issue has been encompassed within five interrelated dimensions:

patient-related factors; condition-related factors; social and economic factors; healthcare team and systems factors; and therapy-related factors (World Health Organization, 2003). Following stroke, patient- and condition-related factors such as depression, fatigue, perceived self-efficacy and fear of recurrence/exacerbation; social factors such as a lack of family support; and economic factors such as transport costs, have been identified as barriers to engaging with and adhering to physical activity (Morris et al., 2012, Nicholson et al., 2013, Rimmer et al., 2008). Relatively little research has been undertaken to understand patients' perspectives on and beliefs about adherence to specific exercise programmes to build intensity and dose of practice rather than either physical activity or exercise in general (Donoso Brown et al., 2015; Karingen et al., 2011; Levy et al., 2021). Findings from such work showed that although people post stroke report receiving instructions, the training was often felt to be vague, and the exercise programmes themselves non-specific. As a consequence, the exercises were done infrequently and often reduced by the person to better fit their lifestyle which resulted in decreased intensity (Donoso Brown et al., 2015).

1.3.3 Therapeutic Patient Education

Health literacy is described as the capacity of individuals, families, and communities to make sound health decisions in the context of their everyday lives (Nutbeam, 2008). Successful health literacy involves people having enough knowledge, understanding, skills, and confidence to take an active role in maintaining their health and wellbeing (Robertson et al., 2019). However, low or problematic health literacy is common, at around 50% (Rowlands, 2014), and is associated with lower self-rated health and higher rates of long-term health conditions (Rowlands et al., 2018). A review of the role of health literacy in the development of self-management skills in long-term disease management concluded that low health literacy was an obstacle to the successful acquisition and maintenance of necessary behaviours (MacKey et al., 2016). Importantly, developing sufficient levels of health literacy involves people not only acquiring the knowledge and skills through patient education, but additionally being supported to use these so that they can optimise their interaction with the healthcare system.

Therapeutic patient education is a planned, systematic, sequential, and logical process of teaching and learning provided to patients (Lorig, 2001). It is an interactive process (Pellise et al., 2009) that aims to improve health by helping people develop knowledge and skills to optimally manage and adapt their lives to their health condition (Pétré et al., 2017). Whereas poor education leading to people not knowing, understanding or remembering has been shown to limit adherence to health management plans (Coulter and Ellins, 2007; Institute of Medicine (US), 2004), effective therapeutic patient education has significant beneficial effects on health outcomes for people living with chronic conditions (Lagger et al., 2010; Simonsmeier et al., 2022).

Considering these benefits, it has been questioned why such limited use of patient education is made in practice (Simonsmeier et al., 2022). One suggestion is that health practitioners may not know how to effectively design and deliver this type of education (Simonsmeier et al., 2022). When questioned about patient education, therapists believe it empowers their patients and forms an extensive and integral part of their practice (Caladine, 2013; Rindflesch, 2009). However, it is often delivered in a passive and inconsistent way, and based largely on what therapists think patients need (Forster et al., 2012; Hafsteinsdottir et al., 2011; Hoffmann and Cochrane, 2009;). It also only infrequently relates to specific guidance regarding how to actually undertake independent exercise practice (Breese and French, 2012; Gahimer and Domholdt, 1996). These findings raise questions not only about whether patients realise that they are receiving education, and whether they know that they are supposed to learn from the experience, but also whether the therapists are sufficiently cognisant of the contextual factors that influence a successful educational interaction.

In his commentary on ‘Rehabilitation, A new approach’, Wade (2015a) highlighted the importance of patient and carer learning as one of two key processes that make rehabilitation different from other medical care: ‘the central process of change is learning, learning by the patient and also often by family members of how to achieve wanted activities in the presence of altered or limited skills and abilities’. In his discussion he cited what he considered were important principles concerning learning: that the patient must want to learn and that learning may involve mastering basic skills before wanted functional activity such as standing and walking; that the patient must practice, which of itself does not require a therapist to be present; that patients need feedback so that they can improve; that patients need to take on responsibility for their learning so that they can be more satisfied and more successful; and that, as far as possible, practice should be contextually similar to where the activity normally takes place. What is not established is whether these principles resonate with the perceptions of the stroke survivors who undertake the learning and therefore whether they can be relied upon to guide healthcare practice or not. This type of research is important for the development and implementation of more effective rehabilitation programmes early after stroke (Prout et al., 2017).

1.4 Summary and Problem Statement

Although practice is fundamental to rehabilitation and recovery post stroke, whether undertaken with therapists, with other stroke survivors or independently, most people do not do enough. Effective rehabilitation is dependent upon effective learning but research to date has focussed on education and transmission of information rather than learning. The views and perspectives of patients have not been fully considered. The aim of this research is to develop greater understanding of the learning undertaken by stroke survivors in the early to late subacute stage. To achieve this aim, two studies have been undertaken:

Study 1: A meta-ethnography of qualitative studies of patients' views and experiences of therapy-based exercise prescription.

Study 2: An ethnography of learning and recovery in the context of stroke and neurorehabilitation, from the perspectives of patients.

1.5 Overview of Thesis

Chapter 2: The Meta-ethnography

As the literature on the perceptions of information giving, exercise prescription and learning in respect to home exercise programmes is limited in relation to stroke, the aim of the first stage of the research was to explore these issues more widely in other areas of therapy practice. The initial area of interest was what patients said about the prescription of independent exercises and what they wanted regarding this aspect of their rehabilitation. The aim of the meta-ethnography was therefore to explore how patients viewed being prescribed therapy-based exercise by healthcare professionals, the information they were given, the education they received and if/how they independently practised and adhered to their treatment programme. The findings were developed within three themes of the person as learner, the therapist as teacher, and the guidance received. In respect to the initial aim, these findings broadened out much further than just the prescription of exercise to include what teaching and learning involved in the context of being a patient who was having to learn from need and not from choice. The focus on the patient as a learner in particular was a novel theme that led into the next stage of the work, which was to explore learning theory, particularly in respect to adult learners.

Chapter 3: Overview of the theoretical constructs of adult learning

This chapter picks up the theme of adult learning theory and presents an overview, focusing particularly on the work of three prominent educational theorists: Peter Jarvis, Knud Illeris and Etienne Wenger-Trayner. The topic of adult learning is extensive and therefore this chapter introduces key thoughts and understandings that are then developed and applied in both the subsequent and later chapters of this thesis.

Chapter 4: Translation of findings from the meta-ethnography using the framework of adult learning

Having outlined key theories related to adult learning within an education and/or work-based context, Chapter 4 links this literature to findings from the meta-ethnography. Deeper explanations are offered with respect to the three themes inferred from the review of the literature. This chapter particularly addresses the multifaceted aspects that learning involved – not just learning the seemingly simple exercises but also: (1) learning about the health condition, its wider treatment and management and what working on the body through exercise might mean, involve and achieve; (2) learning about the consequences of the condition and the impact of this on everyday life, identity and roles, as well as hopes and expectations for the future; and also (3) learning about the structure and expectations of the various communities of both the healthcare systems and wider society and life. For patients, balancing these different aspects of learning means that at times learning might occur as was planned by healthcare professionals, but it can also be quite different from what was intended.

Chapter 5: The Ethnography

Building on the work from the meta-ethnography, this chapter begins by setting out the research question, aims and objectives for Study 2 – the ethnography. It then introduces the theoretical basis of interactionism as the interpretive framework to underpin the ethnography. This perspective was selected as it acknowledges learning as a social phenomenon that is a manifestation of human behaviour that can only really be understood if explored within the context of the social world in which it is occurring. It then introduces ethnography as the selected methodology to explore learning from the personal experience of the people involved and the observation of their practice of everyday life within the context in which it takes place.

The second part of the chapter then details the methods of the study itself.

Chapters 6-11: Findings

The findings are presented across a number of chapters.

Chapters 6-7: Findings – Setting and Patient Participants

Chapter 6 introduces the settings for the study, presenting a picture of both the places and the people – particularly of the rehabilitation unit where most of the data collection was conducted. The aim is to transport the reader to the places integral to the study so that they have context for the findings that follow.

Chapter 7 introduces the patient participants and begins with a short pen portrait of each person. It then sets out what knowledge and understanding they brought to each stage of their learning (their knowns and unknowns) and the influence this had on their sense making of what they were experiencing in respect to stroke, rehabilitation, and recovery (their conceptions and misconceptions). Key concepts introduced in this chapter include the visible and invisible rehabilitation curriculum, and the invitational and dis-invitational aspects of the learning context.

Chapters 8-10: Findings – The Places of Rehabilitation

Chapters 8-10 cover the places of rehabilitation – first the acute setting, then the rehabilitation unit, and finally home. This chronological structure was decided upon as it reflects the evolving nature of the patient participant learning and how learning at each subsequent stage of the pathway was strongly influenced by what had come before. Each of the three chapters is divided into three parts, with findings first presented about the places themselves, then about the people in the places, and finally the processes enacted by the people in the places. Based on whether the experiences of patient participants made sense or not (visible or invisible, and invitational or dis-invitational), the places were experienced as being either the right place for their rehabilitation and recovery or the wrong place.

Chapter 11: Summary of the Findings of Study 2: the ethnography

This short chapter summarises the findings by presenting them in respect to the four objectives set out for the ethnography. It focuses on how the patient participants made sense of their recovery and accompanying rehabilitation, and introduces the importance of aligning the planned curriculum, the delivered curriculum, the received curriculum and the desired curriculum. The chapter finishes with reflections on the strengths and limitations of the ethnography.

Chapter 12: Discussion – The rehabilitation curriculum and the processes and places of its enactment

This theme of the curriculum of rehabilitation is taken forward in the discussion chapter. Focus is given to who the patient participants as learners were at the heart of the curriculum, what the overall purpose of rehabilitation was/could be, how it was enacted, and how it was experienced. In addition, the discussion stresses the importance of articulating and making visible a curriculum for the patient participants and their families. Being new to stroke, the patient participants embarked on their journey of recovery with neither a map nor compass. By making a curriculum more visible, the hope is that fewer opportunities would be lost for both those delivering and those receiving rehabilitation, with greater alignment of understanding between the two. With this alignment comes greater sense making, from this greater emotional wellbeing, and from this the greater likelihood of desired actions and outcomes.

Chapter 13: The development of a theoretical model to underpin learning in rehabilitation

This penultimate chapter presents my reflections and overarching thoughts about both the process undertaken and the findings reported in this thesis. It discusses the stages of analysis, before bringing together the findings from both studies to propose a theoretical model to underpin learning in rehabilitation. The chapter ends by offering clinical implications for rehabilitation professions, considerations for future research and plans for dissemination.

Chapter 14: Conclusion

This short chapter offers a final conclusion that draws together the main points from the thesis.

Explanation of terminology

Before embarking on reading this thesis, a point about terminology and the terms used to refer to the ‘patients’ in both the meta-ethnography and the ethnography. For the meta-ethnography, because the people involved were from across a wide range of groups and at different time points, it was simplest to refer to them collectively as patients. This recognises that the term has been criticised by some because of its association with passivity and paternalism within healthcare, both of which sit contrary to the focus on active learning of therapy-based exercise (Neuberger and Tallis, 1999). In the ethnography, the term that is most used is patient participant. Where the wider body of people on the ward is referred to, the term patient is used as this reflects the terminology that was used on the inpatient rehabilitation unit. Where the wider post stroke community is referred to, the term used is stroke survivor to reflect the chosen identity from the stroke community.

1.6 Initial position statement as the researcher

To give this work context, I am a physiotherapist specialising in neurorehabilitation. I have worked with people post stroke in different settings from acute to community. For the last 20 years, I have worked in physiotherapy education. Part of this work involved short course delivery to local National Health Service (NHS) trusts, including the site where this ethnography was based. I was therefore known to some of the staff in this capacity before commencing the research.

Over my years in education, I often reflected on how different the use of teaching strategies, tools and techniques aimed at enhancing student learning away from the classroom was compared to those used, or not used, to support patient learning. Whereas recording and/or filming lectures and practical classes was standard in education, I was aware that little similar practice was employed to help patient learning. The question that stemmed from this and which was the catalyst for this PhD, was how much did stroke survivors fail to engage with, and adhere to, therapy-based practice because when they returned home they did not know, or could not remember, what to do?

Although the thesis is primarily written in the third person, at the end of Study 1 there is a short personal reflection to show how my thinking developed from that first stage and how this led into the design of Study 2. The first person is retained in the methods chapter to describe decisions made and then is used again as the work is brought together in the penultimate reflection chapter at the end.

Chapter 2 Study 1 Meta-ethnography: Therapy-based exercise from the perspective of adult patients: a qualitative systematic review conducted using an ethnographic approach

2.1 Aim

To undertake a qualitative evidence synthesis of the literature concerned with patients' perspectives on prescribed exercise, independent practice, adherence, and education and information giving, with the aim of understanding more about the influence of patient education as a variable to successful engagement with, and adherence to, independent therapy-based practice.

This study has been published: Davenport, S. Dickinson, A and Minns Lowe, C. (2019). Therapy-based exercise from the perspective of adult patients: a qualitative systematic review conducted using an ethnographic approach. *Clinical Rehabilitation, 33*(12) 1963–1977. (Appendix 1)

2.2 Study Design

Syntheses of qualitative research aim to develop a greater awareness and understanding of a subject than is possible from the interpretation of individual primary research alone (Campbell et al., 2003, 2011). They fulfil a number of roles either as independent works in their own right or to help enhance or further explain other research (Hannes and Macaitis, 2012; Paterson, 2011). A number of methodologies have been proposed which fall along a continuum from those that are more aggregative of the data where the context in which the primary findings were generated is of less importance, to those methods that are more interpretive where the aim is to help generate new theories or models (Campbell et al., 2011; Dixon-Woods et al., 2007a; Gough et al., 2012). As this work aimed to develop a comparative understanding from across a range of sources of the influence of teaching on practice, an interpretive approach was adopted.

One of the most commonly used interpretive methods within health research is meta-ethnography (Dixon-Woods et al., 2007b, France et al., 2014, Hannes and Macaitis, 2012, Ring et al., 2011). Noblit and Hare's (1988) seven phase iterative comparative approach to meta-ethnography was selected for this work as it provided structure and rigour (Table 1). In this approach the findings from the papers retrieved are translated into one another to create new interpretations and to develop new theories, whilst preserving the meaning and context of the primary research. As Noblit and Hare (1988) identify, however, the translation and interpretations are just those of the reviewer(s) and are developed in the context of their world-view. It is recognised that someone else doing the translation could arrive at different understandings and interpretations, and therefore the findings from a meta-ethnography reveal as much about the researcher(s) as they do about the work being synthesised. The findings from a meta-ethnography, however, help the reader interpret the phenomena being described within their own frame of understanding and from this shape the discourse and discussion on the topic area. It is this last aspect that is of potentially greater value than any generation of new knowledge that a meta-ethnography might achieve (Noblit and Hare, 1998).

Table 1 The seven stages of a meta-ethnography (Noblit and Hare, 1988)

Stage	Focus	Stage involves:
1	Getting started	Identifying and choosing the research topic; developing the research question; determining that a meta-ethnography is the best approach to address the research interest
2	Deciding what is relevant to the initial interest	Defining the focus of the synthesis; locating relevant studies; making inclusion decisions/selecting the studies; quality assessment
3	Reading the studies	Repeat structured reading/re-reading of the papers; identification of metaphors, concepts and themes
4	Determining the relationship between studies	Pulling together/comparison of the metaphors, concepts and themes to identify a relationship that might be reciprocal, refutational or with the development of a line of discussion
5	Translating the studies into one another	Translation of meanings from one study into another with the aim of arriving at translated concepts
6	Synthesizing the translations by identifying concepts that can encompass those found in other studies	Comparison of the potentially multiple translations from across the studies, one to another, to allow the new overall interpretation to emerge
7	Expressing the synthesis	Selecting the method best suited to sharing the information

2.3 Methods

Stages 1-2: Getting started and deciding what is relevant to the initial interest – defining the focus of the synthesis and locating the relevant studies

Systematic searches were conducted to identify papers to include in the review. The search strategy (Table 2) was developed through discussion in the research team[1] and with the assistance of a librarian. It was structured around the categories of 'engagement/adherence', 'exercise/therapy', 'allied health profession' and 'qualitative research'. As the literature on the perceptions of both information giving/ prescription and learning in respect to home exercise programmes was limited in both stroke and other neurological conditions, the decision was made to extend the search more widely to include all areas of physiotherapy and other allied health professional practice. Recognising that practice of exercise for some people can require the assistance of others, if perceptions of carers and /or family members were available, they were also included.

In recognition of the limitations of identifying qualitative papers due to issues of titling and indexing (Atkins et al., 2008; Campbell et al., 2011; Evans 2002; Finfgeld-Connett and Johnson, 2013; Ring et al., 2010), the comprehensive terms describing qualitative methods developed by Toye et al., (2013a) were used. Since initial exploration of the literature suggested that terms related to patient education/ information giving/ prescribing/ teaching/ learning were not included within titles, abstracts or key words of potential papers, these terms were not included within the search strategy. Databases: PubMed, CINAHL, SCOPUS and EMBASE were searched from January 2000-December 2018 to identify studies relevant to current clinical practice.

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[1] The research team at this stage of the PhD comprised an Associate Professor in Research (Department of Allied Health Professions, Midwifery and Social Work) (CML), a Senior Research Fellow within the field of older people's health and complex conditions (AD), and myself (SD). Both CML and AD had experience in qualitative synthesis, but SD was new to the task.

Table 2 Meta-ethnography: Example search strategy developed for PubMed

1. Patient participation[mh] OR patient compliance[mh:noexp] OR compliance[tiab] OR complying[tiab] OR engag*[tiab] OR empower*[tiab] OR concordan*[tiab] OR adher*[tiab]
2. Exercise[mh] OR exercise therapy[mh] OR exercise movement techniques[mh:noexp] OR physical activity[mh:noexp] OR motor activity[mh] OR exercis*[tiab]
3. Physical therapy modalities[mh:noexp] OR physical therapy specialty[mh] OR physiotherap*[tiab] OR physical therap*[tiab]
4. Occupational therapy[mh] OR “occupational therapy”[tiab] OR “occupational therapist”[tiab]
5. Rehabilitation of Speech and Language Disorders[mh] OR Speech Disorders[mh] OR speech therap*[tiab] OR language therap*[tiab] OR oral motor therap*[tiab]
6. Dietetics[mh] OR diet therapy[mh] OR nutritional therapy[mh] OR dietitian[tiab] OR dietician[tiab]
7. Qualitative research[mh] OR Interviews as topic[mh] OR Focus groups[mh] OR Nursing methodology research[mh] OR Life experiences[mh] OR Attitude to health[mh] OR Qualitative[tiab] OR ethno*[tiab] OR phenomenolog*[tiab] OR focus group*[tiab] OR interview*[tiab] OR grounded theory[tiab] OR narrative analysis[tiab] OR lived experience[tiab] OR theoretical sampl*[tiab] OR purposive sampl*[tiab] OR ricoeur[tiab] OR spiegelberg*[tiab] OR merleau[tiab] OR field stud*[tiab] OR fieldnote*[tiab] OR field record*[tiab] OR field note*[tiab] snowball[tiab] OR maximum variation[tiab] OR audiorecord*[tiab] OR taperecord*[tiab] OR videorecord*[tiab]OR videotap*[tiab] OR action research[tiab] OR metasynthes*[tiab] OR meta-synthes*[tiab] OR meta-summar*[tiab] OR metastud*[tiab] OR meta-stud*[tiab]
8. 1 AND 2 AND 7
9. 1 AND 3 AND 7
10. 1 AND 4 AND 7
11. 1 AND 5 AND 7
12. 1 AND 6 AND 7

Stage 2: Deciding what is relevant to the initial interest – making inclusion decisions

Papers were downloaded into the bibliographic management tool, EndNote, and duplicates deleted. Initial title and abstract screening were completed based on *a priori* criteria developed by the research team (Table 3). Papers were progressed to full text screen where there was doubt about inclusion. Both stages were undertaken by SD with involvement of the wider team where there was uncertainty.

Table 3 Meta-ethnography: First stage a priori screening criteria

Category	Description
Setting	Delivery of the information/intervention/therapy teaching/prescription to participants within an inpatient, outpatient or community environment; delivery either to an individual or to a group.
Perspective	Those living with any health condition; older people; family/caregivers of those living with the health condition; not healthy young people or children with or without a health condition. Older people were included as a group in recognition that although they may not necessarily have a specific diagnosis of a health condition, they are frequently prescribed exercise therapy because they are at risk of falls and/or another health conditions that may be mitigated through adherence to exercise prescription.
Intervention /exposure	Exposure of the person or their caregiver to some recommendation/intervention regarding their healthcare that was to be followed as independent practice – either at the time of the study or at some previous stage.
Evaluation	Experiences, thoughts, perceptions, preferences related to information giving/ teaching/ patient education and subsequent engagement with/adherence to independent structured exercise.
Study design	Any established qualitative methods e.g. interviews, focus groups and questionnaires with open ended questions, either as the entirety or in conjunction with quantitative methods as long as the two could be separated; qualitative method in relation to data collection and analysis.

Due to the heterogeneity of studies from the initial screen, and in line with the inductive and emergent nature of meta-ethnography, iterative refinement of the criteria followed discussions between the team. This narrowed the focus to therapy-based exercise rather than broad healthcare advice, independent exercise rather than group based, and that the perspectives were sought primarily through interview or focus group rather than questionnaires. Based on the revised criteria (Table 4), full text reading was undertaken by SD. Data extraction was completed independently by two members of the team (all SD and part AD/part CML) and entered into predefined tables developed through discussion of the team. This included: authors, title, source, country; theoretical framework; aim; participants, recruitment, setting; data collection method, analysis; themes, themes of interest for the review, discussion points; key quotations (Appendix 2). There were no significant differences between the team members and agreement regarding the data extracted and final inclusion/exclusion was reached through discussion.

Table 4. Meta-ethnography: Final Inclusion and Exclusion Criteria

Inclusion criteria	Exclusion criteria
• Qualitative studies involving focus groups, interviews, observation and mixed methods with a defined qualitative element • Full paper published in English and post 2000 • All health conditions • Aged over 18yrs • Perceptions/thoughts/views of person living with health condition, and also for their carer/spouse • Focus of the paper related to perceptions of engagement with a specific exercise/therapy intervention and not to more non-specific health advice/broad concept, e.g., physical activity /nutrition • A theme(s)/category within the results that related to information giving/prescribing/patient education	• Review papers, editorials, conference abstracts • Primarily quantitative methodology, including surveys • Primarily questionnaire based data collection • No, or very limited, section of results related to information giving/patient education • Perceptions related to undertaking a group class/activity unless specific reference was made to how skills would be carried over to independent practice at home • Perceptions related to medication management

The broad search strategy meant that many titles were initially retrieved. From the combined title/abstract search, 652 papers were read in full. Data extraction was completed for 39 studies and through discussion a further 21 were excluded. This resulted in 18 papers being included within the review (Figure 1).

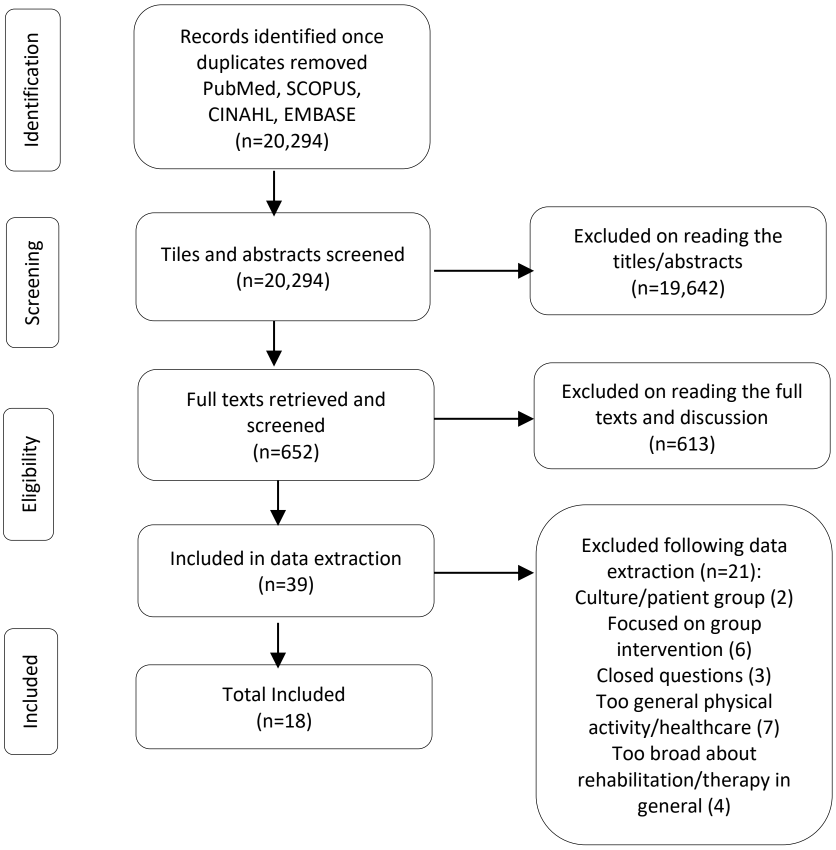


Figure 1 Modified PRISMA flow diagram representing the identification, screening and inclusion/exclusion of studies

Stage 2: Deciding what is relevant to the initial interest – quality assessment

Two methods of quality assessment were conducted for this meta-ethnography. Although not originally recommended by Noblit and Hare (1988), in their review of meta-ethnography reporting, France et al., (2014) identified that most reviewers had undertaken some assessment of quality and suggested that this is considered by many to be best practice. In line with common practice for qualitative reviews (France et al., 2014), the Critical Appraisal Skills Programme (CASP) qualitative framework was used (Critical Appraisal Skills Programme, 2018). Two members of the research group completed this independently for all papers and final agreement was arrived at through discussion (again all SD and part AD/part CML).

As identified by Toye et al., (2013b, 2013c), however, to fully assess quality, consideration needs to be given to both the conceptual clarity of the work, that is how clearly the authors articulate the concepts that facilitate theoretical insight, and to the interpretive rigour, that is the context of the interpretation, how inductive the findings are and whether the interpretation has been challenged. To fulfil these criteria, and to provide structure for the researcher's tacit judgement, further assessment of quality was undertaken using a data extraction/comment sheet designed by the researcher, with the two key headings and sub-headings identified from the work by Toye et al., (2013b) (Table 5).

Table 5 Meta-ethnography: Example of quality assessment table/comment sheet

Conceptual clarity

Is there a clear concept(s)/conceptual categories?

- Is there a clear construct that one could take away – on reading the piece is it clear what one can actually do with the findings; is there a new theoretical insight
- Does the analysis seem to be complete – do you as the reader want to do more with the data to condense it into higher order categories
- What is the balance between description and analysis
- Has the experience been understood and not just described
- What was the balance between quotes and interpretation
- Overall, does the work sit at the conceptualisation end of the continuum
- Are there translatable concepts?
    - Are the findings generic
    - Is it possible/difficult to translate the findings without further analysis

Interpretive rigour

1. What is the context of the interpretation – what was the situation in which the data were gathered

- Is there a clear and rational aim and is there indication of how this might shape and drive the approach to the research and from there the whole findings
- Is the intended and actual sample defined
- Did the sample serve the research purpose
- Were the sample suitable for the research
- Would the sample influence the findings
- Where was the sample recruited from and how transferable would the findings from them be
- Were any groups excluded or rejected from the sample
- Is there a reflexive statement from the researcher
- Have they judged the significance of their role as part of the process
- Have they stated their viewpoint/bias
- Have the researchers stated the ethical relationship between them and the participants, e.g., power discrepancy
- Is there a clear sense of where the interpretation of findings has come from
- Does it adversely affect the findings

2. How inductive are the findings?

What were the researchers' prior expectations, in what context were the data interpreted, were the findings grounded in the data or imposed upon it

- Do the data seem to have been cherry picked to support *a priori* points of view
- Has the researcher discussed contradictory data, findings, points of view
- Have they suggested why there might be none – have any missing voices been accounted for
- Does data seem to have been omitted

- Is there a clear link between the proposed concept and the data used to illustrate the themes – do the exerts selected adequately represent the concept
- Does there seem to be resonance between findings and own point or view or does it challenge them and provide new food for thought
- Do the findings have face value
- Can the results be trusted
- Have they been generated in a rigorous way

3. Has the interpretation been challenged

Has the researcher looked at the data from different points of view; have ideas been challenged and modified

- Has there been co-creation of findings from different members of the research team
- Has there been overt questioning of how the findings were arrived at
- Have methods such as member checking, co-coding by members of the research team, constant comparison been used
- Was there an alternative explanation that could/should have been considered

Accepting the limitations of the appraisal process, and in line with many other qualitative reviews, no papers were excluded based on this assessment alone. This recognised that conceptually rich papers do not always have strongly described methods, and vice versa. Instead, the process of undertaking quality appraisal meant that a detailed understanding of the papers started to be gained (Campbell et al., 2011).

Stages 3 and 4: Reading the papers and determining the relationship between them

Stages 3-6 were conducted in line with the process indicated by Noblit and Hare (1988). Little is written in the original work to inform these stages and therefore guidance from other authors was also used (Atkins et al., 2008; France et al., 2014; Hannes and Macaitis, 2012). Each paper was read multiple times to establish familiarity and meaning in the context of this meta-ethnography. No index paper (Campbell et al., 2003; France et al., 2014) was identified against which all others were read and there was no clear rationale for reading the papers in chronological order as no change or development in practice, or significant pattern of progression was seen over time. Instead, categories were constructed that allowed papers with greater commonality to be read together (Table 6).

Table 6 Meta-ethnography: Categories for grouping and structuring the reading of the studies

Setting	• Studies based mainly in inpatient settings or reflecting back to this and those based in outpatient/community settings
Participants	• Pathology group/nature of participants
Intervention/ exposure	• Studies with either contemporaneous comments about the early stage of rehabilitation or overtly reflected back to this • Studies where participants commented on the receipt of exercise/therapy specific to the paper and those where participants commented on having been in receipt of exercise/therapy at some stage in the past • Studies where participants had been part of a group and then progressed to independent exercise
Other	• Studies where participants commented particularly on the practical aspects of engaging/adhering • Studies where participants commented particularly about the psychology of engaging/adhering

During the multiple readings, different methods were employed to firstly identify and then group the metaphors as they developed. These included annotating, highlighting and re-highlighting the papers, tabulating the terms using an Excel spread sheet, and using QSR International's NVivo V.11 computer software to assist with organising and visualising the data. Although not indicated by Noblit and Hare (1988), and whilst recognising that direct quotations selected are out of context from their original setting (Atkins et al., 2008; Toye et al., 2014), key words and terms from both the original themes and quotations from each paper were identified to form the metaphors (second order and first order interpretations, respectively (Britten et al., 2002)). Following the development of initial codes, duplicates were removed, and then through comparison and grouping of terms with similar and differing meanings, further refinement enabled broad concepts and themes to be arrived at. Once developed, each paper was re-read to consider its findings in relation to these themes, and through further comparison, the nature of the relationship between the papers was discussed and established.

Phase 5 and 6: Translating the studies into one another and synthesising the translation

Developing concepts were expanded upon, defined and then through constant comparison, reciprocally translated into each other to form conceptual categories, looking firstly within the clustered groupings and then between them. Shared meanings were explored, and comparisons were made of how much these meanings related to that of others. By bringing together the translations from across the different papers, the overall aim of the synthesis was achieved with the development of a conceptual framework representing a higher, third order interpretation that offers a new interpretation and understanding whilst at the same time preserving the features and integrity of the original research. The iterative nature of these stages meant that these final interpretations were regularly taken back to the first and second order constructs both to make sure that they were still aligned and had not been translated too far, and to check that there were no unsupported concepts that did not align to the findings of the original papers.

2.4 Characteristics of the included studies

Table 7 summarises the key characteristics from the 18 papers. Patient participants (n=280 women, 136 men) with sudden onset and progressive health conditions were included: stroke (n=3); head and neck cancer (n=2); mixed rehabilitation (n=2); various speech pathologies (n=1), low back or neck pain (n=7); jaw pain (n=1); chronic fatigue/myalgic encephalomyelitis (n=1) and older adults post hip fracture (n=1). A wide age range was represented (range where stated 20-101years). Exercise and activities were either specific to the study (n=10) or not defined but undertaken at some previous stage (n=8). Fifteen studies were located in outpatient/community settings and three involved reflections on an inpatient stay. All studies explored the views of the person undertaking the practice, with one study also including the views of caregiver (Eng et al., 2014). Three papers included the views of the staff delivering the intervention but, as these did not relate to the aim of the meta-ethnography, these data were not extracted (Eng et al., 2014; Rathleff et al., 2017; Stilwell and Harman, 2017). The studies were completed in the UK (n=5), Australia (n=4), US (n=3), Canada (n=2), Denmark (n=1), France (n=1), Spain (n=1), and Sweden (n=1).

Table 7 Meta-ethnography: Key Characteristics of the 18 Included Studies

STUDY/YEAR COUNTRY	STATED AIMS	SAMPLE	PARTICIPANTS PEOPLE WITH:	DATA COLLECTION	TYPE OF DESIGN/ ANALYSIS	MAIN THEMES
CHESHIRE ET AL 2020 UK	To explore differences and similarities in treatment perceptions and experiences of GES among CFS/ME participants reporting improvement compared with those reporting deterioration in their condition	N=19 17F:2M Mean 43yrs for those 'a little worse' and 39yrs for those 'much better'	Chronic fatigue syndrome	Semi-structured Interviews – either by phone or face to face	Qualitative study nested within RCT	Five themes: 1) Getting started and false starts; 2) The indeterminate phase of GES; 3) Competing commitments; 4) Interfering symptoms and comorbid conditions; 5) Maintaining motivation
CONSTANTINESCU ET AL 2017 CANADA	To identify determinants of successful adherence to home-based therapy to inform design of a swallow based health app	N=10 4F:6M Mean 60yrs	Head and neck cancer	Semi-structured Interviews	No theoretical approach stated Thematic analysis	Six themes: 1) Perceptions on outcomes and progress; 2) Role of clinical appointments; 3) Cancer treatment; 4) Rehabilitation programme; 5) Personal factors; 6) Connection
EMMERSON ET AL 2018 AUSTRALIA	To explore patient experience of utilizing smart technology to support an upper limb home exercise program post stroke,	N=10 0F:10M Mean 72yrs	Stroke	Semi-structured interviews	Convergent mixed methods Phenomenology Thematic analysis	Three themes: 1) Exercises on the tablet helped rehabilitation; 2) Participants could use the tablet for their home exercise programme; 3) But not everyone liked the tablet
ENG ET AL 2014 AUSTRALIA	To explore factors affecting ability of the stroke survivor to drive own recovery outside therapy within inpatient stroke rehabilitation	N=7	Stroke	Semi-structured interviews	Qualitative research design Conventional thematic analysis	Four themes: 1) Lack of opportunities …dead and wasted time; 2) Out of control …at everyone's mercy; 3) Knowing what to do and why; 4) Passive rehab culture and expectations
ESCOLAR-REINA ET AL 2010 SPAIN	To explore how the intrinsic characteristics of home-based exercise programme or care provider' style in clinical settings affect chronic neck or low back pain patients' adherence to prescribed exercise	N=34 23F:11M 22 neck pain Mean 48yrs Range 25-70yrs	Low back or neck pain	Focus groups	Qualitative focus group design Data analysis based on grounded theory	Two themes: 1) Conditions of prescribed home-based exercise programme; 2) Care providers style

Table 7 Meta-ethnography: Key Characteristics of the 18 Included Studies (cont)

STUDY/YEAR COUNTRY	STATED AIMS	SAMPLE	PARTICIPANTS PEOPLE WITH:	DATA COLLECTION	TYPE OF DESIGN/ ANALYSIS	MAIN THEMES
GOVENDER ET AL 2017 UK	To identify key factors that may inform design of a new intervention to support swallow exercises in people after head and neck cancer	N=13 4F:9M 4 over 60yrs Mean 63yrs 9 under 60yrs Mean 50yrs	Head and neck cancer	Semi structured Interviews	No theoretical approach stated Content analysis	Three themes: 1) Capability; 2) Opportunity; 3) Motivation
HAMILTON ET AL 2018 AUSTRALIA	To explore how technologies were used and experienced in rehabilitation when prescription was tailored	N=20 7F:13M Mean 64yrs Range 20-101yrs	Stroke, hip fracture, brain injury, generalised deconditioning	Semi-structured interviews	Qualitative aspect nested within RCT Grounded theory	Two key themes: 1) A process of patient engagement with technology; 2) Key conditions that influenced the level of patient engagement with technology
HORNE ET AL 2015 UK	To assess stroke survivors' views and experiences of two patient-led therapies: mirror therapy and lower limb exercises	N=20 3F:14M Mean 63yrs Range 38-84yrs	Stroke	End treatment questionnaire and semi-structured telephone interviews at 4wk follow up	Qualitative aspect nested within RCT Framework approach	Three themes: 1) The benefits of patient-led therapy; 2) Practical difficulties and solutions; 3) Barriers to patient-led therapy
LIDDLE ET AL 2007 NORTHERN IRELAND UK	To investigate experiences, beliefs and expectations of a group of CLBP patients in receipt of advice and exercise as part of their treatment	N=18	Low back pain	Focus groups	No theoretical approach stated Manual analysis taking categories into themes	Five themes: 1) Effects of LBP on the individual; 2) Treatment received; 3) Limitations to recovery; 4) Expectations from Rx; 5) Patient recommendations
LINDFORS ET AL 2017 SWEDEN	To investigate patients' experiences of therapeutic jaw exercises for treating masticatory myofascial pain	N=10 9F:1M Mean 35yrs Range 21-58yrs	Masticatory myofascial pain	Semi-structured interviews	No theoretical approach stated Analysis through Systematic text condensation	Four themes: 1) Patient adherence; 2) Symptoms; 3) Treatment effects; 4) Participation

Table 7 Meta-ethnography: Key Characteristics of the 17 Included Studies (cont)

STUDY/YEAR COUNTRY	STATED AIMS	SAMPLE	PARTICIPANTS PEOPLE WITH:	DATA COLLECTION	TYPE OF DESIGN/ ANALYSIS	MAIN THEMES
MAIERS ET AL **2016** **US**	To investigate patients' satisfaction with conservative treatments for BRLP.	N=174 115F:59M Mean 57yrs	Back-related leg pain	Semi-structured interviews	Qualitative aspect nested within RCT Content analysis	Four key themes: 1) Satisfaction; 2) Perceptions of home exercise with advice; 3) Perceptions of chiropractic treatments; 4) Worthwhile care
PALAZZO ET AL **2016** **FRANCE**	To assess the views of patients with chronic LBP concerning barriers to home-based exercise programme adherence and solutions to increase adherence	N=29 Mix M&F Range 24-85	Low back pain	Semi-structured interviews	Inductive qualitative research	Seven themes: 1) Barriers to adherence; 2) Barriers associated with the healthcare journey; 3) Barriers associated with patient representations; 4) Barriers associated with environmental factors; 5) Strategies to enhance adherence; 6) Improving patient performance; 7) Expectations regarding new technologies to enhance adherence
RATHLEFF ET AL **2017** **DENMARK**	To investigate feasibility and acceptability of an unsupervised progressive strength training intervention monitored by the BandCizer for frail geriatric inpatients	N=13 M<F Mean from n=15 involved in the trial 86yrs Range 71-98yrs	Frailty associated with a range of conditions including fracture, pneumonia, UTI	Semi structured interviews	Qualitative study within a feasibility trial	Two themes: 1) Advantages of unsupervised exercises; 2) Challenges of unsupervised exercises
RESNICK ET AL **2005** **US**	To explore experiences of older women post hip fracture exposed to a home-based self-efficacy motivational intervention, the Exercise Plus Program	N=70 70F:0M Age: 81yrs +/- 6	Post hip fracture	Interviews mostly by phone	Qualitative aspect nested within RCT Naturalist or constructivist inquiry Content analysis	Fourteen themes: 1) Real and expected benefits; 2) Visual cues and knowing what to do; 3) Simplicity; 4) Individualized care; 5) Verbal encouragement; 6) Regular schedule; 7) Confidence; 8) Determination; 9) Social support; 10) Reciprocity; 11) Goal identification; 12) Unpleasant sensations; 13) Constraints to exercise; 14) Getting back to baseline

Table 7 Meta-ethnography: Key Characteristics of the 18 Included Studies (cont)

STUDY/YEAR COUNTRY	STATED AIMS	SAMPLE	PARTICIPANTS PEOPLE WITH:	DATA COLLECTION	TYPE OF DESIGN/ ANALYSIS	MAIN THEMES
SLADE ET AL **2009** **AUSTRALIA**	To determine the experience of exercise programmes by people with chronic low back pain	N=18 12F:4M Mean 51yrs	Low back pain	Focus groups	Qualitative focus group design Principles of grounded theory	Two themes: 1) Experience of exercise; 2) Helpful and empowering skills
STENNER ET AL **2016** **UK**	To explore the experiences of involvement in treatment decision making, and the information and decision support needs of patients with NSCLPB who have been offered exercise as part of their management plan	N=8 4F:4M 35-74yrs	Non-specific chronic low back pain (NSCLBP)	Semi-structured interviews	Interpretive phenomenology (Hermeneutic approach of Gadamer) Thematic analysis	Four themes: 1) Patients' expectations and patients' needs are not synonymous; 2) Information is necessary but often not sufficient; 3) Not all decisions need to be shared; 4) Wanting to be treated as an individual
STILWELL & HARMAN **2017** **CANADA**	To explore chiropractors' and chiropractic patients' experiences and beliefs related to exercise adherence	N= 6pts Mean 35yrs	Low back pain	Semi-structured interviews	Focused ethnographic design using just interviews and not observation	Four themes: 1) Diagnostic and Treatment Beliefs Motivating Behaviour; 2) Passive-active Treatment Balance; 3) The Therapeutic Alliance and Patient-centred Care; 4) Exercise Delivery
VAN LEER & CONNOR **2010** **US**	To directly document patient perspectives of voice therapy barriers & facilitators, and to frame them within a theoretical and interdisciplinary context	N=15 12F:3M Range 21-76yrs	Various speech	Interviews Face to face or by phone	No theoretical approach stated Content analysis	Three themes: 1) Voice therapy is hard; 2) Learning voice techniques; 3) The (clinician-patient) match matters

Key: F: female; M: male, yrs: years; GES: Guided graded Exercise Self-help; CFS/ME: chronic fatigue syndrome/Myalgic encephalomyelitis; CLBP: chronic low back pain; BRLP: back related leg pain; LBP: low back pain; NSCLPB: Non-specific chronic low back pain; RCT: randomised controlled trial

2.5 Quality appraisal

Results from the CASP quality appraisal can be found in Table 8. Quality ratings were variable. All studies had a clear aim and qualitative methods were appropriate in all cases. A mix of convenience and purposive sampling was used, with resultant samples often being heterogeneous in respect to age and, for the more chronic presentation, length of time living with the condition. In some papers the interview/ focus group schedule was provided. Variable details were provided about the location and duration of the interviews/focus groups. In most instances, the identity and profession of the person collecting the data were provided. Only one paper offered clear reflective comments about the influence of the researchers on the methods, data collection and interpretation of findings. Category six of the CASP 'Researchers' influence' was therefore often rated as 'no' or 'unclear'. It was unclear whether this was a case of lack of reporting or the limitation of the word count for the journal (Atkins et al., 2008). 'No' or 'unclear' was also often given for ethical considerations where many of the studies stated that ethical approval was given but provided little or no further information. Not all papers detailed their underpinning theoretical stance either for their data collection or their analysis. Overall, although the methods for most of the studies were well described, the interpretive rigour and conceptual clarity of these papers was fairly limited.

Table 8 Meta-ethnography: Final agreed quality appraisal results using the Critical Appraisal Skills Programme (CASP)

STUDY REF	IDENTIFIED AIM	METHOD APPROPRIATE	RESEARCH DESIGN	RECRUITMENT STRATEGY	DATA COLLECTION	RESEARCHERS' INFLUENCE	ETHICAL ISSUES	DATA ANALYSIS	EXPLICIT FINDINGS	CLINICAL VALUE
Cheshire et al 2020	Yes	Yes	Unclear	Part	Yes	Unclear	Part	Yes	Yes	Unclear
Constantinescu et al 2017	Yes	Yes	Yes	Part	Yes	Unclear	Unclear	Yes	Yes	Yes
Emmerson et al 2018	Yes	Yes	Unclear	Unclear	Unclear	Part	Part	Yes	Part	Unclear
Eng et al 2014	Yes	Yes	Yes	Unclear	Yes	Part	Part	Yes	Yes	Yes
Escolar-Reina et al 2010	Yes	Yes	Yes	Yes	Unclear	No	Part	Yes	Yes	Yes
Govender et al 2017	Yes	Yes	Yes	Part	Yes	Part	Part	Yes	Yes	Yes
Hamilton et al 2018	Yes	Yes	Yes	Part	Yes	Part	Part	Yes	Yes	Yes
Horne et al 2015	Yes	Yes	Yes	Unclear	Part	Part	Part	Yes	Yes	Yes
Liddle et al 2007	Yes	Yes	Yes	Yes	Unclear	Part	Yes	Yes	Yes	Yes
Lindfors et al 2017	Yes	Yes	Yes	Unclear	Yes	Unclear	Yes	Yes	Yes	Yes
Maiers et al 2016	Yes	Yes	No	No	No	Part	Part	Yes	Part	Unclear
Palazzo et al 2016	Yes	Yes	Yes	Unclear	Yes	No	Part	Part	Yes	Yes
Rathleff et al 2017	Yes	Yes	Yes	Yes	Part	Yes	Part	Unclear	Part	Part
Resnick et al 2005	Yes	Yes	Unclear	Unclear	Part	No	Part	Part	Yes	Unclear
Slade et al 2009	Yes	Yes	Yes	Unclear	Part	No	Part	Yes	Yes	Yes
Stenner et al 2016	Yes	Yes	Yes	Unclear	Part	No	Part	Part	Yes	Yes
Stilwell & Harman 2017	Yes	Yes	Yes	Part	Part	Part	Part	Yes	Part	Unclear
van Leer & Connor 2008	Yes	Yes	Yes	Unclear	Part	No	Part	Yes	Yes	Yes

2.6 Synthesis

Despite the heterogeneity of health conditions and the wide range of therapy-based or structured exercise practice, the findings from the different papers were aligned, and reciprocal relationships were identified. Although some divergent views were evident, the balance was more strongly towards a convergence of findings in respect to perceptions on prescribed exercise across the different studies.

The initial reading and data extraction focussed on overt references to the more technical/practical aspects of exercise prescription and information giving. Although comments about this featured in all 18 papers, through the multiple readings, it became apparent that this element was only part of the picture about engagement and adherence that was painted by patient participants in the studies. As much a part of the findings were comments about why the prescribing or information giving was needed and what it meant to receive this and act upon it. To make sense of, and to develop understandings from the findings from the studies, comments more purely about the exercise prescription and delivery could not be separated from these other dimensions. From the first stage of synthesis, therefore, the key concepts that were developed and which were initially translated one into the other were: ‘the need for the practice/why the participants were patients’; ‘starting from scratch – having no idea, being unsure and frightened’; ‘learning and continuing – whose responsibility?’ ‘the recipe’; and ‘the teacher’. From these, and through further synthesis, three third order themes were developed: ‘the person as a learner’, ‘the guidance received’ and ‘the therapist as teacher’ (Themes, subthemes, supportive constructs shown in Table 9; and illustrative quotes, and sources shown in Appendix 3). As will be seen in the discussion that follows, these three themes reflect the beginning of a shift in focus by the researcher from thinking that engagement and adherence to therapy-based practice could be explained and explored solely in the context of the prescribing or teaching being delivered, to understanding that prescribing or teaching could themselves only be understood in the context of the wider learning taking place.

Table 9 Meta-ethnography: Themes/subthemes with supportive comments/constructs

THEMES	SUBTHEMES	SUPPORTIVE COMMENTS/CONSTRUCTS
The Person as a learner: starting – having to engage and learn	Need, expectations/ hope, ownership/ readiness	**Need**: persistent symptoms; worried; frightened me; no control; painful; stressed out, mentally and physically; killing me; scared for the future **Expectations/Hope:** get rid of the pain; help symptoms; don't know what hoping for; don't know what to expect; previous experience; building hope; expectations different now; validation; knowing more; return to baseline; expecting a miracle **Ownership/readiness:** determined; pushing a little bit extra each time; tenacity to get better; motivation; personal attributes/coping/ responsibility; own destinies; response/attitude from others; waiting for others; own practice; active input; quick fix; ambivalence; trust in others
	Starting from scratch – unsure, scared, overwhelmed	**No idea:** can't help myself; don't know how to help myself; not knowing what doing; starting from scratch; inadequate understanding of why exercises; lack of clinical knowledge; suspicious; sceptical **Sure/Unsure**: no certainty; avoid aggravation; make it worse; worrying; don't know; no certainty on that; do it, but don't know why; sort of slightly kind of worrying; doing them right; lacked confidence; unsure on accuracy; prefer to stop; prior success with exercise made think that could do it again **Fear/scared:** alone; scared; unpleasant sensations; scared of getting hurt; dare not to train; not scared before but am now; things would go again as it did before; can do thing better if supported and guided **Information:** need to understand; desire for information; lack of knowledge; motivated when received explanation; given information but don't know why; overwhelmed; bombarded with stuff
The Person as a Learner: Continuing – having to adhere and practice	On-going needs, expectation/ hopes, ownership/ readiness, responsibility	**Needs/expectations:** Stopping when better/ perceived as better; didn't think needed to do it anymore; wish it was just like…quick fix; capacity in lives to keep going; don't see any more progress, not doing this anymore; rapid progress providing motivation **Have to keep going:** become negligent, low back pain returns; easier if perceiving benefits but hard if not; not doing any good; good to know what to do if pain returns; do all of the exercises because they are going to help **Ownership/readiness**: have to do it; commit 100%; gotten to point when can't quit; have to continue it…on my own; stubborn; more aware more motivation
	Practising – unsure and hard	**Hard/effortful:** hard to continue; hard to motivate; hard work; forgetting to do exercises, no system of keeping track; degree of attention; awareness and compliance needed; lack of support; effort involved **Embarrassing/Boring:** didn't ask what thought and wanted **Sad/lonely/miserable/despondent:** initial improvement, plateau, exercises tougher to complete

Table 9 Meta-ethnography: Themes/subthemes with supportive comments/constructs (cont)

THEMES	SUBTHEMES	SUPPORTIVE COMMENTS/CONSTRUCTS
The Guidance Received	Recipe	**Recipe:** boundaries; limits; specificity; ambiguous; being told what exercises to do and how to do them helpful; what to do, how to do, when to do **Routine:** routine and/or having a trigger to do the exercises; routine and structure key to facilitate recovery outside of therapy; information on how to structure day; clear, step by step; explicit education; strategies; exercise at desk/when hoovering **Personalisation, individualisation:** person more important than the exercises; exercise matched to level of ability – both high enough and low enough; individualized objectives **Complexity/attractiveness of programme:** simple v complex; functional, relevant; schedule v fits with lifestyle **Teaching:** pace/timing; demonstration; feedback; supervision; observation; renewal; exercise more difficult when care providers failed to observe; more difficult if lack of feedback, inadequate instructions leading to poor adherence as insecure and lacked confidence in whether properly doing exercises at home or not
The Therapist as Teacher	The teacher	**Support/feedback/monitoring:** access to staff for guidance, instruction and safety; role of clinical staff as key to equip with knowledge /understanding of what could do independently outside of therapy; confidence; improvement; motivation **Characteristics of person:** kind; caring; nice; interested; valued; believed; trusted; non-judgmental; helpful and empowering; effective educator, motivator and communicator; praise; enthusiastic; gentle; understanding; role of the care provider's style **Relationship:** therapist on one's side; helping to get through it, in it together; my spirit you are taking care of; physiotherapist close to me; asking me what I think not telling me what to do; listening; not judging; trust; helping me get through this **Adjuncts:** likes/dislikes; supportive; motivation; interest; reminder; apprehension; easier to follow; self-correction; cueing

2.7 Findings and Discussion

Three key findings were inferred from the meta-ethnography. Firstly, ill health imposed the need to learn rather than this learning being primarily from choice. Secondly, and in this context of imposed learning, engaging and continuing with therapy-based practice were perceived as endeavours that the patient participants hoped to experience as shared activities and with connection between themselves, ‘the person as a learner’ and their ‘therapist as teacher’. Within the framework of this relationship, importance was placed on the teaching or ‘the guidance received’. Finally, and also in the context of learning being imposed, the patient participants often articulated uncertainties and contradictory positions that impacted on their ability to begin and sustain exercise practice.

2.7.1 Connectedness of teacher and learner: Contradictions and Uncertainties

The findings showed that the success or otherwise of achieving the planned learning (the teaching or therapy) was influenced by factors related to the patient participant as well as with their perceived interaction and connection with others. The attention and importance that the participants placed on their therapist, naming them overtly as a teacher or educator, revealed the role they gave to this person, and therefore by default the role of learner that they then gave to themselves. Within this framework, the participants valued learning as a shared activity with their therapist, or teacher. This relationship was, however, not straightforward. Being a learner and what this meant for, and demanded of, the person, and what was wanted from, and afforded by, the teacher and the teaching, encompassed many uncertainties and contradictions both within and between individuals. These could be seen in relation to each of the three themes.

2.7.1.1 The person as a learner – readiness and engagement

This first theme represented the patient participants’ needs, motivations and emotions as they initially engaged with the therapy-based learning and then progressed to continuance of practice. The need or reason for practice, the expectations of this, and both the resultant ownership of responsibility and readiness for the learning, all influenced initial engagement and starting to learn. Participants had experienced sudden onset pathology such as stroke or were living with long-term conditions such as low back pain or chronic obstructive pulmonary disease. Engagement with learning was therefore for some at a point of loss, grief, vulnerability and/or fear, which reflected different levels of ownership and readiness. From this, a range of motivating factors were expressed from ‘having no choice’, ‘wanting things to be different’, and not wanting ‘that happening to me’, to being ‘determined’, to ‘reach my former level’, to wanting to ‘know more’, and to having ‘hope’.

For many, initial engagement with exercise was associated with ‘starting from scratch’, with the patient participants describing themselves as having either no idea or being unsure about how to start or what to do. This uncertainty was seen irrespective of condition or setting. The participants were fearful about engaging in prescribed exercise and perceived themselves as lacking in relevant experience. Within a learning context of uncertainty, insecurity and perceived inexperience, practice was either not started, stopped prematurely, or continued but only in familiar, simple, and safe ways. The participants spoke about their fear and anxiety about exercising. They were concerned that if done incorrectly they could damage themselves more, that they might regress in terms of their recovery, and that exercising might make them feel worse. Participants described feeling enabled to undertake activities with others but not alone and lacking the confidence to modify activities independently. They looked to therapists to recognise their anxiety, provide information about what to do, allay their fears, give them time to build confidence, and not to assume that they would know what to do or would be able to work it out by themselves.

Having engaged with learning, the patient participants moved into a phase where learning and practising needed to be sustained. For many, this was perceived as being ‘hard’, ‘effortful’, ‘miserable’, ‘boring’, ‘lonely’, ‘demoralising’, and requiring ‘energy’ and ‘attention’. Some were able to continue to practise because it was perceived as beneficial for symptom management, and others saw it as a means of positive coping. The participants who expected to get better, however, and those who did not realise that long-term practice would be necessary and did not want to persist, were less able to sustain practice. For those who spoke of looking for a ‘quick fix’, this was not so much looking for a short cut but for a means of escape from what was perceived as an unwelcome and difficult situation. Low mood or transitioning from supported practice to practising alone was described as overwhelming and under these circumstances practice was often discontinued.

2.7.1.2 The guidance received – recipe and choice

The second theme reflected the nature of the guidance received and the process of education or prescribing that was delivered, and/or which the patient participants would have liked to have been delivered. The participants saw therapy-based practice as a new type of learning for which they felt inadequately prepared. Fear about not knowing or being unsure about what to do, meant that participants not only sought clarity about the specifics of the exercises but also guidance about how to carry these out in the correct, non-harmful way. For this, a “recipe” with clear boundaries about the nature of the exercises and individualisation to match and adapt the exercises to the person’s capabilities was wanted by many. Within this desire for rules was the perception by some that trial-and-error learning was either burdensome or might aggravate symptoms. Participants positively appraised demonstration, observed practice, careful progression and time spent with their therapists. With time, participants believed they could be guided to reacquaint themselves with their own body, its capacities and aptitudes; develop the confidence and knowledge to cope with fear, negative emotions, and unwanted sensations; and be empowered to take risks.

Recognising that personal coaching was not possible, participants emphasised the importance of personalised programmes. Whereas many sought simplicity, a few wanted to be challenged, and whilst some desired a fixed schedule, others wanted flexibility to fit exercises around their lifestyle. While a standard programme that suited everyone would be impossible to construct, the patient participants believed that good programmes shared certain features, such as: being individualised and adapted to personal interests and motivations; offering regular feedback, guidance and correction; and not being too boring or onerous. As part of living with a long-term condition and to assist with continuance of practice, the participants sought renewal and progression of their exercise schedules. Checklists and booklets, as well as adjuncts and technology to support practice, were considered helpful for some but not all. Instead, continued review, exercise progression and external motivation were sought both by those who sustained practice and those who discontinued. Participants wanted to continue to practise in the same manner and location as when they first started. When this was not possible, clear options and quick re-access to services were highly valued. The patient participants did not want to be abandoned to continue with and progress practice alone. Instead, they looked for on-going contact and support and not just reminders to exercise. Overall, the participants wanted to learn and know what to do and how to do it, they wanted explanations and they wanted to be taught by people who attended to their concerns, anxieties, needs, experiences, and feelings.

2.7.1.3 The therapist as teacher – responsibility and being able to demand

The final theme brought together what patient participants wanted from others, and the strong connection and importance of interaction between themselves and their therapist, or the learner and their teacher. In response to their perceived lack of exercise-related experience, many participants drew upon the experience of being a learner under the guide of a teacher, but in the context of the healthcare system. With this often came the expectation of being rehabilitated or "fixed", as well as uncertainty about whose responsibility learning and practice was, and what it was reasonable to demand or expect from their therapist. Across the different studies and health conditions, although responsibility was wanted, sought, accepted and followed by some, this was not the case for all. Feeling ready to engage and taking responsibility for learning was influenced by factors related to the individual and to their perceptions of both their teacher(s) and their place within the healthcare system. At the individual level, those experiencing loss and pain needed time to realise that recovery would be slow and on-going with no quick fix. Patients with these characteristics may be slow to engage and to take responsibility for their learning. At the extreme end of this continuum, these patients might be viewed as being resistant to learning and therefore as having weak ownership attachments, or as having low levels of self-determination. They may also be described as being unempowered or poorly compliant. At the cultural level, some participants perceived that the healthcare system, for example its structures, processes and policies, as well as its people, prevented them from taking responsibility and engaging in independent practice. Both these perceived healthcare system-related factors and the individual-level factors might operate jointly or independently. Delayed engagement with learning could be due to multiple interacting factors that may not simply reside within the capacity of the individual to solve.

The patient participants wanted to be understood as people first. They looked for a therapist who was caring, warm, kind, professional, positive and optimistic. Good communication skills were valued and were influential to a person’s motivation. Information needed to be accurate, trustworthy and convincing, and articulated so that it could be understood. Therapists who offered patience, encouragement, praise, belief, feedback, and motivation were highly regarded. The participants spoke of their need for allies, with therapists who were able to be there and to listen and who, through their actions, demonstrated that they were on their side. Therapists who asked but did not dictate, those who supported but did not threaten, and those who shared decision-making but were also able to offer expert views and make decisions when asked, were seen as capable of making a positive contribution to learning.

Within the learning context mutual trust was important, with participants wanting to be valued and not judged, blamed or made to feel guilty. Some wanted a friend and most wanted security to build a relationship and to be enabled to see life with a health condition in a different way. Anxiety and uncertainty and an individual’s beliefs about their competence and confidence meant that where some were able to move away from the support of the teacher, this was not the case for all. Contradictions were seen between trying and needing to find internal motivation and to take responsibility, and the strong feeling from some of wanting and needing this to come from an external source. Overall, the patient participants wanted and valued a good teacher, both to engage and continue with practice.

In summary, what was of importance for exercise prescription was not only the nature of the teaching or guidance received, but also the expectations, ownership, and readiness of the participant themselves as the recipient of the teaching, as well as their interaction with their therapist or teacher. Apparent across all three themes were the uncertainties and contradictions both within and between individuals as they attempted to engage and continue with therapy-based practice. All the patient participants perceived themselves as needing to engage and practise but only some wanted and expected to take full responsibility. Some looked for rules and recipes and structured practice, but this was balanced against the desire for options and choice. Equally some wanted to play an active part whilst others wanted to be more passive. Learning the content of the exercises and how to do them was balanced against learning about living physically and emotionally with the health condition, learning what the body could do, and learning about the healthcare system and what one might reasonably demand. Individual learners could not therefore be easily categorised into a specific type of learner or as having a particular learning style. Patients held contradictory positions and uncertainties about their competence and confidence to learn which often resulted in patients either failing to engage in prescribed practice or stopping prematurely.

2.8 A conceptual model of the uncertainties and contradictions related to learning therapy-based exercise

The connectedness between the patient and their therapist, or the learner and their teacher, and the uncertainties and contradictions related to learning therapy-based exercise are shown in Figure 2. This conceptual model, developed from the meta-ethnography, reflects the patient as the learner at the centre, with the therapist as a teacher acting within the healthcare system around the outside. The spokes joining the two represent the uncertainties related to motivation, experience, and empowerment, with a continuum from patient owned characteristics in the middle to therapist expected or desired characteristics at the edge. This model could provide a framework for clinicians to assess these uncertainties, and from this be guided as to the individual nature of a patient's particular readiness, expectation and needs for learning. By gauging this both initially and over time, the degree of stability or change could be revealed. This would indicate those patients who, in response to needing to learn and sustain practice, will always be more passive, those who will always show independence and those who sit in the middle or move between these two. Understanding the patient and their particular stance towards learning, would enable therapists not to adopt blanket expectations of learning which, as the patients in the meta-ethnography highlighted, can lead to perceptions of judgment and blame, but instead to match their therapy or teaching to the individual and support them in their learning relevant to the stage or moment in time.

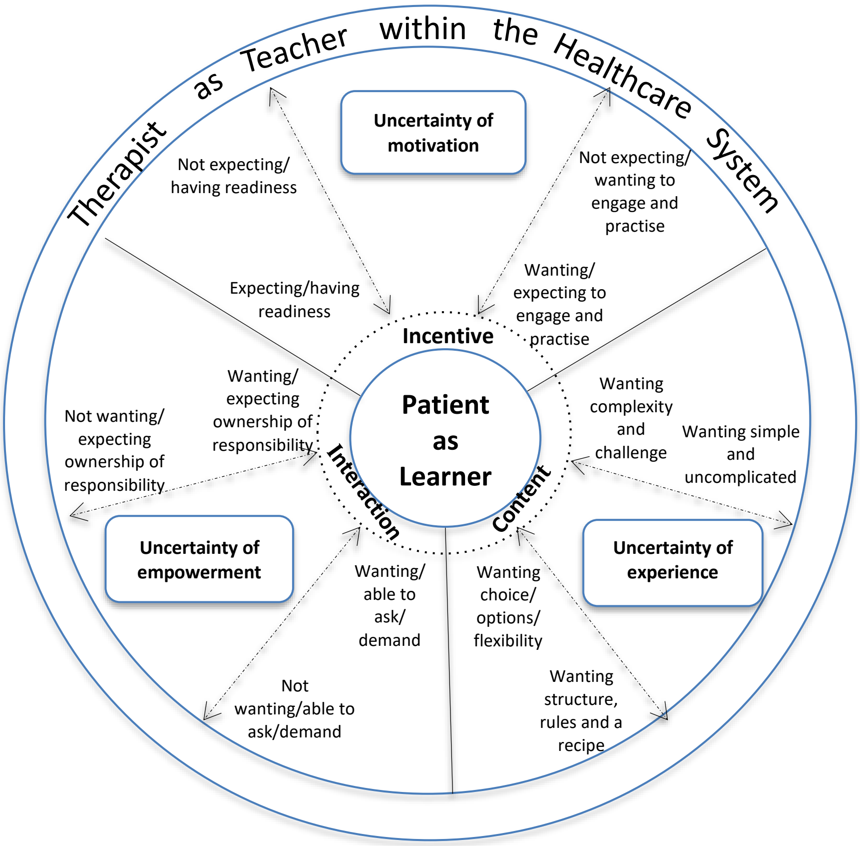


Figure 2 Conceptual model illustrating the connection between the patient as learner and their therapist as teacher when engaging with therapy-based practice

2.9 Strengths and Limitations of the Meta-ethnography

As the search was not limited to any specific patient group or type of exercise, broad terms were used. The resultant retrieval of a large number of papers necessitated the iterative revision of the inclusion criteria as the relevance of possible papers became apparent. The final criteria arrived at meant that the papers included were specifically focused on engagement with/practice of independent exercise, and excluded those papers where participants, reflecting on wider aspects of engagement with therapy or rehabilitation, also shared perceptions on learning and teaching. Whether searching should be undertaken with the intention of retrieving all possible papers in the field, or purposively until saturation is reached is debated (Atkins et al., 2008; France et al., 2014, Hannes and Macaitis, 2012, Toye et al., 2014). Noblit and Hare (1988) proposed that unlike systematic reviews, the search does not need to be exhaustive unless there is clear justification and reason for doing so. Campbell et al (2011), also suggested that incomplete retrieval is unlikely to significantly influence the findings. However, if an extensive search is not undertaken there is a risk that studies offering important insights may be overlooked (Toye et al., 2014).

The search was also date limited. As qualitative methods have evolved over the last twenty years, extending the search further backwards in time may have identified a large number of papers whose methodology was less rigorous and therefore their quality less secure. Studies published since 2000 might also best reflect current practice with the use of technology and other adjuncts to support the prescription of independent exercise. It is recognised though that conceptually important papers published before this time may have been excluded. The review was also limited to papers published in English. The included studies were all from nations with well-developed healthcare services. Across the papers, little mention was given to the socio-economic status of the participants and no comments were made about their health literacy. The broad search criteria meant that the views of participants with a range of health conditions were included in this review, but it is important to acknowledge that only four related directly to stroke and only one of these was in an inpatient setting. Despite the limitations of the search strategy, the included papers provided a foundation to better understand learning in the context of ill health.

Limitations also need to be considered with respect to the assumptions that are made when synthesising qualitative research and the degree to which the particular elements of individual qualitative studies lend themselves to synthesis. These include acknowledging the importance of the context in which the primary research was undertaken (Paterson, 2011); the particular philosophical stance underpinning each study (Campbell et al., 2003); the methods of analysis and theoretical assumptions of the primary authors (Britten et al., 2002); and the potential dilution of the depth of the original work (Campbell et al., 2003). At the same time, these limitations should be balanced against the value of developing cumulative knowledge and new insights. It is also important to note that the individual perspectives of the authors of the studies within this meta-ethnography who were, where stated, from a range of both health professional and health researcher backgrounds, will have influenced the conduct and the findings of the review. Nonetheless, meta-syntheses do not claim to develop definitive knowledge but to offer one possible higher-order interpretation of what is considered known or understood about a particular topic.

2.10 Critical Reflection

The aim of the meta-ethnography was to explore the influence of patient education and exercise prescription on engaging and adhering to therapy-based practice. The findings, however, showed that patient education sat within a wider perspective of the patients themselves as learners, and the therapists as teachers within the context of the healthcare system. Teaching therefore needed to be seen alongside the learning, and the learner alongside the teacher. The meta-synthesis revealed that the ability to engage in learning and adhere to exercise prescription was highly individual. Levels of motivation and empowerment, and the perceived utility of prior experience varied between and within individuals through time and contributed to different degrees of learning uncertainty and adherence to prescribed practice schedules. The quality of interactions between therapists and patients may be integral to successfully engaging with and sustaining practice. However, a better theoretical understanding of learning in the context of rehabilitation is needed to help clinicians to improve their understanding and planning of treatments, taking into account the tacit, often hidden, personal and cultural learning that patients undertake.

Most of the studies included in the meta-ethnography used descriptive methods to understand how patients made sense of therapy-based learning but these studies were, on the whole, under-theorised. Deeper insights about learning in the context of rehabilitation may be developed by taking an interpretivist stance to further explore perceptions about what is delivered and also to explore what is understood and considered meaningful to people. Only one study in this review included the views of carers, but as partners in rehabilitation, research about their views should also be undertaken. Further understanding may also be developed by investigating how well existing learning theories apply to learning in a rehabilitation context. To start to address this, the following chapter critically reviews relevant adult learning theory to understand whether it could be applied to the conceptual model of learning developed from the meta-ethnography.

Chapter 3 Overview of the theoretical constructs of adult learning

In parallel with the evolution of patient education and health promotion and, in many ways driven by the same emancipatory ideals, adult learning both in practice and understanding grew slowly through the twentieth century, reaching real theoretical interest from the 1970s-80s and onwards (Jarvis, 2010). Malcolm Knowles was an early contributor to this field. Knowles proposed six key principles of adult learning: 1) that adults need to know why they need to learn something before undertaking to learn it; 2) that adults have a self-concept of being responsible for their own decisions and own lives, and a strong desire to be seen and treated by others as being capable of self-direction; 3) that adults have a level of experience that is different in quantity and quality from that of children; 4) that adults become ready to learn the things they need to know to cope effectively with real life situations; 5) that adult learning is life centred and not subject/content centred, and 6) that adults are motivated more by internal pressures than external motivators (Knowles et al., 2015). Despite these principles being much criticised for their lack of empirical evidence (Illeris, 2016; Jarvis, 2010), they were very influential within adult education and have been used in the small amount of literature that has employed an adult learning framework to understand and design tools for patient learning (Gallagher and Bell, 2016; May et al., 2006; Mitchell and Courtney, 2005; Padberg and Padberg, 1990; van Wyk et al., 2015; Vines et al., 2017).

Recognising some of the limitations of the early work on adult learning, the focus in understanding shifted in more recent years to place greater emphasis on the importance of the person as the learner who is learning within the wider context of the society in which they are based. This emphasis on the social function of learning and of learning being intrinsic to the development of self and identity, was summarised by the educational theorist Peter Jarvis. He stated that to understand learning one needed to start with the realisation that it is the person who learns, that this person has experiences to which meanings are assigned and that these experiences are always embedded within a social context (Jarvis, 2012). Based on this understanding, Jarvis offered one of the more comprehensive definitions of learning, describing it as:

> "The combination of processes throughout a lifetime whereby the whole person – body (genetic, physical and biological) and mind (knowledge, skills, attitudes, values, emotions, beliefs and senses) – experiences social situations, the perceived content of which is then transformed cognitively, emotively or practically (or through any combination) and integrated into the individual person's biography resulting in a continually changing (or more experienced) person." Jarvis, 2009, p25

Jarvis' (2009) main stance on learning, was that it involved the whole person, body and mind, and that it shaped their biography as they continually changed. This focus on the person was epitomised in the title of a lecture that he gave and then used in subsequent articles and book chapters "Learning to be a person in society: learning to be me" (Jarvis, 2012 p.9). As he argued, learning is human and therefore any discipline that is interested in or involves humans is related to learning (Jarvis and Parker, 2005).

Central to Jarvis' existential philosophy was that it is the person who learns, and that this person is placed within the society and culture in which they live (Jarvis, 1987). This life world is the person's point of harmony where they have convergence between their perception of the world and their lived world, their biography, and where things are familiar and feel at ease (Jarvis, 2009). It is at this point of harmony where one can draw upon previous learning, act almost without thinking, and take the world for granted (Jarvis, 2009). In contrast to times of harmony, Jarvis proposed that learning is triggered at moments of life disjuncture when there is no longer a convergence between the world and a person's biography and therefore their life world can no longer be presumed upon (Jarvis, 2009). Disjuncture can result from factors local to the individual or from changes imposed by the outside world. It may be emancipatory and liberating but can also lead to learning being imposed from necessity and compulsion. With disjuncture comes not just the conscious knowing and recognition of the divergence between the expected and experienced, but also often a sense of unease, a consciousness of one's situation in the world, and a sense of unknowing (Jarvis, 2012). Whether, as Jarvis proposed, learning is always resultant from disjuncture is debated (Illeris, 2017a), but it is certainly an important trigger as the learner tries to find a position of harmony once more within their life world.

With a similar focus of the person learning within a social context, the educational theorist, Knud Illeris, proposed that learning itself comprises two interlinked processes: acquisition, the process that comes from within the person, and interaction, the external process between the person and their environment (Illeris, 2017b). This inter-relationship is represented as an inverted triangle with acquisition as the bidirectional horizontal line across the top representing the person’s will and capacity to learn as well as what they actually learn, and interaction the bidirectional vertical line bisecting its mid-point and travelling down to the apex of the inverted triangle (Figure 3, Illeris, 2009). The three points of the triangle represent the three dimensions, or tension fields, that Illeris suggests are inherent to all learning: the learner’s incentives, the content or what is learnt, and the individual’s interaction and relationship with the environment and people in it. Learning, Illeris (2002) states, cannot be understood unless all three elements are considered.

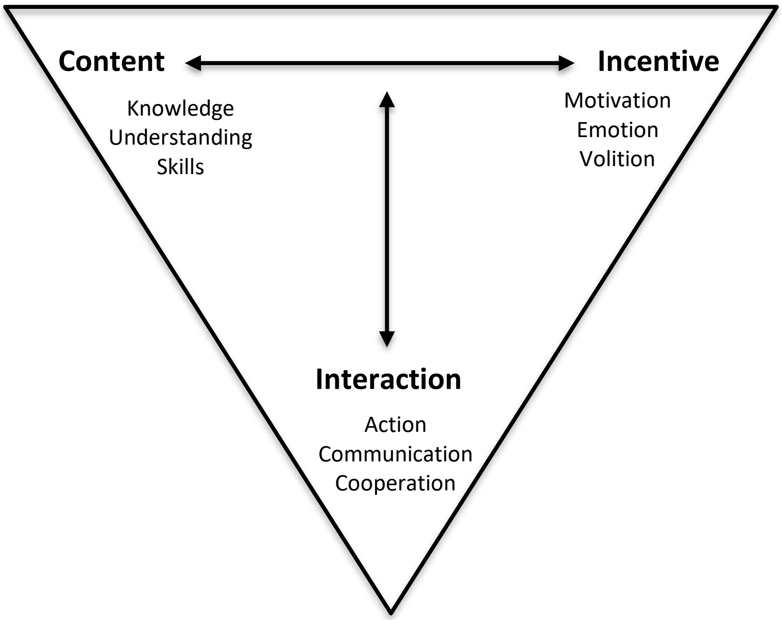


Figure 3 Illeris’ learning triangle (2009, p10)

The incentive dimension refers to the learner’s emotions, feelings, motivations, volition, and attitude for learning (Illeris, 2017b). It represents the will of the individual and the drive or mental energy that needs to be mobilised to direct attention sufficient to initially engage and then keep the person within the learning situation so that learning is sustained (Illeris, 2017b). Related to their incentive, adult learners come with aspirations, intentions, and expectations and, linked to these and the energy mobilised, is a level of ownership, responsibility, and readiness, or otherwise, to engage. To generate incentive, Illeris (2016) proposes that the learner needs to know why they are there, and indeed that learning is required at all. Motivation and volition are hard to raise if one has little or no context or knowledge about what the future might look like, what outcomes one is aiming for and what would constitute success. For a learner, this uncertain future is often unsettling and frightening, although it can also be exciting and liberating. Emotions and motivations are therefore rarely straightforward, often presenting as a combination of negative and positive feelings linked to both the consequence of learning and not learning (Illeris, 2016). Importantly, from the learner’s incentive stems the quantity and quality of what is learnt, both in the short term as well as in the longer term in respect to permanency and utility (Illeris, 2017b).

Important to understanding learning is that one is not just learning but one is learning something (Illeris, 2017b). Learning content, Illeris’ second key dimension, refers broadly to the cognitive aspect of learning, and involves not just acquiring knowledge, skills and understanding but wider attributes such as opinions, insights, meanings, beliefs, attitudes, and behaviours (Illeris, 2017b). The aim of learning content is to build understanding, capacity, and competence in the learner so that they can use what they have learnt freely and appropriately across known as well as new and unpredictable life situations.

The two dimensions of incentive and content sit bi-directionally connected at either end of the horizontal line of Illeris’ inverted triangle and represent the individual. Both are tightly linked, with incentive impacting on the quality and quantity of the content learnt, which in turn further shapes the incentive of the individual to learn. As Illeris (2017b) identifies, adult learners learn what is meaningful for them and will not learn things that are of little interest. Learning content and the challenge or context in which it is placed therefore needs to be appropriate for the learner. When exploring their content, Illeris (2016) suggests that learners need to have the opportunity to ask questions, express doubts and resistances, and to try things for themselves. It can be euphoric for people to realise that they can achieve and make active use of experiences, as well as then seeing that what they are doing is the foundation for future learning (Illeris, 2016). Equally, it can be demoralising to fail in learning content, potentially blocking success in any future learning in that field.

Illeris' (2017b) third dimension is learning interaction, the social aspect within which learning by the individual occurs. All learning is situated, with the interaction with the environment shaping both the learning process and the learning that then takes place. Learning is of little use in the abstract and knowing is not enough unless it can be applied and made a reality in a specific situation. It is important to learn about the social world so that one can act within and on it.

This theme of the social world being integral to learning has been developed by others. Central to social learning theory is that as humans our lives are made up of series of multiple connected communities of practice which are situated within a learning landscape (Wenger-Trayner et al., 2015). Some communities we embrace fully and some only briefly, some will merge, and some will split, some align, and some compete, some we reject and some we are rejected from. From each of these we learn and the resultant learning shapes our identities and who we are. These communities of practice are not just groups of individuals but social processes with a history and context, and customs, rules and languages that are developed over time. For the communities that we embrace and encounter, we gradually become part of their history and they part of ours. From each we develop varying degrees of competence and knowledgeability of their rules and practices, and the complex dynamic interplay between the hierarchy of those members with knowledge and those that receive it. As Wenger-Trayner (Wenger-Trayner et al., 2015) comments, learning is political and as a social process always involves issues of power.

Like Jarvis' (2009), reference to learning being triggered at points of disjuncture, Wenger-Trayner (Wenger-Trayner et al., 2015) refers to learning occurring at times when boundaries between communities within one's landscape are encountered. On reaching a boundary, there is always a point of negotiation, to cross or not to cross, join or not to join, to taste, to embrace, to leave, to reject. Although rules, customs and practices may be similar between communities, they may also be new and in some instances may overtly conflict. On encountering a new community there may therefore be confusion and misunderstanding with even supposedly and seemingly common words and practices having different meanings and interpretations. What a community believes and purports to do may be hidden or open and thus what in reality it turns out to be might be what one expects or may be quite different.

When encountering a new learning environment or situation, although in some instances planned learning will result, in others it might not, or not in exactly the way that was expected and hoped for, by either the teacher or the learner (Cohen, 2011). As Rogers and Horrock (2010) state, everyone is motivated to learn but they might not be motivated to learn what the person guiding the learning would like them to learn. One can just as easily learn what one believes one cannot do as what one believes one can. Barriers to learning can be in the form of both passive learning defences and/or more active learning resistance. These resistances and defences develop subconsciously throughout life to provide a necessary degree of harmony and stability, particularly in response to threats to our identity. A particular form of learning defence is learning ambivalence, the awareness of needing to learn but simultaneously not wanting to (Illeris, 2017b). When returning to learning, many adults feel a strong sense of learning ambivalence with on the one hand the hope for enrichment and enlightenment whilst on the other, the fear of humiliation and not being able to cope. These contradictions often lead to a vulnerability and scepticism for formal learning that is common in adults and, for many, the option of not engaging proves stronger than the one to engage.

In summary, this brief review of contemporary adult learning theory has highlighted some of the complexity of learning and interconnectedness between the individual, other people and society in the context of learning. Of particular note was the resonance felt on reading about the theory of learning, often related to learning in the classroom, and the learning experiences of patients as they engage in independent practice of therapy-based exercises and/or wider aspects of self-management. Learning theories suggest that learning involves the acquisition of knowledge, skills and understanding but also beliefs, attitudes and meanings. It is always in part, emotional, cognitive and social, and can occur as planned, differently from what was planned or not as per the plan at all. In instances where planned learning does not occur, of interest is what is being learnt instead and what impact this might have on any future planned learning success.

From compiling this overview, the next phase of work was to interpret the findings from the meta-ethnography within the context of this theory and explore whether the findings and themes arrived at could be further understood within this framework of learning. This forms the basis of the next chapter.

Chapter 4 Translation of findings from the meta-ethnography using the framework of adult learning

For the participants in the meta-ethnography, the need to engage and learn occurred at a point of life disjuncture due to a change in health status. Described within educational literature as a disruption to a person's bibliographicity (Illeris, 2017b), and in health as a biographical disruption (Bury, 1982), learning for the participants was, as for many with ill health, imposed upon them. To try once again to find a position of harmony and ease with life, the participants of the studies largely had to learn rather than necessarily wanted to learn, and they had to sustain this learning and practice, again whether this was wanted or not. The contradictions and uncertainties that were shown revealed how complex and challenging this learning was.

4.1 Learning as a patient – learning to be an expert

Successfully undertaking independent practice or following a self-management programme necessitates having both knowledge of what to do and mastering planned task-based learning. As identified by Illeris (2017b), the cognitive domain of learning is one of the three dimensions of learning. This dimension encompasses not just knowledge and skills but also attitudes and beliefs; it is gained both at the point of acquisition as well as, importantly, at the time of use (Eraut, 2000). For successful learning 'knowing that' and 'knowing how' needs to progress to 'being able to', and through this for the person to gain both the competence and confidence to put the learning into practice (Jarvis, 2012). To achieve this, primary experiences of things that we have sensation of ourselves need to sit alongside the secondary experiences that come indirectly from others (Jarvis, 2012). The provision of secondary experience is common in both education and health with the passive giving of 'knowledge of what' and possibly 'knowledge of how'. Jarvis (2012) suggests it is a mistake made by those who teach to assume that there is a relationship between secondary knowledge and 'being able to'. Fear, experienced by many of those in the meta-ethnography, was related to a perceived lack of 'knowing that' and 'knowing how’, and then, especially, ‘being able to’. Reflecting on Knowles’ principle (Knowles et al., 2015) that adult learners are able to draw upon a depth of experience, in relation to the experience of therapy-based practice, for many ‘being-able-to’ was lacking and led in the conceptual model to the section of the circle linked to learning content that was labelled ‘Uncertainty of experience’ (Figure 2 p.59).

With this lack of experience, within the meta-ethnography, participants overtly expressed the desire for support, opportunity and time for both primary experience of task practice and secondary experiences of information giving, with the latter first so that they ‘knew that’ and ‘knew how’ and then the former to enable ‘being able to’. Instead of adopting typical adult learning behaviours such as ‘giving it a go’ and task-conscious-learning (Rogers, 2003), participants in the meta-ethnography often felt like novice learners. What they wanted instead was learning-conscious-learning, where there is demonstration and knowledge first before being followed by guided practice. Learning through problem solving and trial and error, inherent to how adults typically learn (Rogers and Horrocks, 2010), and so important for developing expertise (Jarvis, 2012), was largely not trusted nor wanted by the participants and instead was judged as being too risky, taking up time, or just being too overwhelming. Although structured supportive learning is often needed and desired in the early stages of learning, one consequence is the translation to longer-term practice. The learning style sought by many of the participants who wanted a recipe and rules, was to learn through modelling and imitation. The limitation of this approach to both learners and teachers is that although imitation may be useful and appropriate for initial engagement, it has limited utility for transfer and generalisation to new situations (Eraut, 1994). As a sole method of support for patient learning therefore imitation might be a barrier to achieving long-term engagement.

The challenge of living with a health condition and engaging with exercise-based practice and self-management is the demand of often starting as a novice but needing to learn to be an expert. This necessitates not just the mastery of the knowledge and skills for competence but also the mastery of attitudes and beliefs for confidence. In line with the original premise of the overall body of work, how guidance is given, i.e., the teaching, and how it is received, has great importance to learners and to learning success. Teaching needs to be attentive and to meet the learning needs at the point of acquisition as well as the learning needs for sustained use. As described by Cohen (2011 p.50) “students depend on teachers for help, but teachers’ success depends on students learning”. As seen in the meta-ethnography, unsuccessful teaching resulted in learning uncertainty which led to fear and ultimately failure to achieve the planned learning.

4.2 Learning as a patient – learning who to be and how to be

As identified by Illeris (2017b), successful acquisition of learning content is also intricately linked with the learner’s incentive and thus their emotions, motivation and will to learn. From the meta-ethnography, being a patient and experiencing a point of life disjuncture raised many different emotions. Alongside the fear linked to the perceived lack of therapy-relevant experience, participants experienced wider fears, both for the moment and for the future. These fears were within the context of the learning taking place on a background of vulnerability, loss, shock and distress. Learning when under threat, with negative feelings such as insecurity, confusion, frustration and anger, is recognised as being a poor condition for learning and from this, there being a higher likelihood of failure of achieving the planned learning (Ahrenkiel and Illeris, 2016; Illeris, 2016). For both learners and teachers, recognising and understanding a person’s incentive is vital as it represents the driving force through which the quality and quantity of learning is shaped (Illeris, 2017b). The influence on learning of the uncertainties of motivation was shown in the second segment of the conceptual model (Figure 2 p.59) with parameters related to expectation and readiness to learn. For planned learning to succeed, the learner needs to mobilise sufficient mental energy for without incentive, learning will not take place, or at least not in the way that it might have been planned or in any way that might be sustained (Illeris, 2017b).

Parallels can be drawn between the experiences described by patients and those described by another group of adult learners who have had to return to learning, this time as a result of unemployment (Illeris, 2016). Both groups involve individuals who know they need to learn, partly want to learn, but at one and the same time often do not want to be back in structured/formal learning and do not want to, and/or are fearful of learning. This learning ambivalence seen in both groups where learning is only partly chosen, reflects one of the contradictions faced in learning and is an important consideration for the very common outcome of planned learning failure (Illeris, 2016). In contrast to the premise that adult learners are excited by the future (Illeris, 2016) and that adults become ready to learn the things they need to know to cope effectively with real life situations (Knowles et al., 2015), for both people without work and patients, the future is often faced with fear and uncertainty about what the learning might involve and bring.

A further threat to the learning success experienced by both those who are unemployed and people with ill health, is to the potential impact of the learning on identity and self. Both groups represent people who have an established identity that is linked to their self-respect and self-worth. Development of identity is particularly prominent in adolescence and is often associated with a depth of associated emotions and, for some people, episodes of active learning resistance (Illeris, 2017b). As adults, identity continues to develop, but usually slowly through assimilative learning, actively leading to consolidation of a preferred identity rather than in a radical change (Illeris, 2016). Both ill health and unemployment can threaten personhood and identity stability, forcing change and bringing feelings of loss of self-respect, irrelevance, and worthlessness (Illeris, 2016). With these feelings come the unwelcome questioning of, who we are, who we were and who we want to be. These existential concerns can result in a strong defence of identity, holding onto the old and not wanting to give this up when so much of one's self-respect and dignity are being challenged (Illeris, 2016). To overcome this defence, accommodative learning which breaks down some of the old and rebuilds the new, is required (Illeris, 2017b). Such reconstructive forms of learning, however, demand great physical effort and energy and can often be emotionally profound experiences (Illeris, 2017b). As was seen in the meta-ethnography, these more challenging forms of learning were being asked of people who were physically vulnerable, fearful, and uncertain. The consequence again was that for some people, only part or none of the planned learning occurred.

For the participants in the meta-ethnography who managed to sustain practice, continuance of therapy-based practice was reported as hard and effortful and at times boring, lonely and demoralising. Unlike learning in childhood where learning is broadly recognised as being for the long-term, with expectations of there being a delayed outcome, learning for adults is usually time-bound, short term and task orientated (Illeris, 2017b; Rogers, 2003). For many adults, the mental energy and emotion required for learning cannot be sustained and therefore learning needs to be episodic (Jarvis, 2006). In response therefore to encountering a problem or challenge in life, adults normally find the simplest and quickest solution so that learning can be stopped, and they can move on (Rogers, 2003; Rogers, 2007). In the main, long-term learning is not what adults choose to do, and having to do this when it is not wanted has been linked with learnt emotions of humiliation and failure (Illeris, 2016; Rogers and Horrocks, 2010). Persistence is, however, what is often expected from patients although, as the meta-analysis showed, not usually what they expect for themselves.

Both initially engaging and continuing with learning is effortful and in order to be successful learners really need to have to expect and want to learn. Wanting and not wanting to learn is a complex paradox. The emotions and feelings underpinning a person’s motivations and drivers to start and continue learning compete with, and are often overwhelmed by, those that make them want to stop. One potentially competing element that may sit alongside and possibly influence the success of planned therapy-based learning is the learning that takes place in respect to one’s new identity and life roles. As Jarvis (2009) identifies, in its broadest context, learning is about becoming and shaping the self. From experiences gained through living, reflections are made and meanings are given which are gradually incorporated into our identities. Through this we create our biographies and we shape who we are and how we are. For those with ill health, learning to reconstruct one’s identity can be part of the learning that is derived from episodes with healthcare. Of importance is whether this is expected, wanted and followed. From the meta-ethnography, even though it was not planned for, part of the learning taking place was enabling the patients to construct a new sense of self, such as a “stroke survivor” or “person with low back pain”, or at least to integrate an old sense of self with a new one.

4.3 Learning as a patient – Learning who to be alongside others within communities

One of the defining features of the more recent writing on adult learning is the emphasis placed on learning being situated within a context, both locally to the person and more globally in society (Illeris, 2018). Within this context, all learning is influenced by both wider political, social and economic factors that have an over-arching bearing on what takes place, as well as by local factors related to people and systems of work. That learning is situated means that through interactions, the context of the learning shaped by both people and place, becomes integral to the success or failure of the learning for the individual. Within our world, if viewed as proposed by Wenger-Trayner (Wenger-Trayner and Wenger-Trayner, 2015), as a learning landscape, are many different learning spaces or communities of practice. At its broadest level, two of these could be considered as the learning spaces of therapy and life, and at a narrower level, the learning spaces of the therapy session and the ward, therapy sessions and home, gym and home, or a group and an individual. Within each community are rules, practices, languages and customs that need to be understood and mastered and between each community are boundaries that need to be crossed. One complexity to these boundaries is who owns the responsibility to enable entry into each new community and once there, for entry to be sustained. This challenge was represented in the third and final section of the conceptual model (Figure 2 p.59) and was shown as ‘Uncertainty of empowerment’.

Although the patients in the meta-ethnography made reference to the value of peers and family to their learning, in respect to the influence of people as part of the learning process, they placed greatest importance for learning on their therapist or trainer. The qualities of this person as someone who was attentive, and who was kind, cared, listened and showed an interest were not different from both qualities of therapists expressed previously by stroke survivors (Galvin et al., 2009; Peiris et al., 2012), but also, more generally, qualities of good teachers who know the needs of their learners and have a mutual commitment to share their skills and knowledge with them (Cohen, 2011; Tough, 1979). As Theodore Roosevelt is reputed to have said, 'Nobody cares how much you know, until they know how much you care'. In the absence of therapy-based practice experience, the teacher/pupil relationship was an experience that participants were familiar with and drew upon with resultant expectations of the role and place of the teacher and that of them as the learner. Clear in the findings of the meta-ethnography was that the patients as learners knew how to adopt the role of student as did the therapists/trainers in adopting the role as teacher. Adopting these roles meant that therapists and patients conformed to socially prescribed identities.

Although recognising that it is a challenge, in his writing on adult learning, Illeris (2016) strongly advocated that it is the responsibility of the teacher not to fall into the easy and accustomed role of assuming responsibility for both the teaching and the learning. Instead, he urges teachers to hand over the responsibility of learning to the learner (Illeris, 2016). It is, after all, the learner who has to do the learning and the teacher can never do this for them (Cohen, 2011; Rogers, 2007). Despite this, and Illeris' assertions that adults want responsibility and feel humiliated if they do not get it, the findings of the meta-ethnography suggested that this ownership of responsibility was much more nuanced and was influenced in part by the participants as learners and what they wanted and expected but also by the healthcare system and staff within it and what they enabled and empowered. These uncertainties about responsibility are not unique to patients, with similar findings again shown from the unemployed. Within this group, the wish to take on the responsibility for learning was influenced by resignation – knowing that ultimately decisions for learning would be made for them (Illeris, 2003a; 2003b). The structure of formal education with its curriculum-based approach, organised notionally in such a way as to assist learning and ease mastery, can send contradictory messages to the people receiving it with respect to when and how learning might take place, and whether inherently each person will be viewed and treated like the adult they are (Illeris, 2016). Similarly, the meta-ethnography showed that the rules, practices and curriculum for therapy and rehabilitation were designed in such a way that responsibility for learning did not simply reside with the adult learners.

Readiness to learn and to take on the responsibility for learning is influenced by factors related to the patient themselves and to their learning about the culture of the healthcare system and being a patient. Equally the healthcare system, with its many rules and practices, acts back and through this interaction, and influences the learning that takes place. Combining a patient who is fearful and who perceives a lack of experience with a system and its structures and therapists who might not want to, know how to, or be enabled to give up responsibility, can make asking the patient to take responsibility for their learning complex, and often unsuccessful. Handing over some or all responsibility to the learner does not diminish the role of the teacher but instead does the opposite by demanding of them teaching practice that is most likely to bridge the gap between teaching and learning and successfully enable the learner to learn (Cohen, 2011). The challenge is how to support the learner to own their learning as they learn, with time, to once more understand their new selves as a person in the context of their everyday lives.

4.4 Summary

For many, engaging and adhering to therapy-based exercise involves not just learning seemingly simple exercises but also learning about their health condition, its wider treatment and management and what working on the body through exercise might mean, involve and achieve. In addition, it encompasses both learning about the consequences of the condition and the impact of this on everyday life, identity and roles, as well as hopes and expectations for the future; and also learning about the structure and expectations of the various communities of both the healthcare systems and wider society and life, and how one fits into these broad structures. Seeing the treatment and management of ill health as one part of a complex learning journey for patients, and also often for their family, provides a useful lens through which to view the experience of being a patient with the potential enormity of the learning demands that this involves. The challenges and complexities of learning due to ill health parallel many of the challenges and complexities of learning in other domains of life. To help understand the learning journey for patients and to hopefully support them to be successful learners, theories about how people learn, particularly how adults learn, provides a novel avenue for further research which, to date, has been insufficiently applied in healthcare contexts.

4.5 Visualisation of the three dimensions of learning when linked to learning therapy-based exercises

By modifying Illeris’ (2009) inverted learning triangle, it is possible to illustrate how learning the content required for therapy-based exercise can be seen alongside the learning involved in the other dimensions (Figure 4). Learning in therapy necessitates learning the exercise-based content to be an expert with the required knowledge, skills, attitudes and beliefs. It also includes learning about one’s new sense of self, and from this, the incentive and motivation for acquiring and using the learning content. Finally, it encompasses learning about the interaction with healthcare services and personnel as well as the wider societies/contexts in which the person practising the therapy-based exercises are placed. The two triangles, with the inner one representing initial engagement (dotted triangle) and the outer one adherence or continuance of practice (striped triangle), show how these two stages of learning acquisition and then continuance, again need to be considered as linked entities with different demands related to each of the three dimensions. When starting to learn, because the incentive for learning was imposed and the content of learning uncertain, supported interaction with others was sought out by participants in the meta-ethnography. To achieve adherence, the learner’s incentive needed to be sustained and the content revised and for both of these, sustained interaction and support from others was desired. For all three dimensions there are uncertainties and from these opportunities for partial or failed learning in response to different learning barriers. Figure 4 could be used by clinicians as a reminder about the different dimensions and the relationship between them, and to consider at the time of seeing them, what the main focus of a patient’s learning effort might be.

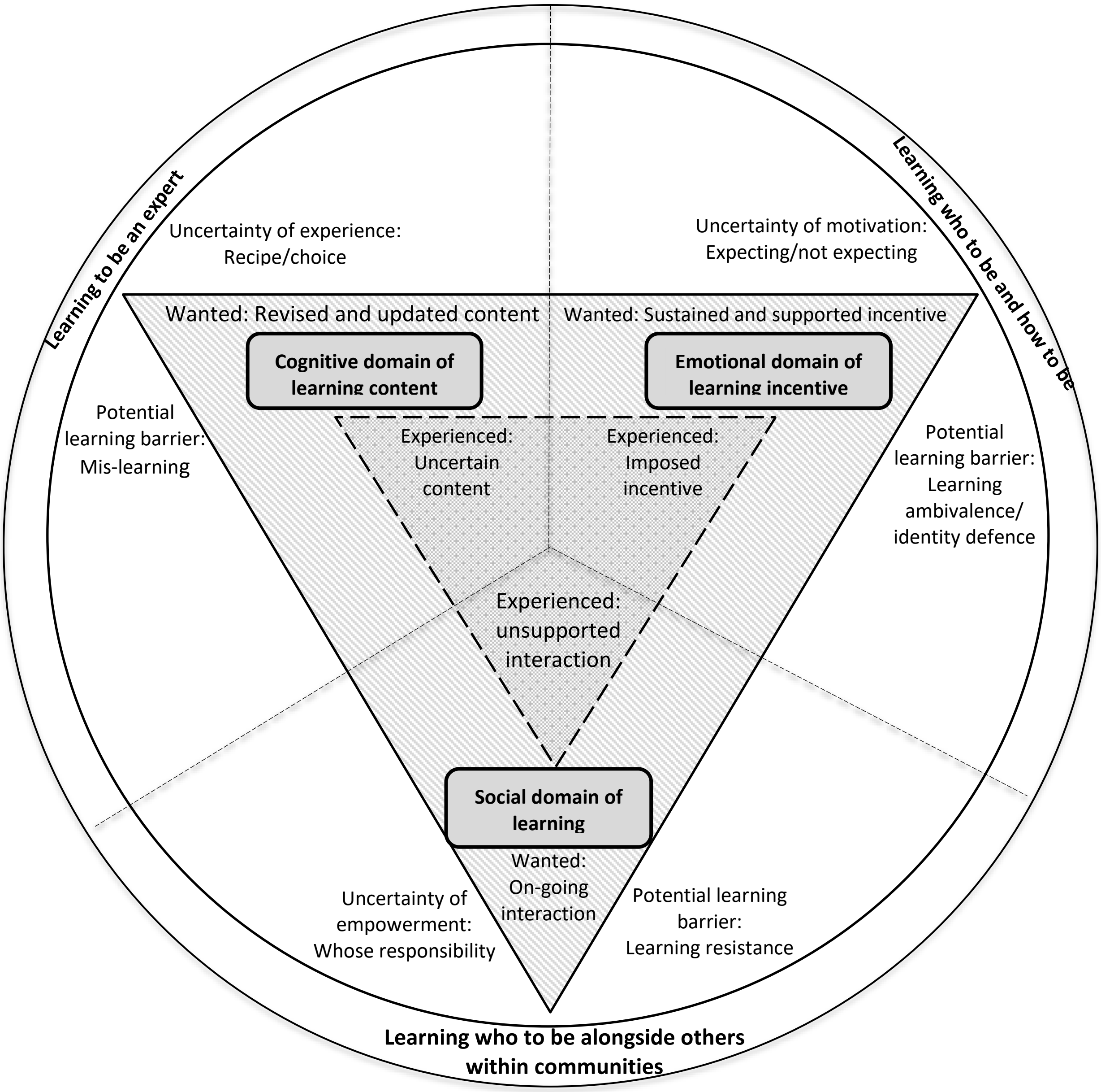


Figure 4 Visual representation illustrating the different aspects of therapy-based learning

4.6 Personal Reflection

At the outset of my PhD, my assumption was that if therapy was delivered differently, particularly teaching and exercise prescription, then enhanced clinical outcomes would follow. What I came to understand from the meta-ethnography and my reading about adult learning was that learning therapy-based exercise is much more complex and involved than purely mastering the prescribed content. The belief that there is a correspondence between what is delivered in formal teaching and the learning that results is, Illeris (2017b) believes, one of the key misconceptions held on to for convenience by many of those who educate. As he states, “Only some of what is taught is learnt, what each individual learns is different, there is a great deal of mis-learning and that we learn things that are other than what is taught” (Illeris, 2017b p.224). Learning sometimes results therefore as was planned by those delivering it, but learning can also be very different. Something, however, is always learnt whether intended or not, and it can just as easily be what one perceives one cannot do as much as what one can do, what one does not want to do as well what one wants to, and what one should not do as well as what one perhaps should. As has been stated about adult learning, most people learn something, they may just not learn what it was hoped that they would (Rogers and Horrocks, 2010). The impact of these uncertain learning outcomes is that resources and effort can be spent on activities that may be inappropriate, have no effect, and in some cases work contrary to that which was intended (Illeris, 2017b).

Recognising the potential dissociation between what is taught and what is actually learnt, led to the shift in my understanding and therefore the direction of the PhD. From the initial interest in teaching and prescribing practice, I felt that it was important first to understand more about patient learning. After all, a teacher can never do the learning for the learner and, in the case of therapy-based exercise, the learner is the one who has to do the practice. As a consequence of this shift, this opened up a body of literature about how we learn, especially how we learn as adults, which allowed me to explore the similarities between how we learn in other domains of life and how patients learn. From this last chapter, some of the resonances between the adult learning theories and patient learning in the context of neurorehabilitation could start to be seen. The conceptual model (Figure 4) was developed at this stage to offer insights to therapists about learning contexts and strategies that might be applicable to increase the chances of successful learning.

A limitation of both my thinking and the conceptual modules was that the literature on which these were based was not explicitly designed to explore patient learning.

With the exception of four studies from the meta-ethnography, they were also not based within a neurorehabilitation setting. To progress some of the understandings that had started to be developed, the main study for the PhD aimed to explore the early to late subacute stage post stroke explicitly through the lens of patient learning and being learners. The short to medium term post-stroke could be understood as an intense period of new learning, and rehabilitation as a community of learning with the aim of enculturating patients and their family members with enough knowledge and skills to resume aspects of their pre-stroke living. By understanding more about how patients learn, their perceptions of what they learn and what it is like to learn and be a learner, the aim was to enable the work from Study 1 (the meta-ethnography) to be refined or revised. From this, the aim was that findings from this new examination of learning would enable healthcare professionals to better meet the needs of their patient groups and, in a reversal of Illeris' (2017b) concerns, help increase the time spent on activities that are appropriate, work in the way in which they were intended and thus hopefully have a positive effect.

The remaining chapters of this thesis focus on Study 2 – the ethnography. Writing starts with a description of the methodology and methods, followed by a presentation of findings and discussion – the latter progressing the translational work of education-based learning theory to learning as a patient at a time of disjuncture imposed by ill health.

Chapter 5 Study 2: Ethnography: Understanding Patient Learning in a Stroke Rehabilitation Setting

5.1 Research question, aim and objectives

Research question

What is patient learning in the context of recovery from stroke/acquired brain injury (ABI) in a rehabilitation setting?

Research aim

The aim of Study 2 was to investigate the learning that takes place by patients in a rehabilitation context by undertaking an in-depth exploration of learning at a point of life disjuncture imposed by stroke/ABI.

Research objectives

From the perspective of the patients, this second study was designed to address the following objectives:

To explore, through observation and focused conversations,

- what it is like to learn and be a learner in the early to late subacute rehabilitation period post stroke/ABI
- what patients perceive that they learn and how they make sense of this learning in the early-late subacute period post stroke/ABI
- where and how the learning occurs
- what factors shape the level and direction of the learning effort.

Definitions

To give clarity to, and to more easily operationalise these objectives, the following definitions to the key terms were chosen.

Learning was considered in relation to the broad definition referred to previously by the educational theorist, Peter Jarvis (2009):

> "The combination of processes throughout a lifetime whereby the whole person – body (genetic, physical and biological) and mind (knowledge, skills, attitudes, values, emotions, beliefs and senses) – experiences social situations, the perceived content of which is then transformed cognitively, emotively or practically (or through any combination) and integrated into the individual person's biography resulting in a continually changing (or more experienced) person."
> Jarvis, 2009, p25

The term rehabilitation is complex in as much as it can refer to a place, a period of time within the stroke pathway, and, more broadly, a general process. In respect to the latter, it has been defined by the British Society of Rehabilitation Medicine (2019) as:

> "A process of assessment, treatment and management with ongoing evaluation by which the individual (and their family/carers) are supported to achieve their maximum potential for physical, cognitive, social and psychological function, participation in society and quality of living."

For this study, the term rehabilitation was variably used to refer to all three aspects of place, time and process. Data collection took place primarily within a rehabilitation unit and covered the subacute phase, often referred to as the rehabilitation phase, whilst the patient participants were inpatients within the specialist unit. Recognising, however, that the process of recovery and rehabilitation starts from the moment of the stroke/ABI and progresses after discharge, reflections were also gained of patient learning that had occurred in the hyper acute and acute stages, as well as in the early chronic phase once back at home.

5.2 Theoretical perspectives

Learning is a process of gaining knowledge, skills and understanding as well as the acquisition or revision of attitudes, values and beliefs. All learning, including the learning that takes place in rehabilitation, is highly situated and affected by social and cultural contexts. Although the content learning of rehabilitation can be, and often is, measured, implicit personal and cultural learning are much harder to observe, quantify and articulate. This type of hidden learning is not well understood in the context of rehabilitation but may be key to uncovering some of the challenges that face professionals and stroke/ABI survivors in this setting. This study aimed to explore learning in rehabilitation contexts from the perspective of stroke/ABI survivors and to offer insights about this concept that may improve the experience and outcome of rehabilitation for people following stroke/ABI.

I adopted an interpretivist constructivist stance to underpin this study because it is consistent with the view that learning is a manifestation of human behaviour that can only be understood if explored within the context of the social world in which the learning takes place. Within the relativist ontology of interpretivism, reality is understood not as a single entity governed by fixed measurable laws that are waiting to be discovered, but instead as being multiple and varied based on an individual's interpretations of their experiences, beliefs and understandings (Whitehead, 2004). This subjective stance posits reality as a social product, a construction rather than a given, which cannot be understood without considering the interaction between people within the setting and between people and the setting (Atkinson, 2017; Rosen, 1991). This position acknowledges that learning in rehabilitation is a social phenomenon that occurs in a social world and is not fixed and separate from social actors but instead is based on meanings drawn by them from their actions and interactions as they construct their continually changing social realities (Vanderstraeten, 2001, Vanderstraeten and Biesta, 2006).

5.2.1 Interactionism

Interactionism is an interpretative approach to looking at and understanding the mutual relationships, or intersections, between people (actors) and places (Atkinson and Housley, 2003). Within this approach, the units of interest are not the people per se but instead the interactions that take place between the people and between the people and the place more broadly. By observing the actual embodied occurrences of the processes, performances, and negotiations, all sides of an interaction can be seen. Through the study of processes of socialisation and of everyday social interactions, encounters and conduct, it is possible to start to understand not only how social actors come to be who they are but also the social construction and transformation of self and identity (Atkinson and Housley, 2003).

Integral to contemporary symbolic interactionism is the understanding that people act towards things based on the meanings that they assign to them, that these meanings are a social product derived from interactions with others, and that they arise and change through processes of interpretation (Blumer, 1969). How a person acts and behaves therefore is not pre-determined and the result of society per se but instead is constructed based on the meanings and interpretations that an individual places on their interactions with society (Gibson and vom Lehn, 2018). Important within symbolic interactionism is that actions are considered to be influenced by the environment but not absolutely determined by it. As Goffman (1983) identified, social encounters have their own grammar and their own formal properties.

Interactionists believe that social phenomena are the result of the actions of individuals and therefore these actions and interactions should be the focus of research (vom Lehn and Gibson, 2011). As this study is focused on understanding learning in a rehabilitation context (the people and the place), interactionism provides a fertile and substantive framework on which to base this study. Qualitative ethnographic methods are commonly used within this interactionist framework (Atkinson and Housley, 2003).

5.2.2 Ethnography

Ethnography was chosen to understand patient and family member learning within rehabilitation through the lens of interactionism. Ethnography is a methodological approach that enables the exploration of the socio-cultural contexts, processes and meanings of a cultural system (Whitehead, 2004). This orientation allows complex social phenomena to be understood from the personal experience of the people involved and the observation of their practice of everyday life within the context in which it takes place. It provides a uniquely privileged opportunity to enter and share the everyday lives of particular people in a particular setting (Atkinson, 2015). Through a commitment of effort to participants, involving systematic fieldwork and analysis, drawing upon previous work, and intense critical reflection (Hammersley and Atkinson, 2007), the aim is to understand their world and to transform and reconstruct the richness of knowledge gained into text (Atkinson, 2017; Emerson et al., 2001).

Ethnography recognises that the place and its culture impact on the social actions of the social actors and equally, in turn, the social actions impact on the place and the culture (Hammersley and Atkinson, 2007). How a person acts therefore is not set and automatically prescribed, but instead is based on the person’s interpretation of the situation and the social knowledge that they have acquired. In turn, this interpretation is shaped by the meanings that the person ascribes which themselves are influenced by the person’s beliefs, values, motivations, rules, and expectations (Hammersley and Atkinson, 2007). The role of ethnography is to explore and understand these meanings.

Ethnography is an open-ended emergent learning process that is highly flexible, cognitive, interpretive, reflexive and constructivist (Whitehead, 2004). It is not so much about studying people but about learning from them (Spradley, 1979). As members of a social group, people are the experts of their world, and it is from their perspectives and their actions as the inhabitants of that world that understanding is built. Studying the place of that world, as well as being situated in the place, enables observation of not just the personal but also the social. Further, beyond just listening to the voice of the actors, by being in the place it is possible to see and experience what is taking place and what the social actors think about it: the real and the ideal (Atkinson, 2015). In constructing meaning from this dwelling, interaction and observation, the task is to look for spatial and temporal arrangements and patterns constructed from the socially acquired and shared knowledge of the people within the setting that reflect both frequent behaviours and any uniqueness (Atkinson, 2017; Whitehead, 2004; Willis and Trondman, 2000). Having identified these patterns and links between behaviours, the task is then to seek to understand and explain why they are there, why things are as they are, and what one is seeing and experiencing is really an example of (Atkinson, 2015). More than just that something is, the construction, what is important is how and why it is. Things happen for a reason, and ethnography, by exploring interactions between people and contexts, helps to illuminate what might otherwise be misunderstood, taken for granted or left unacknowledged.

These understandings are then reflected in part through description that is built up of the behaviours of the social actors and in part through the decoding and interpretation of the meanings the social actors themselves construct of these behaviours. The description and meaning cannot therefore be separated, a point made by Van Maanen (1985, p.119) in his citing of Heidegger (1929), 'nothing is anything without context'. To achieve the generic sense making of the local sense making undertaken by the social actors, understanding is derived not just from the perspective of the actors but also of the researcher (Whitehead, 2004). Resultant are therefore second order constructions of the first order construction that the learners are doing. Interpretations of interpretations; etic with emic to build up a social reading of a social world (Atkinson, 2017).

Having introduced the philosophical and theoretical frameworks underpinning this study, the next section details the methods.

5.3 Methods

5.3.1 Study Design

In adopting ethnography, the aim was to try to understand with an open mind what elements constituted the social reality of patient learning within neurorehabilitation. Ethnographic methods including participant observation and both contextualised and opportunistic conversations enabled this exploration over time and within the social context in which the learning was taking place. By doing this, the goal was to learn about the learning from the personal experiences of those involved, taking into account the complexity of the people doing the learning, as well as the wider factors that framed the task of learning, including the site itself.

Contextualised conversations are recommended as an alternative to formal interviews within ethnography as they allow for more informal and emergent sharing of thoughts, and recognise that through open dialogue, both parties, researcher and participants, create knowledge together (Stage and Mattson, 2003). To be able to really listen and respond in a meaningful way within the contextualised conversations, opportunistic conversations and observation enable context and understanding of the setting to be gained. Through these methods of watching and seeing, and listening, talking and asking questions, ethnography results in learning that is from, with and about the participants.

With the focus that ethnography places on these different methods of data collection, it was hoped to mitigate against some of the recognised challenges of researching learning such as: 1) informal learning being largely invisible, with much of it either being taken for granted or not recognised as learning; 2) the resultant knowledge being either tacit or regarded as part of a person's general capability, rather than something that has been learned and could be reported on; and 3) discourse about learning often being dominated by codified, propositional knowledge, so that those doing the learning often find it difficult to describe the wider aspects and the nature of the understanding that they develop (Eraut, 2004).

5.4 Sensitising ideas

First referred to by Blumer in 1954, sensitising ideas refer to the lines of direction or methods of seeing employed by the researcher as they enter and progress through the work. Although not starting with a fully formed hypothesis to be tested and answered, within ethnography the researcher enters the field with an open but not empty mind, with prior thoughts and considerations to inform their observation and initial analysis (Atkinson, 2015; Hammersley and Atkinson, 2007). Through an iterative process of considering both data and wider thoughts from comparative literature, ideas are brought to the field and are not just drawn from it (Atkinson, 2017). Routes into understanding ‘what is this a case of’ are therefore informed by analysing the findings in the context of other comparable ideas drawn from both the field of interest and elsewhere (Atkinson, 2017).

For this study, the lines of direction were informed both by the findings from the meta-ethnography and the subsequent exploration of adult learning theory, as well as from my clinical experience of working as a physiotherapist within neurorehabilitation. As very little is known about patient learning, and as is common in ethnography (Hammersley and Atkinson, 2007), no single learning theory was selected through which to structure the observation or analysis. Instead, I decided to maintain a broad perspective of both education based and adult learning, with a possible additional emphasis on understanding gained from literature related to learning within the workplace. Organisational ethnography has been described as the process undertaken to ‘uncover and explicate the ways in which people in particular work settings come to understand, account for, take action and otherwise manage their day-to-day situation’ (Van Maanen, 1979 p.540). Although rehabilitation cannot be described as a workplace per se, at least for patients, on reviewing the literature on organisational/ workplace learning, there seemed to be possible resonances to learning in rehabilitation. Institutions or organisations are partial in as much as they do not reflect all of society but are specialised as they are organised for a specific objective or set of objectives (Rosen, 1991). Within organisations, everyone has an identified status and role, and relationships are constructed in respect to these, as well as in respect to the end product or reason for being of the place. People therefore interact with each other in ways that are likely to be different from how they might interact in other walks of life. Everyday social awareness is suspended as people interact in the organisational space, and the longer people are in the space the more they act as per general social awareness; an inside/outside dichotomy (Rosen, 1991).

Importantly, even in organisational ethnography, the researcher does not set out to study the place, but to study in a place with the recognition that different things can be studied in different places and different things can be studied within a place (Rosen, 1991). Reality, such as it is constructed, is multiple and it is therefore never possible to consider all aspects within one study (Gobo, 2008). When developing the sensitising ideas, it was important to stay mindful that, as can be common in educational research (Delamont, 2014), the focus of interest did not broaden to become an ethnography of the rehabilitation unit as a whole, with all its associated cultures, but to remain instead related to the phenomenon of learning itself with its associated behaviours, rituals and actions.

5.5 Setting

By being close to the setting of interest and breaking down any barriers that may exist, the aim of ethnography is to observe the phenomenon of interest in situ and to talk to those involved to explore with them what they think is taking place (Atkinson, 2015). Through this, it is possible to see how the social actors build knowledge and competence and how they use this in different social situations. To be close to the phenomenon of patient learning within rehabilitation, an NHS Trust was chosen which provided both inpatient and community based neurological rehabilitation services to a mixed urban and semi-rural community within the Southeast of England. Undertaking data collection in one site, or a small number of sites, is common in ethnography with the aim of spending sufficient time within a site to really start to understand it (Hammersley and Atkinson, 2007). Although there is a loss of breadth, richness and depth are gained which allow for the generation of the thick description integral to ethnography and from this, despite the data coming from just one site, for broader generic inferences to be made (Hammersley and Atkinson, 2007). The particular service was selected not for its uniqueness or for its foreshadowed problems, but as being emblematic of a typical neurorehabilitation service and therefore typical of patient learning that might be found elsewhere in the UK. By doing this, the aim was for the findings and understandings that developed to have potential for some degree of horizontal generalisability to other similar services and places of work, alongside the greater role of vertical generalisability in respect to theory building.

5.5.1 Access to the setting and negotiation of units of observation

The site selected was already known through my role as both an educator and researcher, but not as an employee. Described as a site of convenience, it also fitted the requirement of being typical of neurorehabilitation provision. Once identified, an approach was made to senior management and, following face-to-face discussions, pending ethical approval, permission in principle was given for the study to take place. Although I was the primary beneficiary of this permission, the site was attracted to the research by the opportunity to learn generally about their service, and specifically to learn more about views of patients and their family members in respect to the post discharge self-management classes which had for a long time been poorly attended.

Having identified the setting, incidents sampling was then required to determine the agreed units of observation (Gobo, 2008). For this, discussion and negotiation took place in respect to what could be observed and where the observation could occur to best see and experience the learning as it was taking place. As it was determined that learning would not just take place in more formal structured settings, it was agreed that areas of observation would involve both open spaces within the inpatient unit including those on the ward and therapy areas as well as, with their agreement, patient's bedrooms. The types of activities and rituals that could be observed included therapy sessions; time patients spent on the ward either with nurses or other staff, or alone; group times such as mealtimes; and, with their agreement, family times/visits. Aspects of intimate personal care, such as bathing and toileting, were not observed. The unit itself was physically small and naturally there were few places where patients and their family members could not go. Staff were allowed anywhere on the unit and therefore, as a temporary member of staff with an honorary contract, it was agreed that there was nowhere that I physically could not access. Through this process of negotiation, the nature and boundaries of the field for the field work were constructed (Atkinson, 1992).

Throughout the negotiation and indeed throughout the research, both my aims and those of the study were transparent and overt, with all participants informed that the research related to my seeking to understand more about patient learning. Identifying a role that is understood by participants can result in being more readily accepted into the setting (O'Reilly, 2009). In choosing a role, therefore, I did not intend to hide that I was a physiotherapist but explained that this was now more secondary to being a researcher and educator of students. By doing this, the hope was that the participants would feel more enabled to comment freely about the physiotherapy (and other therapy) that they received and also be able to reflect more widely on learning beyond what was involved in therapy sessions.

As a physiotherapist by background, and known to a number of staff within the site as a teacher and educator, I was a partial insider, at least to the staff, at the start of the study. As the goal of ethnography is to gain an insider perspective (O'Reilly, 2009), being a partial insider at the outset can confer an important level of trust from the beginning, enabling rapport to be developed more quickly and for people to feel generally more at ease (Hay-Smith et al., 2016). Insider ethnographers are also potentially less likely to construct stereotypes and caricatures and to see beyond the ideal picture that can be presented which an outsider would at least initially not know to be any different from reality (O'Reilly, 2009). Researching in a setting where one is known, however, can lead to a greater likelihood of being treated in respect to preconceived concepts and ideas (Hay-Smith et al., 2016). Participants in the rehabilitation unit may have felt more obliged to participate and then to perform to what they perceived to be expected of them. Being an outsider, especially at the outset, can also, in some cases, make it more likely to really question what is being observed and also be told things which an insider would not be told (Gobo, 2008). Despite the possible limitations, being known to the team meant that there were no issues with access, and I entered the scene with as open a mind as possible, looking to see strange in the familiar.

5.6 Research Ethics

Ethical approval was gained in two parts – the initial application and an amendment. The initial application was for the main body of the work and the amendment was to undertake additional group discussions with a small number of people who were attending, on site, an outpatient upper limb treatment group.

Both approvals were from the London-Surrey Research Ethics Committee (number 18/LO/1086) (Appendix 4). HRA approval from the HRA and Health and Care Research

Wales (HCRW) was gained alongside the initial application (Appendix 5). Local R&D governance approval was obtained from the Trust (Appendix 6).

The research followed the principles of autonomy (full consent was gained from all those involved), non-maleficence (the researcher aimed to do no harm) and justice (the research followed equal and non-discriminatory practice). If I had observed or suspected poor practice, safety issues or abuse, this would have been addressed by following the reporting practices that were already in place within the Trust.

Overall, the ethical risks for this study were considered to be low, with the following specific considerations:

5.6.1 Access and permissions and the emotional risk/anxiety from being observed

As described, consideration was given to both initial overall access to the site as well as to the local permissions/access issues when in the field. For the latter, it was important that all those within the field were aware of my presence and fully understood my role and what I was doing on the unit. An important concern was to recognise the potential emotional risk/anxiety from being observed and that those on site were not fearful that they were being judged. This was felt to be particularly so for the staff involved but also potentially related to the patient participants and their family members should they also have had similar concerns. Reassurance was given that the focus of the research was on the practical and theoretical understanding of patient learning and that the site and the individuals within it were selected as typical examples and not because there were any underlying concerns. It was stressed that there was no requirement for any individual to be involved in any stage of the study, including the observation, and that no-one would be judged based on their agreement to be involved or not. Modes of communication were put in place such that if anyone had concerns, they were able to report these safely and confidentially to the unit manager.

For this study, a particular consideration was that I had taught some staff, and therefore they might have felt more acutely that their practice was being judged. To help mitigate for this, it was stressed that my role was not to comment on any particular individual and the choices of treatment that they made.

5.6.2 On-site relationships and power differential

As I was known to a number of staff within the site and therefore, as a partial insider, a number of professional relationships already existed. The advantage of this was that some of the initial relationship building and trust was already in place. The disadvantages, however, were that the staff may firstly have felt obliged to participate and then to perform to what they perceived to be my expectations. Throughout, it was important to reflect on the nature of these relationships and how they continued to build and develop. One specific challenge that I needed to address was how to balance polite conversation with data collection and for all to understand and feel happy with what these boundaries were. It was important to value pure sociability and to build trust and relationships and for me not to be seen to be there entirely for my own self-interest and gains.

To help address these two ethical concerns, as part of initially gaining access to the site, discussions about permissions, relationships and roles took place. Agreement was reached about the spaces where the staff were happy for me to go, how I would indicate when I was in researcher role (being clearly with my notepad in hand), and how the staff could indicate if they wanted me not to be in role (either verbally or non-verbally indicating to put the notepad away and not to record what was occurring). All decisions were communicated to the wider staff group, both when the study was first introduced and then again when consent was obtained.

5.6.3 Emotional distress in patient/family member formal conversations

The ethical issues for the patient/family member formal contextualised conversations related particularly to the possible emotional distress when discussing topics related to learning and recovery of function after stroke/ABI. Although the focus of the discussion was related to learning within the context of rehabilitation, this did raise issues more generally related to recovery of function and living with the consequences of the pathology, which in turn did, on occasions, lead to distress/sadness. This was never to the extent that the conversations or observations needed to be paused but the sadness was acknowledged and support offered by the researcher in the first instance. Where there was concern of any unresolved distress, this was mentioned to the nurse in charge of the patient's care that day. Appropriate support could then be offered by the wider healthcare team.

5.6.4 Confidentiality and anonymity during observation

It was important that at all times the confidentiality and anonymity of all those involved was maintained. Specific field notes were taken in respect to only those who had consented to take part. Where that person interacted with someone else who had not consented, then only very broad outline descriptions were given to that person such as "visitor to another patient". No identifiable information was recorded or reported. This was also the case for staff where those who had not consented to take part were described just by their profession.

5.7 Overview of Study

5.7.1 Study Structure

The study was conducted in three overlapping phases (Figure 5):

	July 2018-Sept 2018	April 2019-March 2020
Phase 1	Broad observation and opportunistic conversations with patients and their family members Groups discussions & contextualised conversations with staff	
Phase 2	In depth longitudinal patient/family member formal conversations	→
Phase 3		Focused observation and conversations with patients and their family members – both those on the rehabilitation unit and those attending the outpatient upper limb group. Groups discussions & contextualised conversations with staff

Figure 5 Timeline for data collection

One of the key features of ethnography is that it is usually conducted over a long-time frame (Hammersley and Atkinson, 2007). This longitudinal nature of time spent in the field is important as it allows for understanding of the flow and the inter-relationships to be gleaned and not just to gain a snapshot of one moment in time (O'Reilly, 2012). It also allows immersion in the setting such that it is possible to see the temporal patterns emerge and how this shapes the social actions that the social actors make (Delamont, 2014; Gobo, 2008). Spending time in the field also aligned to stroke/ABI being evolving long-term conditions that change over time (Crichton et al., 2016), and learning occurring not just at the point of acquisition but also at application and use (Eraut, 2000). With awareness also that the phenomenon of interest may not be bound to a particular place (Hammersley and Atkinson, 2007; Wall, 2015), the flexibility of ethnography also enabled the research to move outside of the rehabilitation unit to patients' homes.

5.7.2 Participants

Across the different phases of the research the main participants recruited were patients with stroke/ABI. Family members/informal carer(s) were also recruited If they were present and wanted to participate, and the patient participants wanted them to be involved. The complex nature of stroke/ABI means that family members are often part of the process of rehabilitation and recovery (Evans et al., 1994; Creasy et al., 2013; Haley et al., 2019). Where this was the case and a family member was on site for much of the day, with agreement from both sides, they were included.

The healthcare and wider staff, including nursing staff of different levels, psychologists, therapists, assistants, and ward administration staff, who worked at the rehabilitation unit were included. Additionally, allied health professional staff who worked for other parts of the Trust's Neurological Services, such as in the community, were also part of data collection with both informal and formal conversations held.

By incorporating these different social actors, the intention was to capture the thoughts, perceptions, and everyday actions of those experiencing and receiving care and rehabilitation, and to interpret these within the context of the people involved in constructing and working with them in the learning space. Including this context meant that greater understanding was gained about the day-to-day practices and tempo of the unit, which meant that it was possible to really listen to the patient participant voice (Mattson and Stage, 2003).

The decision to include both people post-stroke and those with other forms of acquired brain injury (ABI) was made because the unit provided rehabilitation for both groups of patients. In both stroke and ABI, the cascade of cellular events that follows the vascular disruption is similar, leading to comparable presentations, goals for rehabilitation, and treatment and management plans. It was felt therefore that the experience of learning would have enough commonality to allow both groups to be considered together. It was also felt that it would be difficult for staff in particular to separate out their thoughts of patient learning for people post stoke from the learning undertaken by people with other forms of ABI. In the end, because of who was admitted to the unit and eligible to participate during data collection periods, only people post stroke were included.

5.7.3 Data Collection Methods

Fieldwork, being out in the field gathering data, lies at the heart of ethnography (Atkinson, 2015). Life is multimodal and ethnography provides a multimodal way of looking at it (Atkinson, 2017). Across the three phases, the following data collection methods were employed with the aim being to create a richness of findings that was greater than that which could be developed from any one source alone (elaborated below):

- Observation of learning as it took place through everyday life and practice within the rehabilitation unit.
- Opportunistic conversations with both patients, their family members, and staff about this learning as they went about their everyday life and practice.
- One-to-one formal conversations with patients and, if present and willing, their family members to explore their experiences and perceptions of learning and being learners within the rehabilitation unit and then continuing with follow up conversations post discharge.
- One-to-one contextualised conversations or group discussions with healthcare professionals and other working on the rehabilitation unit to explore from them more about the everyday practices of the unit and, from their perspective why things were constructed as they were and how this might impact on patient learning.
- Accessing medical notes and documentation related to both patient and staff processes.

5.8 Phase 1: Observation and opportunistic conversations derived from everyday life and practice with patient participants and family members and group discussions/conversations with staff (July-September 2018)

5.8.1 The aims of this first phase of data collection were to:

- Develop trust and build rapport with staff, patient participants, and family members (Raheim et al., 2016).
- Gather a broad overview of the inpatient unit with consideration to its setting, day-to-day tempo, and the activities of the people within it. This information was used to start to paint a vivid picture of the unit so that, when written, the reader could be transported to the place and space, comparing the culture described with their own setting and experiences and reflecting on the resonances that there may be between the two.
- Start to develop a greater understanding of what was being learnt, how and where this learning was occurring, and the factors that influenced the level and direction of the learning effort.

5.8.2 Participants, Recruitment and Consent

5.8.2.1 Participant Eligibility

Inclusion criteria

- All patients post-stroke or ABI, over 18 years old, where the clinical/treating staff identified them as having rehabilitation goals that involved some component of overt planned content learning and who had the capacity to carry out some aspect of this planned learning when away from their more formal treatment sessions.
- Healthcare staff from all professional groups and others employed or volunteering within the rehabilitation unit if they were perceived, or perceived themselves, to have a role in the learning being undertaken.
- Allied health professional (AHP) staff who worked for other parts of the Trust's Neurological Services, such as in the community and early supported discharge teams.

Exclusion criteria

- Patients post stroke/ABI with severe pre-morbid or post stroke/ABI cognitive impairment and/or behavioural challenges such that they were not able to give informed consent.
- Patients post stroke/ABI who were, or became, medically unwell and were not considered well enough to engage in rehabilitation, and people who were receiving, or were moved to, palliative care.

5.8.2.2 Recruitment

All new patients post stroke/ABI who potentially fitted the eligibility criteria were initially identified by the treating clinical team and then brought to my attention. Following discussion, if considered to be suitable, they were informed both in writing and verbally about the research by a member of their clinical team. These members of staff were familiar with the principles of good clinical practice regarding approaching people in respect to participating in research. Separate patient and family member/carer participant information sheets were provided which detailed the purpose of the research and how the research was to be conducted (Examples of participant information sheet and associated simplified leaflet given in Appendix 7 and 8). This information informed the potential participants that, with their written consent, their daily activities may be observed within the inpatient unit and that I may also approach them to take part in informal conversations about their experience on the unit. As well as this introductory information all those who were considered to be eligible had the opportunity to meet and speak with me if they wanted to ask any questions about what their participation might involve.

Staff and volunteers who worked on the unit were also informed about the research both in writing and verbally (Appendix 9) via staff meetings/gatherings and through informal conversations with people outside of these occasions.

5.8.2.3 Consent

I obtained written consent in all instances. The consent forms indicated that the person signing had read and understood the information sheet and was willing to participate (for an example see Appendix 10). Once completed, all consent forms were kept in a locked drawer in my office at the University.

For all participants, it was made clear that agreement to participate was entirely voluntary, that the person was free to withdraw at any stage without needing to give a reason and that this would not impact on either their care or employment in any way.

For patients and family members who were willing to participate, written consent was gathered to indicate that in principle they agreed to being observed and/or take part in conversations. Verbal confirmatory checking of permission then occurred either beforehand if the episode being observed was a discrete entity such as a therapy session or afterwards if the activity being observed was already underway and checking would have been disruptive to the flow.

For staff, written consent was gained to show that in principle they agreed to being observed, and confirmatory checking occurred as above. Separate consent was then gained at the start of any individual or group conversations that the staff were involved in.

5.8.3 Data collection

During this first phase of the study, either full or part-week periods were spent within the inpatient rehabilitation unit over a period of three months during the summer of 2018. This was in part pragmatic to accommodate my teaching work, but in part purposeful as time away from the scene allowed opportunity for fieldnotes to be written up and the early stages of analysis to proceed (Hammersley and Atkinson, 2007). When on site, days tended to be from 8am-6pm, with some starting earlier or finishing later. Some weekends were also spent on site to observe daily life then. In line with the invitational nature of the unit to the patients and their families, they were very welcoming and invitational to me and the research being conducted and opened all areas and aspects of day-to-day life for observation and conversation.

Various methods of data collection were employed.

5.8.3.1 Observation

Participant observation, with the direct engagement of the researcher in the socio-cultural setting and with social actors, allows for the systematic noting and recording of unique intrinsic orders and organisation of events, actions and interactions as they occur (Atkinson, 2017). As a form of data gathering, it is given specific theoretical importance within both ethnography and interactionism with the aim of exploring the phenomenon of interest within its naturalistic setting (Atkinson, 2015; Gobo, 2008). Through detailed examination, it is possible to experience and start to understand the knowledge and skills that social actors develop and employ as they perform the socially organised actions of their everyday lives. By being in the field and seeing what is taking place over an extended period of time, the goal is to be faithful to the people who are living these lives that are being observed (Atkinson, 2015).

The two terms of participant and observation have been suggested to be incompatible with each other. The concern is that the more one becomes a participant in the field, the less, rather than the more, one may observe because seeing strange in the familiar can be harder when more embedded, and more participatory, in the setting (Gobo, 2008; O'Reilly, 2009). It is important as a researcher to be familiar enough with a setting, at least at the start, to know what directions to look in, but not so much so that one cannot observe with the necessary degree of detachment required. Reflecting the strengths and limitations of the different roles, a continuum exists in the degree of participation that may be adopted from nothing, through passive, moderate, active and complete participation (Spradley, 1980 cited in Gobo, 2008). For this study, I took the role of passive participant observer but, as a considered expert by staff and patients in the field of neurorehabilitation, sometimes adopted a more moderate participant role delivering a number of structured teaching sessions to the staff and engaging in some discussions related to the broad principles of therapy and patient management. The role of more moderate participant observer was also reflected at times in social events such as celebratory gatherings and general social discussion. Overall, therefore, the role adopted was somewhat fluid depending on the situation.

By seeing people, as they lived their lives within the inpatient unit, it was possible to observe not only interactions and what happened, but also emotions, identity and motivations of those involved which have all been shown to be important for the acquisition and use of learning (Illeris, 2002). Observing over the course of the day and over several days and weeks allowed learning to be viewed as it took place both formally and informally over the span of time. Through this, it was possible to start to gauge what learning took place through the person's own effort and tempo as well as when this was driven/imposed by others.

During the process of observation, information was gathered in respect to the:

- Physical setting: field notes described the physical setting. These were supplemented by photographs and floor plans of the inpatient unit so that the lived geography of the built environment could be understood and incorporated into analysis. These visual recordings were of spaces and did not include any of the people within these spaces.
- Participant characteristics: information related to age, gender, marital/family status, employment, educational background, and reason for admission was gathered so that the nature of those doing the learning could be richly described. Where possible, this was gained though discussion with the person/people involved. Where this was not fully possible, and it was felt to be less burdensome, with their permission, it was taken from patient notes.
- Nature and chronology of events as they unfolded: documented through field notes, actions and inactions that occurred or did not occur, as well as specific phrases and topics pursued as part of naturalistic conversations.
- Nature/type of knowledge: notes were taken of the type/nature of knowledge being conveyed/learnt, of what was observed/heard. This encompassed aspects such as propositional knowledge; practical skills knowledge; cultural knowledge (people, place and processes of the healthcare system) and personal knowledge.

Areas of observation involved both open spaces within the inpatient unit including those on the ward and therapy areas as well as, with their agreement, patient's bedrooms/personal living space. As is common in ethnography, the process of choosing what, where and how to observe was relatively unstructured and fluid (Hammersley and Atkinson, 2007), with regular movement between different places on the unit. The natural daily and weekly order of the unit with the collective patient-focused activities, such as meals, social groups and bedtimes, as well as collective staff-focused activities, such as ward meetings and timetabling sessions, provided a structure that shaped in part the pattern of observation. Additionally, the individual patient daily timetables also provided structure with identified treatment sessions observed at specific times. Outside these more structured elements, time was spent watching the general scene with the comings and goings of the ward, the gym, or the other general open areas of the unit. Mealtimes were sometimes spent alone, sometimes with staff and sometimes with patients. Refreshments were made over the course of the day in a shared staff kitchen where, if others were present, opportunistic conversation would occur. Desk space was made available in the senior management office, so time was spent there, and conversations were held that encompassed more managerial discussions about both the daily running of the unit as well as its future. Having such wide access to the rehabilitation unit meant that most aspects of the patient’s routines were observed from formal therapy sessions and formal goal setting meetings to informal time spent either alone or with family.

Two complementary methods of observation were adopted, an experiential approach recording what was taking place naturally on the unit, and the approach of participating-in-order-to-write, where specific activities and interactions were identified to observe specific things (Emerson and Bromley, 1995). As is quite common, the latter was adopted both more often at the start where it was a bit less clear what to observe and at the end where it was much clearer what specific events might be of value (Emerson et al., 2001). For both approaches, I positioned myself on the periphery of the scene, always visible to all but not so much as to be an audience and in the forefront of the minds of those involved (Hammersley and Atkinson, 2007; O’Reilly, 2009). By being at the edge of the scene, the aim was to limit my influence as much as possible in the events as they occurred.

Fieldnotes, recording what was observed and heard, were made freehand, in an open-ended, evolving fashion, in a notebook. Fieldnotes aim to capture and represent in written form, a description of what was seen and experienced, turning a transient moment in time into a resource that can be referred to at a later date (Atkinson, 1992; Geertz, 1973). Although there is much more to fieldwork than just making fieldnotes, they can act as a steer for observation when in the field and then as a reference afterwards to guide thinking and understanding (Atkinson, 2020; Van Maanen, 1985). When making fieldnotes, choices and selections need to be made about what to record and not record, and they are therefore never a literal representation of the setting or complete record of everything that occurred (Gobo, 2008). Instead, they are a construction, an evocation of tellable elements, in respect to both what was chosen to record and then how this was written. An impression therefore of the setting as seen and sensed by the researcher (Atkinson, 1992); the process of observation and thought (Atkinson, 2020). As part of the reflexivity important within ethnography (Emerson et al., 2001), reflections on why decisions related to observation were made as they were, and how things were framed and with what particular stance, were recorded.

Writing fieldnotes occurred either contemporaneously, as the observation occurred, or very shortly afterwards depending on which was least intrusive and less likely to influence the normal everyday being of the people involved. They consisted of organisational descriptive data reflecting what actually happened and the behaviours observed, and presentational data which reflected thoughts on how those observed shaped their appearance and actions for others in the scene, and the side of themselves that they put forward (Van Maanen, 1979). In addition to descriptive fieldnotes recording what was actually experienced, reflective thoughts and first impressions were also recorded on site immediately following the periods of observation and were then added to through more extensive analysis when away from the site (for an example see Appendix 14). These impressions related to both thoughts, emotions and reflections about what was observed and heard (reflective notes), as well as thoughts on the decisions that were made about what to observe and/or record, and why (reflexive notes). Through this, the early stages of analysis started to take place in parallel with the early stages of data collection, with particular consideration to the meaning of observations and what perhaps could/should be looked for further or differently.

Because of the daily and weekly routine of the rehabilitation unit, occurrences that were very similar to each other were recorded regularly. These included both regular structured events, such as ward meetings, as well as general unstructured time on the ward. In addition, any novel or significant events were also noted as they occurred. Through this, a picture of the everyday nature of the setting gradually built up and could start to be seen. In light of learning taking place, in both formal and informal settings, and occurring not just at acquisition but also when the learning was used, these periods of observation aimed to capture opportunities that were designed for:

- Deliberate learning – where there was full intention and awareness, such as therapy sessions.
- Reactive learning – which was near spontaneous or unplanned but where the learner was aware that learning was occurring/had occurred.
- Implicit learning – where the person had no real intention or awareness of the learning.

To guide these observations, the question that I asked of what was being observed was, is learning the principle aim or a by-product? From this, the activities were categorised as:

- Learning through structured therapy/rehabilitation-based activity, for example from timetabled therapy sessions, formal structured independent practice, structured activities of daily living (ADL) sessions, formal education sessions.
- Learning through therapy/rehabilitation-based activity located within everyday living, for example the often short and opportunistic learning that might occur through asking questions, locating one’s own resources, trying something out, and reflecting.

- Living, with learning as a by-product, for example learning from others on the ward through activities such as observation and discussion, or through trial and error of activities.

5.8.3.2 Listening, talking and asking questions

As well as observing, listening, talking and asking questions, are also all important within ethnography (Hammersley and Atkinson, 2007; Gobo, 2008). Interaction is about the verbal as well as the non-verbal with social groups and social life often being based around conversation and discussion. As a result, much ethnographic data is talk based (Delamont, 2016). By listening and discovering more about what is important to social actors, what they understand by the activities taking place in the field, and what the actions mean to them, it can help shape the line of direction of accompanying observations and steer thoughts for the analysis and interpretation (Gobo, 2008). As with observation, listening, talking and asking questions, can be more/less active or passive by directing and leading the discussion to just taking part as a conversation naturally evolves (O'Reilly, 2009).

Within this first phase, the main methods of listening, talking and asking questions were through opportunistic conversations which were generally more lightly steered and then a small number of group discussions which were more overtly led.

5.8.3.2.1 Natural discussion and opportunistic conversations

Data collection that occurred as part of the observation involved listening to, and taking part in, natural conversations as they took place in situ between individuals and groups. In addition, I initiated and led a number of opportunistic conversations in response to what was observed. The aim of both was to capture thoughts, reflections and feelings about things that had occurred, or had not occurred, and to elaborate on elements of discussion already taking place. These were with patients, family members and staff, and again were with individuals or with groups. Field notes were primarily used to record these conversations, but audio recordings were also made where the conversations developed and became lengthier. In these instances, the person or people were asked if they would be happy for the conversation to be audio-recorded.

In addition to taking part in natural discussions and opportunistic conversations, much of the time spent observing was spent just listening to, and reflecting on, the everyday discussions taking place and not taking part in these in any way. Within the associated fieldnotes, comments were made about not just what was discussed but where the discussion was occurring, with whom and with what non-verbal body language.

5.8.3.2.2 Planned group discussions/contextualised conversations

In this first phase, alongside the opportunistic conversations, a small number of semi-structured planned group discussion/contextualised conversations with healthcare and wider staff also took place in order to further explore the everyday practices of the unit and why, from their perspective, things occurred as they did. Rather than formal staff interviews, small group discussions were the main method employed at this stage as they could be more dynamic and allowed for thoughts to be triggered between individuals and from there ideas to be exchanged and experiences to be shared (Krueger and Casey, 2015). Fewer were conducted than had been anticipated as, within the first phase with its more exploratory nature, much of the learning about staff thoughts and motivations was through unstructured observation and opportunistic conversations. The more formal planned group discussion/ contextualised conversations that did occur were guided by a topic guide with questions and prompts developed from published research, the findings from the meta-ethnography, and by the early stages of observation (Table 10). This latter element allowed a deeper and richer understanding from the patients' and family members' perspective to shape the discussion more than pre-existing thoughts. As it was considered that therapists were potentially likely to perceive themselves as being involved in the more formal learning opportunities and the nurses perhaps in the more non-formal opportunities, the group discussions were held separately for the allied health professionals and the nursing staff. Barring the first group discussion which involved a mixed group of therapists, separate sessions were held for junior and senior staff, and for qualified and non-qualified staff. By having separate sessions, it enabled all to share their views freely without self-silencing in response to the fear of being judged (Krueger and Casey, 2015).

Table 10 Topic guide for staff conversations

Initial questions Them	Discussion about: • Role, how long worked at unit, how long worked in region – similarities difference to other places • Background to rehab – what route took into the area • Understanding of stroke, rehabilitation and recovery • Perceived role in patient's rehabilitation/recovery • How patients and their relatives might view their role Description of their typical day
Initial questions Unit/cultural learning	Discussion more widely about XXX (place) • Aspects of the unit, the place or people within it that might influence patient learning • Its specific culture and ethos – its written or unwritten rules, regulations, polices etc… • Understanding of patients of this culture • What it might be like for patients to enter this culture
Initial questions Typical day	Description of/discussion about • A patient's typical day • Of all that patients do in their day, perceptions about what most influences their recovery – their perspective and their perspective on the patient's perspective
Follow on questions – skills	Discussion about learning content – skills • What skills based learning content do they feel patients learn • What influences this – their perspective and their perspective on the patient's perspective • Success – what would constitute success and how would it be recognised – their perspective and their perspective on the patient's perspective
Follow on questions – knowledge	Discussion about learning content – knowledge • Beginning understanding and patients experience of/knowledge of stroke itself, rehabilitation and recovery • Knowledge that they might gain from their time on the unit • Where this learning comes from • What influences this – their perspective and their perspective on the patient's perspective
Follow on questions – emotional learning	Discussion about emotion/personal learning • Perceptions of patients' perceptions of the unit • Drivers for patient learning • Links between content learning and emotional learning • Links between people and place on their emotional learning • Patient learning about self
Final set questions	Final broad discussion on their perceptions of what it is like for their pts to learn and be learners in the early months post stroke/ABI If they were to ask their patients what they felt they had learnt, what might they say

Each group discussion was held in a quiet room in the rehabilitation unit at a time convenient for those who volunteered to take part. All those who attended within work hours had permission from their line manager. Each group conversation typically lasted from between 30-90mins, with the exact length determined by the group. The semi-structured/unstructured format allowed for key areas to be explored, but also for discussions to progress in different directions depending on the responses that were given. With permission, they were audio recorded. The findings from the discussions were mostly integrated into the field notes in the form of explanation as to why what had been observed might have been as it was (for an example, see Appendix 14). This context would often sit along my reflections on why

I thought that things were as they were. At times these aligned but at other times there was a difference, and it was these points, in particular, that would trigger further questioning of what was occurring and why.

5.8.3.3 Examination of relevant documents

As part of understanding patient learning, with permission from the respective staff and patient participants, examples of written sources of information such as patient exercise leaflets, patient timetables and documents indicating staff processes such as staff timetables/rotas were reviewed. Data captured through examination of relevant documents was largely as field notes and were fully anonymised. Where specific to an individual they were offered up by them on request. Any examples captured as images/photos were only of non-patient identifiable information such as an unnamed patient timetable or information/exercise leaflets.

5.9 Phase 2: In depth longitudinal patient/family member contextualised conversations (July 2018-March 2020)

5.9.1 Aim

To capture accounts, thoughts and perceptions of patients about learning and being learners within the rehabilitation unit and then to being at their place of discharge.

5.9.2 Participants, Recruitment and Consent

5.9.2.1 Participant Eligibility

Inclusion criteria: Patients over 18 years old who were post-stroke/ABI were eligible if:

- The clinical/treating staff identified the patient as having readiness/ownership in part for their own rehabilitation, that they had some component of overt planned content learning, and they had the capacity to carry out some aspect of this planned learning when away from their more formal treatment sessions.
- They had the capacity to consent. As potentially suitable patients were identified in the first instance by members of their clinical team, issues related to capacity were initially discussed with the clinicians who knew them. If either during the

process of meeting with the patient/family member to inform them of the study or on gaining consent, concerns were raised about capacity, consent was not taken, but instead this was discussed further with the team and a follow-up attempt was made only if deemed suitable.
- They had sufficient English language proficiency to enable them to give informed consent and to then take part in the contextualised conversations.

Exclusion criteria: People:

- With severe pre-morbid or post stroke/ABI cognitive impairment and/or behavioural challenges such that they had no or a very minimal self-management and/or were not undertaking independent exercise as part of their normal rehabilitation.
- With severe pre-morbid or post stroke/ABI cognitive impairment and/or behavioural challenges such that they were not able to give informed consent.
- Who were, or became, medically unwell and were not considered well enough to engage in rehabilitation, and people who were receiving, or were moved to, palliative care. Those who were unwell for short periods (e.g., days) who were then well enough to recommence rehabilitation were able to continue with or to become eligible for participation in the study if they wished to do so and with the agreement of the responsible clinician.

5.9.2.2 Recruitment

The aim was to recruit 8-15 patients. Sampling was purposive based on the described criteria, with potential participants identified by healthcare staff who knew the patients best. Once identified, the patient was approached first by one of the senior clinical staff to inform them in writing and verbally about this aspect of the study (participant information sheet and associated simplified leaflet given in Appendices 11 and 12). As determined by the patient, this could either be with or without a family member being present. For those interested in participating, I met them to talk through what participating would involve. As part of information giving, I explained that involvement was entirely voluntary, that they could change their mind at any stage without needing to give a reason and that their decision to be involved or not would in no way affect their overall care. All participants recruited into phase 2 were also involved in phase 1 and phase 3 observation.

5.9.2.3 Consent

After being informed about the study, a minimum period of at least 24 hours was given to allow full consideration of involvement. At this stage agreement to participate was sought, but formal consent was only gathered at the start of the first formal conversation to allow opportunity for any final consideration of involvement and to ask any remaining questions.

5.9.3 Data Collection

Starting in parallel with phase 1 but then lasting throughout until the end of phase 3 (total of 18 months), phase 2 involved longitudinally planned ethnographic in-depth conversations with patients and, if they wished, their family members. These contextualised conversations took place over time, spanning the patients' inpatient stay, their discharge home and then up to four months of living back at home. The number of conversations per patient varied slightly depending on what the participants both found manageable regarding their perceived burden of involvement and wanted to talk about. The aim was, however, for each patient to be involved in between three to five conversations.

- Conversation 1: normally within seven days of admission to the rehabilitation unit
- Conversation 2: normally towards the end of the stay on the inpatient unit
- Conversation 3: normally within two-three weeks of discharge
- Conversation 4: normally within three-four months of discharge

Additional conversations were added within the inpatient phase where the patient's length of stay was extended further than the normal six weeks and the patient agreed when asked, or they requested the extra conversations. In all instances, the first conversation tended to be slightly more formal and more structured, loosely following a topic guide (Table 11) which again was informed by both previous research, the meta-ethnography, and the earlier stages of data collection.

Table 11 Topic guide patient contextualised conversations

Initial questions	Discussion on • Stroke journey to that point – any remembrance of the stroke itself, the acute setting, the transfer • How things have changed over that time – able to do things now that could not do initially • Perceptions of how doing now
Questions on broad understanding	Discussion on: • Knowledge of stroke – theirs and in general • Broad understanding of recovery – what this means to them • Broad understanding of the role of rehabilitation in this • Where knowledge from; sources; useful/not useful • What want to know
Questions about specific event	Discussion related to trigger – for example, a therapy session viewed, a copy of their timetable, photos of therapy area • Talking through typical session • Enjoyed/not enjoyed • Perceptions of what working on and why • Like anything done before or not • Perceptions about why having different therapies – what working on and why
Questions about wider unit	Discussion about wider unit +/- use of photos as prompt • What do when not in therapy – how spend day • Is there anything that they do on the ward that they feel influence their recovery • Do they see activities such as wash and dress and eating and drinking linked to recovery – why do they feel they do them
Questions on independent practice	Discussion on • Practising exercises on the ward – do they/don't they – thoughts on why • Do they feel they know what to do • Do they do things alone/with others • Things that would like to do/things that might make it easier • What overall role do they perceive that they play
Questions on people, place and process	Discussion on • The people – important qualities; ways of working; individuals that stand out and why – what do they offer • The place – important qualities; does it matter what the place is like • The ways of working of the unit – important qualities; what works/is liked and does not work/is not liked
Questions more specifically on rehabilitation	Discussion on • Knowledge of rehabilitation as a concept • Any prior knowledge of the unit • Expectations from the acute setting as to what rehabilitation would be like – has it then been similar/different • Like anything done before
Final questions on learning	Discussion about • What feels has learnt • Feelings towards recovery/associated learning – what is like to be needing to learn at this time • What expected/did not expect

Thereafter, particularly for those participants with ongoing rehabilitation, conversations took the format of informal shared conversations which were more unstructured, free flowing and formless with, on occasions with some, a genuine exchange of views and discussion from both sides. Spending time on the unit, observing and talking meant that relationships were developed such that for these participants subsequent interactions were more conversational, picking up on elements discussed previously and on a shared existing understanding. This feature of conversations taking place once a relationship is established is a feature of ethnographic interviews/formal conversations that makes them different from interviews conducted in other forms of qualitative research (Sherman Heyl, 2001). Despite the more conversational style and less reliance on the topic guide in later conversations, the lead role always remained with the researcher who therefore set the agenda (Walford, 2018).

The aim of these contextualised conversations was to create some time and space away from the everyday life on the unit and to explore further some of the thoughts and sense making being undertaken by the patients about rehabilitation and recovery, and from there, their learning. Although they have been criticised for not sufficiently acknowledging the nature of the interaction and the influence of performance (Atkinson, 2015; Walford, 2018), shared conversations do provide the opportunity for participants to express their feelings and reflect on events. From this, the researcher can learn more about what the events being observed really meant to those involved. The purpose was therefore both to gather background information about the social actions occurring and to learn more about the interpretations, orientations and meanings of these to participants. Through this, the aim was to better understand what one was seeing in respect to the learning taking place (Holstein and Gubrium, 1995). By adopting a more conversational form with both sides as active partners, it provided a forum to talk in hopefully an enjoyable way and enable reflections to be expressed. It also allowed the researcher to learn more about the patients as individuals which was important both to build rapport and to put some of their thoughts about learning into wider context (Holstein and Gubrium, 1995). For some participants, the shift in nature of the conversations over time meant that discussion was less governed by cultural norms and what should be said compared to what was really felt. Although staying in an unstructured format, the conversations generally became more focused over time as the iterative process of analysis occurring alongside data collection meant that the lines of direction became clearer.

Recognising that discussion concerning such a multifaceted and tacit topic as learning can be hard to conduct, for the first, more structured, formal conversation, an activity or tool designed to trigger discussion was sometimes used (Eraut, 2004). This was most often an observed therapy session with the conversation taking place shortly afterwards, but also included referring to the patient's timetable as a prompt or commenting on still photographs that were taken of the unit by the researcher and were used to stimulate discussion (Appendix 13). Similar triggers were used for some of the subsequent conversations that took place within the rehabilitation unit but were not used for the home conversations as by that stage, the patients understanding of the research was such that triggers were not considered to be needed.

All conversations were held at a convenient time for the patient and their family member if they were present. For the two inpatient based conversations, date and times were discussed with them and the nursing/therapy staff were informed to check that these fitted with the ward/ therapy routine. The provisional date for the first post-discharge formal conversation was generally made prior to discharge. Recognising that both patient and family member plans may have changed on leaving hospital and that they potentially had many visits taking place and other commitments on their time, contact was made by phone a week before the provisional date to check if the time was still convenient and rearranged if not. Upon request, reminder calls, either a couple of days before hand and/or on the day itself were also made. The provisional date/time for the final conversation was discussed at the end of the first post-discharge visit and a plan made for when the patient/family member would like the researcher to contact them to organise this. Again, reminders were given if asked for.

Most of the conversations were held in a quiet location both within the inpatient unit and then in the participants' homes. When in the rehabilitation unit, these were mainly in patient's rooms, with just a small number in the communal areas of the gym or dining room. On all bar one occasion, these were when these rooms were empty. The conversations held at home tended to be in the person's living room. With permission, audio recording was used, and field notes were made at the time or immediately afterwards. Conversations tended to last from about 30mins to about 90mins, but some were interrupted by mealtimes, therapy sessions and toilet breaks and were therefore carried out in smaller sections.

5.10 Phase 3: Focused observation and conversations (April 2019-March 2020)

Following data gathering and associated analysis from phase 1, and in parallel with ongoing phase 2, a more focused period of data collection took place in phase 3 (six months) with the aim of starting to confirm or challenge understandings developed from the first two phases. The fluid and flexible nature of ethnography meant that inferences being developed through analysis could be reflected in this third phase. The methods of this phase were as they were in phase 1, and included focused observation of specific activities and events, opportunistic conversations, and more group discussions and contextualised conversation. Eligibility of individuals was as per phase 1. Staff conversations were slightly more targeted in regard to both who to speak with so that as many different voices across the multidisciplinary team could be heard, and what to discuss. This included more specific conversation on concepts that had started to be developed through analysis, such as their perceptions on what they felt was visible and invitational to their rehabilitation and recovery.

5.10.1 Amendment to Research

It was in phase 3 that the additional group discussion occurred with a small group of people who had completed their inpatient rehabilitation within the previous few months but who were attending an upper limb exercise group aimed at people post stroke/ABI who had incomplete recovery and therefore needed a short burst of additional rehabilitation to guide them with their independent practice of exercises at home. By involving these individuals who were further along since their stroke/ABI, it provided a richer and more in-depth picture of the learning that had taken place over time about recovery post stroke/ABI and added their thoughts and reflections on engaging in ongoing exercise practice when away from the formal supported pathway. These data acted as a supplement to the home-based conversations when some of this reflection on home-based exercise practice had started to be expressed.

5.10.2 Participants, Recruitment and Consent for the Amendment

5.10.2.1 *Participant Eligibility*

All those attending the upper limb group (maximum of six people per group) were eligible to take part. The inclusion criteria as detailed for phase 1 (p.99: aged over 18, post stroke/ABI, with the capacity to consent and with sufficient English language proficiency) were applied.

5.10.2.2 Recruitment

All those attending the group sessions were informed by the therapist leading the group about the research both in person and in writing via a participant information sheet. As the group met weekly, all had a minimum of a week to decide if they wanted to participate and those that did, informed the therapist who then informed the researcher. The researcher attended the start of the final group session (week 6) to answer any questions that the potential participants had about the study.

5.10.2.3 Consent

All participants consented in writing at the start of the group discussion. As with all other phases, signing the consent form indicated that the participants had read and understood the information sheet, agreed that their participation was voluntary and that they could withdraw at any stage without giving a reason.

5.10.3 Data collection

Group discussions were held at the end of the final upper limb group session, in one of the meeting rooms within the rehabilitation unit. A group discussion was held rather than individual conversations as the group had been together for six weeks for their upper limb sessions and had built up a rapport over this time. The discussion was informed by a topic guide that had been developed based on the findings gathered up to that point.

5.11 Leaving the field

For phases 1 and 3, dates for both entering the setting and leaving were shaped by the researcher’s termly teaching commitments. This provided a start and end point that could be easily articulated. Outside of these defined periods, the setting was then visited on a small number of follow up visits as well as for the ongoing conversations with participants in Phase 2. Although phase 2 lasted throughout the length of the study, time on site was less intense and the gap between phases 1 and 3 provided time for reflection and analysis and allowed phase 3 to be informed by earlier phases. The final leaving in March 2020 was, as with so much else at that time, impacted by the lockdowns imposed by Covid. The plan had been to recruit from one further upper limb group, but this was discontinued and external visitors were no longer allowed on site. There was, therefore, no opportunity for either an in person debriefing and farewell, or any follow up visits to continue my commitment to the team. With the uncertainty of the pandemic, the study came to a more abrupt end than had been planned.

5.12 Analysis/Interpretation

The aim of this study was not to describe the broad culture of rehabilitation or the nature of a specific rehabilitation unit, but instead to develop understandings and explanations about the nature of patient learning post stroke/ABI and the sense making of these individuals with respect to recovery and rehabilitation. To achieve this, data were analysed broadly through an interactionist lens, recognising the importance of both the social context and fellow social actors on the meanings developed of the specific phenomena of learning and recovery. Interactionism does not have a method of analysis specific to it, but it is an interpretive, abductive approach, through which the researcher works hard with the data to abstract information to help guide the process of seeking to understand what one is seeing and hearing (Hammersley and Atkinson, 2007). To achieve this, analysis at all stages was an inquisitive and imaginative process exploring deeply what had been seen, heard, smelt, tasted, remembered and felt, both physically and emotionally (O'Reilly, 2009). By problematising the different aspects experienced through participant observation, the aim was to look with fresh eyes at the setting and the processes taking place (Delamont, 2014) and to transform data to something more and new (Atkinson, 2017).

Atkinson (2017) described this in depth and systematic abductive process as granular analysis and it was this method of working that was adopted for this study. As its name suggests, the process involved tracing the grains of everyday lives of the social actors as they were observed, moving from initial consideration of what people do, to how they enacted what they do and with what social orderliness, norms, beliefs and conventions, and from there to understand why they do as they do. Through this analysis, understanding developed about what shaped and influenced what was firstly accomplished in the social order of the phenomenon of interest and then what sustained this. Resultant from the detailed consideration of these local manifestations was finally the development of wider, more generic ideas, explanations and possibly the modification of existing theories or the development of new ones (Atkinson, 2017).

Within this study, the main units of analysis, or sources of information (Atkinson, 2020), were the inscriptions of field notes, and transcriptions of the contextualised conversations, group discussions and opportunistic conversations. In addition, there were also memories, reflections and records of the global impression gained of all that had been seen and heard but which were not detailed within the minutiae of the inscriptions or transcriptions gathered from day to day being on the unit. The first stage was to transcribe the conversations and type up the field notes verbatim. I undertook both processes, where possible contemporaneously, but sometimes later when more time allowed. Where full transcription was not possible at the time, the recordings were listened to and paper fieldnotes re-read to inform the time spent in the field. Once conversations were transcribed, memos, thoughts and reflections from field notes were added alongside to give context to the interaction. Final documents were saved as Word files and handling the text in this form, as various forms of Word documents, was the main method then employed throughout all stages of analysis without using specific computer software packages (for examples of annotated extracts from a participant transcript, initial participant analysis grid, and combined participant analysis grid, see Appendices 15, 16 and 17).

As is normal for ethnographic work, initial data were fairly unstructured, and time was spent organising them. Both the transcripts and the inscriptions of field notes were handled initially through line-by-line analysis in either the chronological or participant based way in which they had been collected (Hammersley and Atkinson, 2007). From there they were sorted and labelled to inform initial tentative suggested grouping of thoughts/codes. These early codes were in part shaped by sensitising ideas such as thinking about and organising findings in respect to the three dimensions of learning proposed by Illeris (2002). Findings were also handled within a framework that I developed based on areas for consideration drawn from the work of Atkinson (2015; 2017). To structure this, a grid was developed (Appendix 18) and populated with thoughts and summarised data enabling concepts important within interactionism such as negotiation, physical and symbolic boundaries, and trust to be considered in a more formalised way. By working with this framework alongside the line-by-line analysis, it allowed the findings to be considered holistically and not solely in too decontextualised and fragmented a way as can happen through very detailed coding (Atkinson, 2015). This framework was returned to and updated at later stages of analysis as more understandings were gained. In addition to this, data were handled in multiple other simple Word tables with columns for original text and columns for notes, comments and reflections. These became progressively more refined as the iterative process of constant comparison between ideas, codes and categories (to see which ones seemed central and therefore should be developed further) was employed. As this process of analysis progressed, it moved from being more inductive to more abductive, building on hunches and drawing out clearer lines of direction to look along to better understand what the findings might be a case of (Atkinson, 2015; Shank, 2006). Throughout, an open mind was maintained with nuances and differences looked for alongside patterns that were drawn out.

To help guide the analysis, an approach adopted from the start, which is common to ethnography, was to seek comparable ideas and thinking from both similar fields of literature as well as from other disciplines (Atkinson, 2015). As Delamont (2016) points out, to be a good ethnographer, one needs to have three passions: curiosity, reading and writing. The passion for reading is such as to want to read widely at all stages on content and methods and in so doing to help to initially question and then provide answers to whether the findings feel strange or familiar, whether they make sense or lead to puzzlement, and whether similar patterns have been seen before and if so, how they were interpreted. Just as when observing one cannot rely on hoping to ‘see’ the right things, one equally cannot just hope that the right interpretations of data will emerge (Atkinson, 2015). Instead, use of existing theory to guide both one’s looking and thinking is an important precursor and medium for all stages of ethnographic work including, importantly, the analysis (Willis and Trondman, 2000). This proved to be a very recursive process moving between data and, primarily, literature on education and learning, exploring where similar concepts had been considered elsewhere and could be taken back to help make sense of the data.

By entering the field with sensitising ideas and bringing initial ideas to the work to inform the data gathering, it meant that the process of analysis started before data collection itself began. This then proceeded as an iterative process of data gathering, reading to find comparisons, retuning to look at the data again, further data gathering, further reading and onwards. This continued in a spiral like fashion throughout with the line of direction becoming gradually more refined and focused. By looking for comparisons it meant that ideas were brought to the data as well as being extracted from them. In the course of the analysis different concepts from education-based literature were explored, each time seeking to see if the understandings taken from them could help to make sense of the data being gathered and analysed. This process of theoretical triangulation (Denzin, 1989) allowed for the interrogation of the data through a slightly different lens each time with the continual questioning of what each element of theory brought to the data and how it could be interpreted in light of this (for a brief reflection on this, see Chapter 13, p.255).

Through the abductive processes of granular analysis that was very much shaped and informed by a continual returning to the literature, behaviours were noted, from where links between these were identified and finally more generic patterns established with understandings of how and why these might have come about. Throughout, this was underpinned by the questions: what is this an example of? what is going on here? how are the actors making sense of things? and how does one make sense of this?

The findings from all the phases were amalgamated.

5.13 Reflection and Reflexivity

As is common with other methods of qualitative research, within ethnography, second order constructions developed by the researcher result from sense making of the first order constructions done by the social actors; the etic within the emic. One of a number of criticisms levelled at interactionism, especially early on, was lack of recognition of the role of the researcher within the process, and from there, their impact on the outcomes and a questioning of the credibility of findings (Fine, 1993, Gobo, 2008). At all stages, research is a selective process, from generating the initial research idea and question to final writing up. Decisions are made at every stage by the researcher based on presumptions that they have about the world (Gilbert and Mulkay, 1982). It is important to reflect on these and to consider what they were and what impact they might have had. Within ethnography particularly, the participant observer role means that the researcher is central to the role of actively constructing the collection, selection and interpretation of data (Finlay, 2003). Reflexivity is the process whereby the researcher turns their gaze towards themselves and, by so doing, helps to situate themselves within the process and bring some transparency to their role (Finlay, 2003). This has been described as the process of thoughtful, conscious self-awareness (Finlay, 2002), which allows the researcher to consider their position as potentially both insider and outsider and through this for findings to be a joint product of the relationship between the participants and the researcher themselves (Finlay, 2002).

Recognising this important influence, a continual process of self-awareness, reflection and thinking (reflexivity) was employed throughout all stages of the process to assess the assumptions and preconceptions that may have been brought to the work and to provide a way that allowed the impact of the researcher to be recognised, questioned and challenged. These processes involved documenting the foreshadowed problems at the outset of the study, writing reflective thoughts to sit alongside fieldnotes and continually questioning, thinking about, and responding to decisions made along the way and the possible consequences of these. From this, it was possible to maintain a focus on the direction of the analysis to ensure that this was being guided by the findings and not drifting away from this important anchor. Reflexivity allows researchers to be transparent about how decisions were arrived at and the influence of the theory on the reported findings (Gilbert and Mulkay, 1982). Like the fieldnotes, these reflections and thoughts were written contemporaneously and shaped the early stages of analysis when trying to fathom out what the observations may really be an example of. The reporting of this reflexivity and thoughts on my influence on the data are primarily given at the end of chapter 11, p.215-222 (but with further thoughts across chapters 12 p.223 and 13 p.255).

Chapter 6 Findings: Overview

Across the three phases of the study, 53 days were spent on site gathering data. These were mainly on the rehabilitation unit but also included visits to patient participants in their homes. Most days would start with a brief discussion with the therapy staff to review their timetables and then move to the ward to get an update on the patients and review their plans for the day. Time would be spent moving between the ward and the gym, spending a roughly equal time on each for more formal data gathering. Informal time for lunch and tea breaks, and time spent writing up reflective fieldnotes, was largely spent in the therapy area. More recorded data were gathered from the patient participants than from staff, from whom data were gathered more in the form of fieldnotes following informal discussions.

In total, four A5 spiral bound notebooks were used for field notes, 42 photographs were taken, floorplans were drawn and copies of patient documentation, including a blank timetable, were gathered. Group conversations were held involving 41 staff. Fourteen patient participants and seven spouses were involved in the longitudinal contextualised conversations, and many opportunistic conversations were held with others.

The findings from this work are presented over the following six chapters:

- Chapter 6 Findings I: The setting: the place and its people
- Chapter 7 Findings II: The patient participants
- Chapter 8 Findings III: The acute hospital setting
- Chapter 9 Findings IV: The rehabilitation unit
- Chapter 10 Findings V: The home
- Chapter 11 Summary of the Findings of Study 2: the ethnography

Chapter 6 describes the setting and the staff and aligns to phase 1 of the study, which aimed to gather a broad overview of the rehabilitation unit with consideration to its setting, day-to-day tempo, and the activities of the people within it. The information gathered was used to start to paint a vivid picture of the unit so that the reader could be transported to the place and space, comparing the culture described with their own setting and experiences and reflecting on the resonances that there may be between the two.

Chapter 7 sets up the subsequent three chapters by introducing the patient participants. A brief picture is painted of each person and then consideration is given to the knowledge and understanding the patient participants started their learning with and, from this, what beliefs, expectations and wants they developed and held. This is then developed over the subsequent chapters.

Chapters 8-10 align more to phases 2 and 3 of the study, which aimed to capture the accounts, thoughts and perceptions of the patient participants about learning and being learners over time, from the moment of their stroke occurring, through their time in the acute hospital (Chapter 8), then being within the rehabilitation unit (Chapter 9), to finally being at home (Chapter 10).

Chapter 11 returns the reader to the four research objectives, drawing together thoughts and new understanding in respect to these that then lead into the discussion.

Findings I: The Setting - the Place and its People

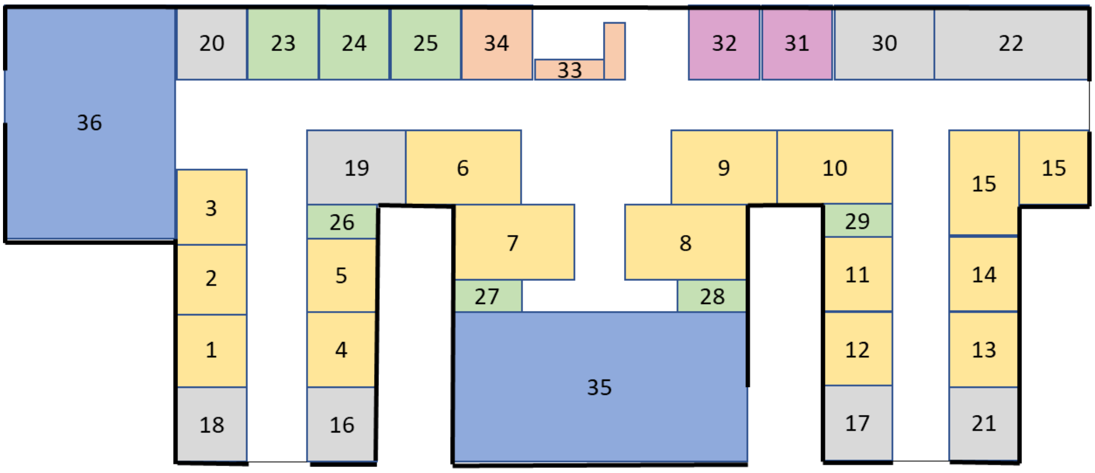
6.1 The Places and People of Rehabilitation/Recovery

The aim of this first section of the findings is to place the reader in the setting, introducing them to the Unit and its staff. The findings presented in the subsequent chapters can be interpreted in the context of this.

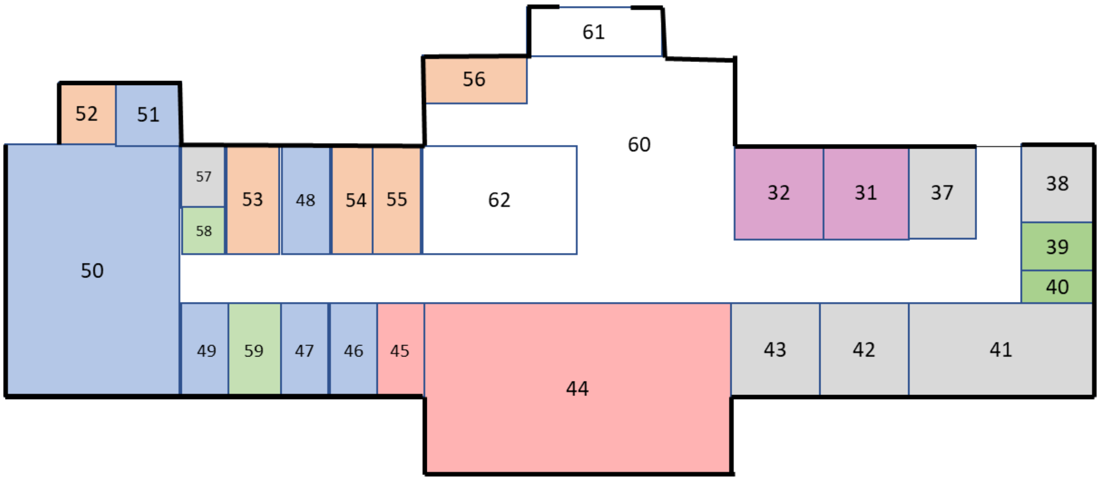
6.1.1 Rehabilitation Unit – The Place

The rehabilitation unit was a small stand-alone, purpose-built building on the edge of a village about 10 miles from the acute hospital. It was built in the 1990s to replace an existing home for people living with long-term neurological conditions. The village itself bordered the countryside and views from the unit were partly of fields.

The building was two storeys, built into the slope of a hillside with offices and therapy areas on the ground floor accessed via the main entrance which was at the rear of the building. The ward was on the lower ground level, which had level access to the gardens. It consisted of 17 beds divided into two ends of a main left-right corridor, with the nurses' station situated in the middle. The rooms were mainly singles, with a small number of doubles, and one transitional living flat consisting of a bedroom, bathroom and sitting room (Figure 6).



Key to lower ground floor: 1-14 bedrooms (yellow); 15 transitional living flat (yellow); 16-17 offices (grey); 18-22 stores (grey); 23-25 bathrooms (green); 26-29 toilets (green); 30 laundry room (grey); 31 stairs (purple); 32 lift (purple); 33 nurses station (orange); 34 pharmacy (orange); 35 dayroom (blue); 36 dining room (blue)



Key to ground floor: 31 stairs (purple); 32 lift (purple); 37-38 stores (grey); 39-40 staff toilets (green); 41 staff common room (grey); 42-43 kitchens (grey); 44-45 meeting rooms (red); 46-48 treatment rooms (blue); 49 psychology room (blue); 50 therapy gym (blue); 51 assessment kitchen (blue); 52 therapy office (orange); 53 senior management office (orange); 54-55 community office (orange); 56 unit administration office (orange); 57 therapy store cupboard (grey); 58-59 toilets (green); 60 reception area; 61 main entrance; 62 light well

Figure 6 Floor plans of the rehabilitation unit

In front of the nurses' station (38 on the floorplan) was the conservatory-style dayroom (35 on floorplan), which led onto the garden. This room contained a small kitchen area where patients and visitors could make breakfast and hot or cold drinks during the day. There were tables and chairs, as well as side benches with computer terminals, jigsaws, and games. In addition, there was a large television, an exercise bike, a computer game console and monitor, bookcases, a piano, and a fish tank (Figure 7).

Figure 7 Images of the dayroom

At the far end of the main corridor there was the dining room (36 on floorplan), which was another large space for patients to take their lunch and evening meal (Figure 8).

Figure 8 Images of the nurses' station and the dining room

As per guidelines to help with orientation for people living with cognitive impairment, the two halves of the ward were clearly identified by being painted in two distinct primary colours. Four bedrooms were located opposite the nurses' station and the others were on two side corridors that extended away from this main corridor. These rooms could not be viewed from the nurses' station. Each room consisted of either one or two beds, with an upright chair in the colour of the corridor, a bedside locker, a small chest of drawers, an over bed table, a wall mounted television, a cupboard, a sink, and an overhead hoist. Each had a large window with a low window ledge which looked out on to the gardens (Figure 9). On the wall were two laminated A3 sheets, one indicating the nurse in charge for that day/night and the other showing the patient's weekly timetable. As needed, other patient specific information was also displayed on separate wall mounted sheets, such as falls risk information and diet modifications. Each bedroom door displayed an A4 piece of paper with the patient's preferred first name.

Figure 9 Images of two of the single bedrooms

On the walls of the ward were a combination of large, printed images and local posters and information. The large images were floor to ceiling professionally installed pictures of flowers, grasses, and butterflies. These were bright and very striking (Figure 10). Behind the nurses' station there was a white board with ward information and a large display showing photographs of the different staff on the unit, including the therapy dog. Above the nurses' station was large lettering welcoming people to the unit.

Figure 10 Examples of some of the wall art

Upstairs, the space was organised differently. Along the main corridor there was a large meeting room in the centre (44 on the floorplan) with therapy offices and small treatment rooms on one side, and kitchens, a staff common room and staff toilets/changing areas on the other. At the end of this corridor there was a large therapy gym (55 on the floorplan) with a small office off the back that was shared between the occupational therapists and physiotherapists, an assessment kitchen, and a small storage room. The gym was large with three wide plinths, a set of parallel bars, two different types of exercise bike, a treadmill, a large central table with two adjustable height tables, a set of assessment stairs and then a large amount of smaller manual handling/therapy items such as hoists, standing frames, gym balls, orthotic equipment, and wheelchairs (Figure 11). In addition to scheduled therapy sessions, the gym was open for all patients to access for their own independent practice from 8-5pm. If help was needed to set up equipment, for example to use one of the exercise bikes, then one of the therapists or assistants would find time between other patients. At times, a small number of patients would be practising independently, but this was more the exception than the rule.

Figure 11 Images of the therapy gym showing elements of the equipment available

Immediately outside the building on the lower level was the garden, which all patients and their visitors could use as often as they wished. This comprised a paved patio area with raised beds and a seating area with temporary awnings for cover in hot weather. Next to the patio was a sensory garden and a slope leading up to a covered seating area (Figure 12). The different spaces meant that the gardens were never crowded and patients could find quiet areas away from others to be with their visitors. As with the other communal areas, at times the garden was used by some patients but it was viewed more from the inside by patients in their rooms than outside being in it.

Within the wider grounds there were several car parking areas as the rehabilitation unit was most accessible by car, being a 10-15 minute walk from the centre of the village, which was served only intermittently by buses during the day.

Figure 12 Images of the gardens surrounding the rehabilitation unit

6.1.2 Rehabilitation Unit – The staff

The ward staff comprised people from a range of disciplines, some permanently employed and some bank or temporary staff. In total there were 15 nurses (13 FTE) from bands 4-8a and 13 healthcare assistants (12.5 FTE), plus associated staff including a ward clerk and housekeeper.

The daily ward management was provided by senior and junior sisters, who worked alongside the nurses, nurse practitioners and healthcare assistants. These staff were based downstairs on the ward, going upstairs mainly to use the staff common room. Many of the nurses had worked at the rehabilitation unit or at other sites in the region for many years, with depth of experience and stability provided at different levels. Regular shortages of permanently employed nurses and/or healthcare assistants, meant that bank or agency staff were often needed. Some of these staff had also worked on the unit for several years.

Other key ward staff included the ward clerk, the housekeeper, the cleaners, and the catering staff. The latter two groups were provided by a contracted company but many had worked at the unit for a long time. The housekeeper's role was to provide patient-focused care and interaction, including managing meal choices, providing breakfast and drinks, and attending to general patient and visitor well-being. A number of both the cleaning and catering staff also became known to the patients and their visitors, and so contributed to their general experience of the rehabilitation unit. The lead caterer knew about diets and food textures/consistencies and what patients could and could not eat. Preparing and serving food in the best way possible was clearly important to this person, as was the patients' enjoyment of what they were eating, with special orders being made for some patients in order to give greater variety and interest to an otherwise limited diet.

Alongside the ward staff were physiotherapists, occupational therapists, and speech and language therapists from bands 5-7 (FTE 7.7), therapy assistants (FTE 2.6), psychologists (FTE 1.6), dietitians (FTE 0.2), social workers (FTE 0.6) and a therapy dog and his handler.

These staff were predominantly based upstairs and would go downstairs to see patients and for occasional meetings. Numbers varied somewhat based on recruitment, maternity, and sick leave but all therapy disciplines were represented. Within these teams there were also individuals who had been within the wider neurology services and/or had worked at the rehabilitation unit for a number of years, again providing stability and experience. The senior leadership team had representatives from psychology, nursing, and the therapy disciplines.

Medical cover was provided by a local GP, who visited on week-day mornings which included the weekly multidisciplinary meeting, and then on an *ad hoc* basis if needed. If a patient's medical status deteriorated such that they needed more supportive care, they were transferred back to the acute Trust.

In addition to the clinical staff, there were also the unit administrators and an active charity group who provided both financial and volunteer services. Finally, there was a therapy dog and his handler, who visited weekly and was incorporated into the therapy sessions of a number of identified patients.

In line with the aim of phase 1, of gaining a greater sense of the setting, day-to-day tempo, and the activities of the people within the rehabilitation unit, conversations/ small group discussions were held with a wide range of staff from across the disciplines. The understanding gained from these was used alongside field notes derived from the observation to interpret the voices of the patient participants. As patient learning over time was the phenomenon of interest, it was considered that their voices were the most important to represent through quotations in the following findings chapters. Although staff discussions were all transcribed, quotations from them have been included only where they serve to add insight to the findings on patient learning.

Reflection on the rehabilitation unit

As an outsider entering the rehabilitation unit, the sense gained was of a well-equipped and well-maintained physical space, with kind, open and welcoming staff who worked hard on behalf of the patients and their visitors. It was a place that the staff felt proud of and where visible distress was shown when patient and staff wellbeing was compromised. There was strong and respected leadership, and a commitment towards improvement, with discussion at all levels of staff about how things could be enhanced both for the patients and the staff. The atmosphere was relaxed and open, with long visiting hours and the freedom for patients to go where they wanted, on or off site, when they wanted – be that for a few hours, overnight or extended weekend leave. With few exceptions, patients and their visitors spoke very warmly of the place and the opportunities it afforded to them. Although they did not want the stroke and therefore in essence did not want to be there, by the end not all were sure that they fully wanted to leave.

A structural feature that shaped the day-to-day practice on the unit was the divide between the ward downstairs and the gym/therapy areas upstairs. This separated ward staff from therapy staff and ward-based living from therapy sessions. The staff more than the patients felt that there were limitations resulting from this, and consideration was given by them to try to bring both aspects together more. The visibility of each to the other was limited though – especially of the therapy areas to the ward staff. Despite there being an open invitation for ward staff to accompany patients to the gym, the ward staff felt that time did not allow for this. They were also not quite sure how well their presence would be received. A more personal and individual invitation, indicating specific value, might have empowered the ward staff rather more than the blanket invitation that was in place.

At a surface level, the overriding impression was of a standalone rehabilitation unit that fulfilled many of the aspects that would constitute an enriched therapeutic environment. There was space, equipment and staff to enable physical activity, other patients to enable social activity, and leisure-based pursuits for cognitive activity. What struck me most was that even with all of these, most patients chose to spend much of their time inactive in their rooms. They enjoyed coming off the ward and doing the activities that they did in the gym, but these did not translate to activity on the ward. Alongside other aspects, the following chapters will explore this paradox of the unit seeming to offer so much to enable practice but the levels of activity from the patients resembling those of people with few, rather than many, opportunities.

Despite this, stepping outside this clinician-based conundrum, what is key to note is that the unit was in many other ways extremely enriching for the patients and their families. As will be explored, it offered them other aspects that were very important for their wellbeing.

6.1.3 Home

Home was unique to each person, but for all comprised their own property, or that of a family member, in one of the towns/villages within referral distance of the rehabilitation unit. This could be anything from within the village itself to 20-30 miles away.

Chapter 7 Findings II: What the patient participants brought to their learning and its influence on their sense making

Exploring patient learning over time and in a situated context, the aim of the ethnography was to address the limited understanding about patient learning that takes place in a rehabilitation setting, in the short to medium period, post stroke. The objectives were to explore: (1) what the patients perceived that they learned and how they made sense of this learning; (2) what it was like to learn and be a learner in this early to late subacute rehabilitation period post stroke; (3) where and how this learning occurred; and (4) what factors shaped the level and direction of the learning effort.

Within this chapter the patient participants will first be introduced. Detail will then be given in respect to what knowledge and understanding they started their learning with and, from this, what beliefs, expectations and wants they developed and held. Subsequent chapters will build from this foundation, exploring how the participants' conceptions and misconceptions shaped how they made sense of each stage as they progressed through the early-middle stages of learning post stroke.

Fourteen patients were recruited – twelve from the inpatient unit and two from the outpatient upper limb group. Eleven were male and three female, and they ranged in age from 49 to 88 years. All were white British, which broadly reflected the demographics of the region.

Seven spouses (all wives) were also involved in the data collection as they were present for some, or all, of the formal conversations. They therefore formed patient-spouse dyads, and reflected that for these seven patient participants, their wives were very much part of their daily living and therefore part of their rehabilitation. Recovery from stroke was something that they were working towards together. Despite the inclusion of the seven wives, the findings primarily reflect the patients' perspective of learning that takes place in a rehabilitation context post stroke. It does not present an in-depth exploration of the learning undertaken by spouses as individuals away from their partners. Only twice did the wives speak separately and this was by chance rather than planned. When transcribing, the comments were noted to have come from either the patient or spouse but then the data were analysed together. Although there were some subtle differences of opinion about small matters, they spoke with one voice and the wives at all times deferred to their husband for their opinion, reflecting that they felt that the work was about the patient participants and not them.

The section below gives a summary of the patient participants. Pseudonyms have been used.

- **Adam**, 53, was five months post ischaemic stroke. Although he had recovered well through his lower limbs and was walking outdoors independently, he remained with severe left upper limb impairment. He was recruited into the research from the outpatient upper limb class which he was attending for his second round of six sessions. Adam had returned part time to the office-based job that he was doing before his stroke and had just started to drive an adapted car. This gave him independence that he greatly valued. He was very keen to try to gain greater function through his upper limb and struggled to understand why his leg had recovered well and not his arm. Overall, Adam, was frustrated by his outcome.

- **Anne**, 78, was 2 weeks post ischaemic stroke when recruited on her arrival to the rehabilitation unit. She had had her stroke at home and had been found on the floor by her milkman. She presented with left sided weakness that was equal through her left upper and lower limb, as well as quite marked expressive dysphasia. She lived alone in her old family house and returned there, independently mobile but with some adaptations, after her six weeks in the rehabilitation unit. Her hopes were to continue to build strength such that she could resume her activities in her local community and church. She did not want to be a burden to her daughter.

- **Gordon**, 78, was nine weeks post his ischaemic stroke when recruited from the outpatient upper limb group. He had originally been approached to participate in the research when on the rehabilitation unit but declined. He then opted to take part when approached again as part of the outpatient upper limb group. He lived at home with his wife who was very supportive of his rehabilitation. They wanted to be helped to progress their exercises so that Gordon could gain greater function and possibly return to driving. Gordon had ongoing right upper limb weakness, and was very frustrated with his outcome and the consequences of his stroke.

- **Jim**, 75, was eight weeks post ischaemic stroke and was recruited towards the end of his stay on the rehabilitation unit. He had progressed well with his mobility such that he could mobilise with confidence indoors and out. He was though extremely frustrated by his limited upper limb function, presenting with a stiff and painful left upper limb/shoulder. Prior to his stroke, he had been very active as a volunteer in a local outdoor museum where he did a lot of the maintenance work. He was extremely keen to gain greater upper limb function so that he could return to this work.

- **Liz**, 60, was seven weeks post her ischaemic stroke which was secondary to endocarditis. She was recruited on admission to the rehabilitation unit. She had been working for several weeks, gradually feeling less and less well until she collapsed and was diagnosed with her heart condition. She had spent a number of weeks on the cardiac and general medical wards at the acute trust but did not spend any time on the acute stroke wards. On transfer to the rehabilitation unit, she was functioning at a high level, being mostly limited by reduced endurance and higher-level balance. She returned home after a short stay in the rehabilitation unit, with the aim of building up function in the community. She was overall quite pleased with her outcome.

- **Martin**, 62, was six weeks post ischaemic stroke and was recruited on admission to the rehabilitation unit. He had sustained his ischaemic stroke early one morning when staying with his wife at her daughter's house. Their home and business were about 80 miles away. He presented with a marked deficit throughout his left side with, over time, more recovery in his lower limb than upper limb. He had had a long and frustrating stay in the acute setting, waiting for a scan. For this, he needed to be able to take a small number of steps to access the scanner. He had been desperate to get to the rehabilitation unit and very much enjoyed his time there. Martin went home when discharged, mobile with a quad stick but still with marked upper limb weakness and associated shoulder and wrist pain. He had made the decision to give up his business and focus his time on his recovery.

- **Paul**, 64, was nine weeks post his ischaemic stroke and was recruited towards the end of his stay on the rehabilitation unit. He had had two previous ischaemic strokes from which, on both occasions, he had recovered quickly and completely. He was taken by surprise that the outcome was not the same this time. His main deficit was marked sensory loss in his left upper limb, with associated limited shoulder movement and pain. He lived with one son and had been working in home maintenance prior to his stroke. His ongoing upper limb impairments caused him much frustration and distress as he was extremely keen to return to work with no prior intention of stopping at this stage of his life. By his final conversation, he wanted to still hope that there was something he could do to gain more recovery, but he was not certain. This left him frustrated, confused and sad.

- **Rachel**, 88, was three weeks post ischaemic stroke and was recruited on her arrival to the rehabilitation unit. She reported never really being unwell prior to having her ischaemic stroke. This left her with fairly mild right sided involvement. Especially through her lower limbs, it was hard to unpick stroke weakness from longstanding, but undiagnosed/managed, osteoarthritis in both knees. She was very keen to return home where she lived independently. Other than to attend her therapy sessions, she wanted to be left to the peace and quiet of her room.

- **Richard,** 80, was four weeks post ischaemic stroke and was recruited on arrival to the rehabilitation unit. He presented with the most marked impairment of all the patient participants. He had limited return in both his left upper limb and lower limb following his ischaemic stroke. His inpatient stay had been marked by high levels of fatigue and this persisted throughout much of his time on the rehabilitation unit. Because of this, his stay was extended by two weeks to enable him to catch up some time that had been lost. On discharge, he went home to adapted single level living – initially with 24hr care and then with carers twice daily to support him and his wife. He was the only one not to be able to mobilise on discharge and instead transferred with the Re-turn standing aid. Despite his marked deficits, he was one of the least frustrated, accepting his new lifestyle. His wife, who had been much involved throughout his rehabilitation stay, remained keen to know if he would be able to step as this would help with car transfers.

- **Roger**, 79, was five weeks post his ischaemic stroke and was recruited on his arrival to the rehabilitation unit. He presented with left sided weakness, more in his lower limb than upper limb. He had undergone thrombectomy at a different hospital before being transferred back to the acute setting where he spent a frustrating five weeks whilst they tried to work out the cause of a bowel issue. This long stay meant that by the time he got to the rehabilitation unit he was uncertain about his possible outcome. His over-riding goal was to regain enough activity to walk his dog. At the end of his stay, he went home to his wife and dog, mobile for short distances indoors with a three-wheeled walker.

- **Steve**, 50, was seven weeks post his ischaemic stroke that was secondary to a heart attack. He spent his seven weeks in the acute setting on various cardiac and general wards but not on either of the two stroke wards. He lived close to the rehabilitation unit, so his wife and daughter were able to visit in advance and report back to him about it. Owing to continued frustration, discharge home from the rehabilitation unit was earlier than initially planned with the aim of continuing to improve high level balance deficits at home. He continued with neuropsychology sessions as an outpatient. He was keen to return to full family life and work as much as, and as soon as, possible.

- **Stewart**, 82, was three weeks post haemorrhagic stroke and was recruited on his admission to the rehabilitation unit. His stroke had occurred one night when alone at home. He was able to alert his son who then called the emergency services. On arrival at the rehabilitation unit, he presented with marked right sided weakness and could not sit independently. Quite suddenly, this dramatically improved such that by the end of his six weeks stay, he was mobile with no aids and had no upper limb impairment. To the amazement of all, he was discharged home where he lived with his wife. He had occupational therapy follow up to check his mobility in the community. During his inpatient stay he found the process of limited communication and waiting for staff very hard and frustrating.

- **Tim**, 49, was five weeks post ischaemic stroke and was recruited on admission to the rehabilitation unit. His stroke occurred at the same time as having a heart attack. He was visiting a different city when this occurred, so spent his first few weeks in a hospital there before returning to the acute setting within the region. After a week there, he was transferred to the rehabilitation unit. None of these transitions had gone well for him or his wife. Tim’s wife was very present throughout his stay on the rehabilitation unit, spending most of each day with him there. He presented with fairly marked left sided involvement – upper limb slightly more than lower limb. After an eight week stay on the rehabilitation unit, he went home to his wife and three older teenage children.

- **Tony**, 77, was three weeks post ischaemic stroke and was recruited on admission to the rehabilitation unit. He had also had two previous strokes which had led to some cognitive deficits but no residual physical loss. He could not understand why recovery was so different this time. Although he would engage in therapy sessions, this was with some reluctance and generally he wanted to stay in his room. He was frustrated overall by his stroke and what it had imposed on him, and his mood got lower over the length of his inpatient stay. He was discharged home but was unable to get in or out of his house because of steps at both the front and back. Within just a few days of being discharged, he was admitted to the acute setting again with a deep vein thrombosis.

The patient participants had varying length of stays in the different inpatient settings and were referred to slightly different ongoing services at point of discharge. These are detailed in Table 12.

Table 12 Participant length of stay and the nature of follow up on discharge

	Acute	Rehab	Follow up
Adam	3 weeks	3 weeks	Outpatient upper limb group
Anne	2 weeks	6 weeks	Community therapy
Gordon	4 weeks	6 weeks	Outpatient upper limb group
Jim	3 weeks	6 weeks	Outpatient upper limb group
Liz	7 weeks	3 weeks	Community therapy
Martin	5 weeks	6 weeks	Community therapy
Paul	3 weeks	6 weeks	Community therapy and upper limb group
Rachel	2 weeks	6 weeks	Community therapy
Richard	3 weeks	8 weeks	Community therapy
Roger	6 weeks	6 weeks	Outpatient therapy group
Steve	7 weeks	10 days	Neuropsychology follow up
Stewart	10 days	6 weeks	Community therapy
Tim	4 weeks	8 weeks	Community therapy and upper limb group
Tony	2 weeks	6 weeks	Community therapy

Across the 14 patient participants, 39 formal conversations were held. These ranged from just one with Steve, to six with Tim and his wife (Table 13). As mentioned in the methods, these conversations lasted from about 30 minutes to 90 minutes. In addition to these formal conversations, many informal conversations were held with the different patient participants and, when present, their wives and other family members.

Table 13 Number of formal conversations/group discussions per participant

	Rehab unit	**Home**	**Outpatient upper limb group**	**Comments**
Adam			1 group and 1 individual conversation	
Anne	3			
Gordon			1 individual conversation	With wife
Jim	1		1 group	
Liz	3			
Martin	3			2 with wife
Paul	1	2		
Rachel	2			
Richard	1	1		Both with wife
Roger	3	1		
Steve		1		With wife
Stewart	3	1		All with wife
Tim	4	2		All with wife
Tony	3			1 with wife

Summary of the learning context for the patient participants

The patient participants arrived at the position where they needed to learn because they had each had a stroke that was severe enough to necessitate inpatient rehabilitation before being discharged home. Entering the acute setting meant suddenly leaving home and the way of life that was familiar, and instead being somewhere new and unknown. Within their pre-stroke world, the participants all had a sense of agency and purpose, with a role and an identity that related to their home life, friendships and interests, and for some, their work. On entering the hospital settings, these roles were either partially or fully dispossessed, with a resulting curtailment of self. Although the stays in the inpatient units were fairly short, consisting of a number of weeks for all, this represented a longer time than they would normally have been away from home. Obviously, none of the participants nor their wider families wanted the stroke and, despite not explicitly asking “why me?”, none wanted to be in the learning situation that they were in.

Although some of the participants overlapped in their time on the rehabilitation unit, many did not. Nevertheless, there was an overriding consistency of message – almost without exception the participants said the same things, using almost the same words and turns of phrase. In the findings presented in this and subsequent chapters, quotations have been used to illustrate the points made. These have been drawn from across patient participants and their respective spouses. Because of the strong consistency of message, in many instances, the quotations were selected because they most clearly expressed the sentiments of a number, or all, of the group.

7.1 Post stroke learning is new and unfamiliar

The first finding about learning in neurorehabilitation is that the patients and their family members were not purely passive recipients of what they encountered in the early to late subacute rehabilitation period post stroke. Instead, they tried to understand and make sense of what they were experiencing. This complex sense making was initially based on the understanding that each participant started with. In turn, this understanding was based on a combination of their: (1) prior experience of learning and knowledge and experience of health, ill health and getting better; (2)

knowledge of stroke and what had happened/was happening to them; (3) knowledge of their impairments and stroke recovery; and (4) knowledge of rehabilitation. The next part of this chapter will describe these different understandings the participants brought to their rehabilitation. These will be categorised as their knowns and their unknowns, to reflect what they were able to express with some reasonable confidence and what aspects they could not. The sections that follow then detail the beliefs, expectations/hopes, and wants/perceived needs they developed. The last section introduces how their conceptions and misconceptions then shaped the sense making of their experience.

7.1.1 Prior knowledge and understanding – knowns and unknowns

As described above, this section is structured around the following four subsections (Figure 13):

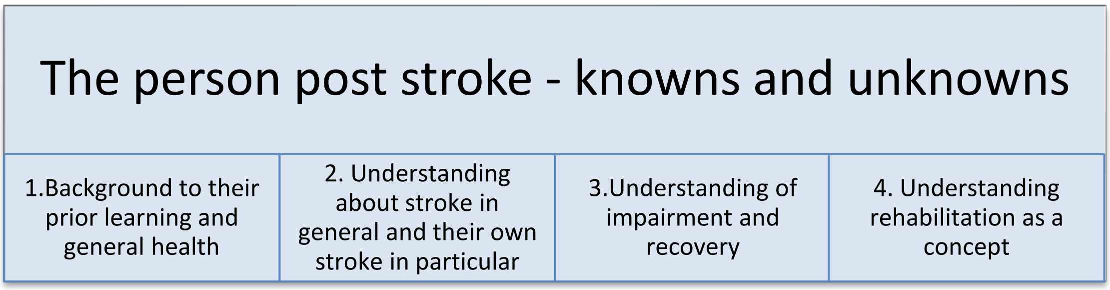


Figure 13 Stage 1 of the foundation to patient learning/sense making

1. Background to their prior learning and general health

All the participants had completed at least secondary school education and, broadly speaking, had all had prior success with either formal or informal learning. They expressed the sentiment that, in life, attainment of success and/or avoidance of failure was due largely to one’s own effort. Putting in the work would result in the desired end outcome. All were either in work at the time of their stroke or had been in work until retirement. They all talked with some pride about their life pre-stroke and how their various roles of employment, leisure, and family status constituted who they were as people. All raised examples of achievements where they had worked hard and that they spoke warmly of. Except for Rachel and Tony who were more reluctant, the patient participants had a fairly strong disposition towards the learning that was involved in their recovery. Although they did not really want to do the learning, most demonstrated an inner motivation to strive to move forward: "*I've learnt that I can't have, I can't be myself, that I've got to work hard if I want to get back to where I was before, it depresses me a bit, I've got to work hard at my age, but there you go, if you want something you work hard at it" (Anne).*

Prior to their stroke, none of the patients lived with a significant life limiting comorbid condition. A number talked about how they had never been appreciably unwell or in hospital before. Rachel, Steve, Tim, and Adam, in particular, repeatedly stated that they had had no meaningful contact with healthcare until this point and that being a patient, and recovering from anything, was new to them.

> ***And have you ever done exercises before in your life like this, have they ever given you exercises?***
> *No, I've never had things to do before, that's why it's all hitting me so hard … I've always been generally fit and able to do everything and anything and suddenly it hits you and you can't, or your body won't, that's more like it … but as I said before, because it's my first experience of everything for me … (Rachel, who was experiencing her first contact with healthcare, other than childbirth)*

Some of the others had had episodes of healthcare for more minor conditions but these had been short term and they recovered. The only participants with more significant previous health conditions were: Richard who had diabetes; Gordon, who had atrial fibrillation (AF); Anne, who had arthritis and AF; Rachel, who also had arthritis (previously undiagnosed); Roger, who had stable epilepsy; and Tony, who had had received treatment for cancer. No one showed deep understanding about their other health conditions and when they talked about medications they were on pre-stroke, this was largely with a lack of understanding about what they took and why. Importantly, in the context of making sense of stroke, the collective experience across this group of patient participants, was that mostly they had got better from being unwell and conditions that they lived with were not markedly life limiting. The concept of living with a body that was different and not as able was an unknown.

2. Understanding about stroke in general and their own stroke in particular

Understanding of stroke was limited across the group. Barring Paul and Tony who had had previous strokes, Roger who had lost an adult son to an intracerebral bleed (not equated to being like a stroke) and Liz whose father, she thought, had had a series of strokes, there was very little other first-hand knowledge or experience about stroke itself. The suddenness of stroke took them by surprise, coming as a *"bit of a bolt out of the blue"* (Tim's wife). As most of the group did not know anyone who had had a stroke, they were not able to draw upon an image or an understanding that they felt confident about. This was both in respect to the short, as well as the longer-term picture. They all stated that everything was new, even Paul and Tony, who had previously had strokes, reporting that they knew little: "*It's the first time I have ever had anything like this, ever, yeah it is totally new … I didn't know anyone personally who has had a stroke and gone through this, no-one, it's just totally new" (Paul).*

The participants were largely not from a health background (just Martin worked in dental health and Stewart's wife was a retired mental health social worker) and articulated some very mixed understanding when discussing stroke in general and their stroke in particular. When asked to elaborate on what they knew, what the group shared was often muddled about what they had experienced between clots and bleeds, how stroke had led to the problems they now faced, and, for some, the possible causes. With the over-riding feeling of everything being new, the most common phrase repeated by nearly all and stated often was 'I don't know'. These quotations from Liz and Martin represent many other similar ones that could have been drawn from any of the participants.

> ***So, you think your stroke was a bleed type stroke rather than a clot type stroke?***
> *I don't know, I'm guessing. The fact that they want to stop clots, I mean I did have a clot in my lungs … but I don't know where, I don't know, I'm guessing there was a bleed but there might have been a clot, I don't know, maybe someone told me and I've forgotten, I don't remember. (Liz, whose stroke was secondary to endocarditis and who had a number of weeks of regular contact with her cardiologist in the acute trust)*

> ***I was wondering what you understood about what happened inside your body with the stroke?***
> *Well, as I understand it was a clot happened, if you have a heart attack sometimes it sends a hardened bit of clot, of blood, which then gets stuck in some part of the vein going to the heart or it can even be after the heart can't it, um can it, after the heart? … So, in other places and the worst place it can go is to your brain, so perhaps that's where, and of course, with the bleed in the brain, I might have got a clot as well but I'm not sure about it … and if the brain is starved of that oxygen it dies which is predominantly on your left, it doesn't matter if you're left or right handed, it will always go to the left won't it? (Martin, speaking about six weeks post stroke)*

Most of the group felt that they had probably been told about stroke when in the acute setting, but no one could remember much about this. They also thought that they had probably been given written information, but no one reported that they had engaged meaningfully with this in any way or wanted more of it. In contrast to the patient participants, their spouses were able to elaborate a bit more on what stroke was and reported that they had read up to learn more. Their interest was more focused around recovery and looking forward rather than back at what stroke was.

> ***Were you given any leaflets at all … did they give you anything?***
> *Stewart: [pause] I'm not sure, we might have collected some stuff, but we've so much paper that lots of it's been lost.*
> *Stewart's wife: Certainly, we had access to them, well displayed in the ward; I think I'm learning something out of this that … I think there is an assumption that having said it once you would be able to retain it so may be people should have said it, reiterated it to you each day.*

For those who did look back, this mostly related to why the stroke had occurred and what could be changed to reduce the risk of it happening again. This aspect of risk reduction baffled and distressed a number of participants. Gordon was an example of a small number who felt that they had been leading reasonably healthy lives prior to their stroke and were very anxious about what they could do differently as they wanted to avoid being in the acute setting again: "*One of the things that I joke about, although it's not a joke really, all my life I've been fairly slim, don't drink, don't smoke, don't overeat do we and I get a stroke, so what's the point? What is the point? I may as well have eaten and drunk."*

Further knowledge about what stroke was and its mechanisms was not wanted by most. This was especially so for Roger, who said that he did not want to look back as what was done was done and there was nothing to be gained from revisiting it: "*Quite honestly, you don't want to read about it, well I mean it is something which has happened, I wished it hadn't happened, so why be macabre and dwell on it and read all about what could have gone wrong, and you could have ended up there and everywhere, no, you are where you are now, so why dwell on it."* Others did not feel ready to know. Richard and his wife, for example, said they did not feel strong enough in the early weeks to ask or learn anything. The one person who differed in this respect was Adam. Several months on from his stroke, he was still desperately wanting what he called a Dummy's guide to stroke so that he could make greater sense of what had happened to him. At least in the early stages, the group mostly reported wanting to read and hear positive things, with some interest shown in hearing about others who had also experienced stroke, such as the television presenter, Andrew Marr.

3. Understanding of impairment and recovery

The loss of agency that happened in the moment of their stroke took the patients from, as they described it, feeling useful, having roles, and having personal value, to feeling vulnerable, frustrated, and embarrassed about being dependent on others. They shared how they could never have believed that they would be in the position that they were in, needing, for example, to learn to stand and walk again. As Stewart's wife said, one of the hardest learnings that he had to do was to be dependent and understand what this truly meant: "*It must be awful, just awful to have no power to influence the situation, being dependent is a horrible thing to have to learn for an adult."* The realisation of what they could not do was distressing and caused emotional struggle.

> *You feel so useless, you can't believe how useless you feel after having to do everything yourself, you know, I've lived on my own for 16 years, and um, silly little things that you can't do; it just brings you down; that's the worst bit about it, it really is a terrible feeling you can't do things for yourself anymore [long pause]. (Paul)*

With so little knowledge about stroke across the group, there was also limited understanding of recovery. Some, such as Richard and his wife, had such little knowledge about stroke that they did not even appreciate that people could recover. Others assumed, at least in the very early stages, that they would recover but did not know how this might occur. From conversations largely with their therapists, they talked about forming new pathways and connections between the brain and the muscles. They also demonstrated some understanding of practice, using phrases such as ‘use it or lose it’.

> ***Have they talked to you at all about recovery and timelines of recovery?***
> *No, well not really, they say it takes a long time, someone said yesterday, a nurse … but that you can, if you have built up muscle, they have muscle memory, I knew about anyway, but if you’ve lost, the thing is I don’t know, I really don’t, I think I’ve had a bleed in the brain, [tutting noise], that’s the thing, I don’t really know, so that’s gone forever right, you have to relearn pathways is that right? (Liz)*

When asked if they knew what they could do to influence their recovery, the patient participants talked uncertainly about sleep and eating good food to give them strength, as well as about perseverance and determination. Despite using phrases like ‘use it or lose it’, only a few mentioned with any assurance anything that equated to intensity or repetition of practice. Mostly they talked about having ‘no idea’ and terms related to plasticity sat alongside the belief that improvement would occur just as a result of time. Linking outcome to action was therefore co-expressed with links between outcome and situation, and recovery occurring by dint of time and place as much as by actions taken.

4. Understanding rehabilitation as a concept

Most of the patient participants did not know about rehabilitation as an overall concept or about any of the elements, such as occupational therapy or physiotherapy, within it. Some talked broadly about knowing about recovering from injury, but no one had experience of anything rehabilitative that they could draw upon. Although some alluded to schooling, and Stewart’s wife to child development, when asked about the learning that they were doing, no one felt that this was like anything that they had done before. They understood that the rehabilitation unit was a place where one probably would work hard and do exercises, but no one was at all certain about this. Only Liz, Steve, Tim, and Jim, knew of the specific rehabilitation unit prior to their admission, and a number expressed surprise that such a place, where impairment was not necessarily removed but was modified, even existed. They expressed that, prior to their arrival, they had no proper knowledge of what the place was like, what it comprised or where it was. Only Steve's family who lived very locally, were able to visit prior to his transfer. This helped reassure them, and then him, that he was going to the right place. Having been extremely frustrated in the acute setting, he could not get to the unit quickly enough.

> ***And the concept of rehabilitation, was that something, when they said that you were going to rehab … is that something that you have awareness of from before at all?***
> *I had no idea that there was a process whereby people would be taken and their handicap, not removed perhaps, but modified as much as possible through a programme; I had hoped there was in my own mind, but I didn't see any evidence of it at [the acute setting]. (Stewart)*

Summary of understanding – knowns & unknowns

In summary, at the early-middle stage post stroke, the knowns and unknowns expressed by the group were fairly consistent. Their knowns, of which they were confident and clear about, were that they had had a stroke from which they hoped to recover. They knew what their everyday life and future plans had been before their stroke, as well as what their purpose and role in life had been, as someone who was independent and gave to others rather than being in receipt of help and support themselves. Their unknowns were related to stroke itself, its pathology and presentation both in general and specifically in relation to them. The how, why, what, when, drivers, and process of recovery; and the how, why, what, when, drivers, and process of rehabilitation were all largely unknown. Indeed, from what they shared, in the very early stages, a number of the patient participants had not realised that they would need any process of rehabilitation, that they would need to work in any special way to regain function, and that any of this might be for the longer term. Most had no clear picture that they could draw upon of the long-term outcome – both what it would look like for them, and how long anything might take. Not having been in this position before (even those with previous stroke), a lot of what they expressed was that they just did not know. Especially in the early stage, many had a confused and uncertain picture of what they were rehabilitating towards. They thought their future would have some limitations but that it would be largely similar to what they had before their stroke.

7.1.2 Beliefs, hopes and expectations for recovery

The second finding in this section was that from their position of understanding with its knowns and unknowns, the patients and their families all developed and held beliefs – beliefs about what stroke was and what had happened, beliefs about what recovery and rehabilitation meant and involved, and beliefs about their futures. It was on these beliefs that they then formed expectations and/or hopes both about their outcome and future, and what they felt they needed and wanted their rehabilitation to look like and comprise. However, because these were developed from limited foundational knowledge and understanding, what they ended up with were some conceptions but also many misconceptions (Figure 14).

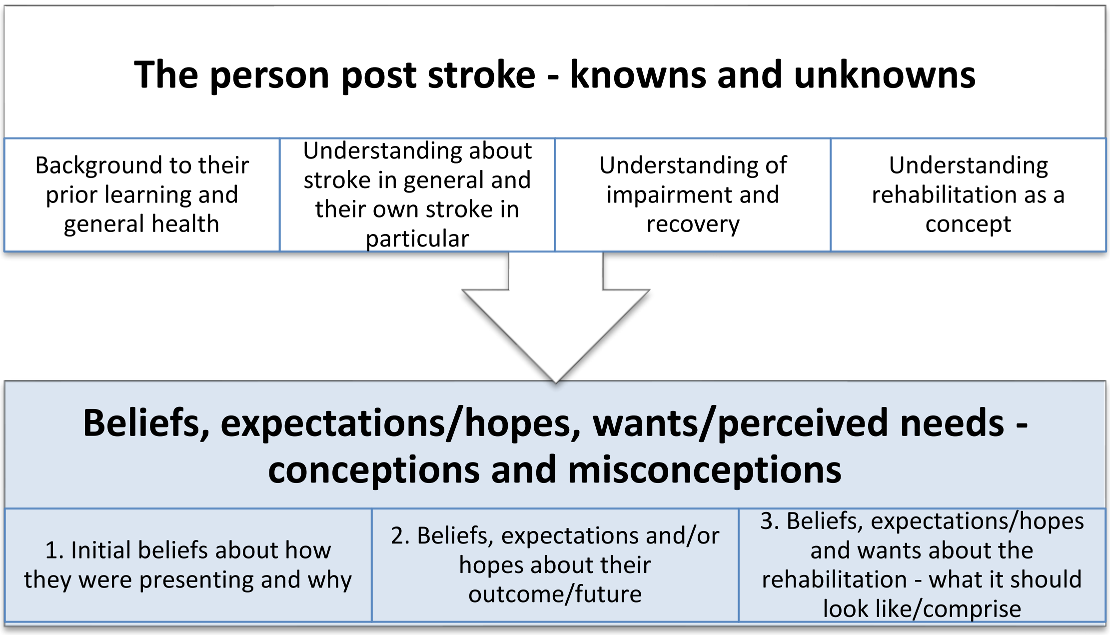


Figure 14 Stage 2 of the foundation to patient learning/sense making

1. Initial beliefs about how they were presenting and why

All the patient participants believed that they were weak and that their muscles did not work. Consequently, they believed that they needed to get stronger. While some also reported loss of balance, pain, and/or sensory loss, it was weakness/lack of strength that was the most reported explanation for their functional loss. This was so whether it was actually the case or not. By the time they got to the rehabilitation unit, a number, such as Martin who had spent a very frustrating five weeks in the acute setting, believed that this weakness resulted, at least in part, from the bedrest and lack of activity there rather than from his stroke alone: "*I said … well with a lot of help, I could probably start to walk again, 'cause it gave me an insight into what I could do, and I couldn't stand being in bed all day, which is why, I think my muscle waste was so bad, if I could have had that built up … you know to build my muscle waste up."* Some, such as Anne, Rachel, and Roger, also made the association between current weakness and pre-existing health conditions/status, such as arthritis or just old age. Others linked their weakness to fatigue, which was an overwhelming issue for a few. Again, the fatigue was believed to be related not so much to the actual stroke but to the effort that the participants felt that they expended in rehabilitation and, for some, including Tim, Richard and Martin, the medications that they were on.

2. Beliefs, expectations and/or hopes about their outcome/future

Prior to their stroke, most of the group believed that life would carry on as it was, not anticipating that this would be interrupted or stopped in any way at that stage. Only Roger and Stewart, and to an extent Anne, reported that they believed that, because of their advancing age, ill health would occur for them at some stage. However, none had thought that this would be a stroke.

With such little knowledge of stroke, when they reflected back to their early days in the acute setting, a number reported expecting that, as with other episodes of ill-health, they would get better quite quickly. They had no notion, and no reason to believe, that this might be different post stroke. Even Paul and Tony, who had had previous strokes from which they had recovered, believed initially that this would be the case again: *"I didn't realise, because the first stroke the arm came back quite quickly, and I didn't realise how lucky I was on that first one"* (Paul). It was really only Martin and Tim, and Stewart's and Richard's wives, who expressed the belief that life would be different going forward and that the outcome was uncertain. This was the group who had been most critically unwell at the start and had had the most severe form of stroke.

By the time they reached the rehabilitation unit, with no one recollecting having had any conversations about their longer-term outcome, most of the patient participants could not visualise their future in any certain way. The exceptions were Steve and Jim, who were both very determined, and strongly believed and expected, that they would return to their pre-stroke life. At the other end of the expectation-hope continuum, were Stewart's and Richard's wives, and Tim and his wife, who saw their futures based much more on fragile hopes of something like their pre-stroke life rather than any clear expectations. The rest were somewhere in between.

A number of the patient participants remembered being told that no one could know what their particular outcome would be as everyone was very different: "*And I'm not being horrible but it's a bit like asking will my arm come back, because that's the last thing that's not functioning properly and everyone just says oh, we don't know, it might do, and that's a double-edged sword because some people do and some people don't, but you're thinking, is it possible" (Adam).* With this uncertainty, it was not uncommon for the participants to co-express thoughts and beliefs about both not getting fully better and getting fully better. They found themselves therefore in the mixed position of believing and not believing, expecting and not expecting, hoping and not hoping. This was demonstrated most clearly by Martin who talked on the one hand about not expecting to get fully better, but on the other about having the lightbulb or lightning bolt moment that he hoped would occur. This left him, like a number of others, questioning themselves and their futures.

> *You learn a lot about yourself yeah, you learn the inward bit of it as well, what you, you know all the things you think you can, can I, will I be able to do this, will I be able to do that, there's a real fear that comes over you that you think how am I going to be able to achieve that again, how am I going*

> *to be able to do that, that's the thing, I think it's a real fear, that's what I was feeling at first, real fear. (Martin)*

3. Beliefs, expectations/hopes and wants/perceived needs about rehabilitation – what it should look like/comprise

By the time that they arrived at the rehabilitation unit, it was clearer for most that recovery was not going to happen spontaneously and suddenly. To achieve their expected or hoped for end outcome, therefore, the participants believed strongly that they needed rehabilitation and that this needed to be provided on a regular basis: *"Well, I'm no therapist but I realised that if therapy, or whatever it was, if therapy consisted of a number of physical activities that needed to be repeated, it would have to be done on a timetable"* (Stewart). Having never done rehabilitation before, the participants did not know what it was and what it involved. Despite this, they expected to be active doing things that looked and felt like exercise, that these would be done in a structured and systematic way, and that people would be kind to them and help them to recover. They also wanted this supported rehabilitation to keep going until the outcome that they envisaged had been achieved. This end outcome varied across the group, but for most it comprised being stronger, standing and walking, and using their affected arm so that they could get back to as many aspects of prior life as possible.

> **And did you have any particular expectations from what she said?**
> Tim: I thought I'd be tap dancing by now [laughter from all], she oversold it a bit.
> Tim's wife: We wouldn't be married if you were, no, well the expectation was that we could see that we needed rehab, we needed physio in order to make progress.

Summary of beliefs, expectations, hopes and wants – conceptions and misconceptions

With such little first-hand experience of stroke, most of the participants had no clear image of what life for someone with stroke might look like in either the short or long term. They were thus trying to recover into a relative unknown with a mixture of part conceptions and part misconceptions to build from. With this muddled and uncertain picture, they had very little visually that they could draw upon to work towards – other than being like they were before. While the most severely affected believed they were unlikely to recover fully, the prevailing belief was that, as with all their other (limited) experiences of ill health, they would get better and be much as they were pre-stroke. Most of the patient participants sat somewhere in the middle of a continuum from those who held strong expectations for recovery, at one end, to those who had much more uncertain hopes, at the other. The participants generally equated effort with outcome and so their expectation was of putting the work in to achieve the end output that they wanted. They all expected/wanted to be helped by people who they felt had greater expertise than them, and they expected/wanted this to be regular and systematic and to continue until their outcome was reached. It was with this background and through these conceptions and misconceptions that they then travelled along the stroke pathway, trying to make sense of what they experienced.

7.1.3 The sense making of the participants in respect to what they experienced and learnt during their recovery/rehabilitation

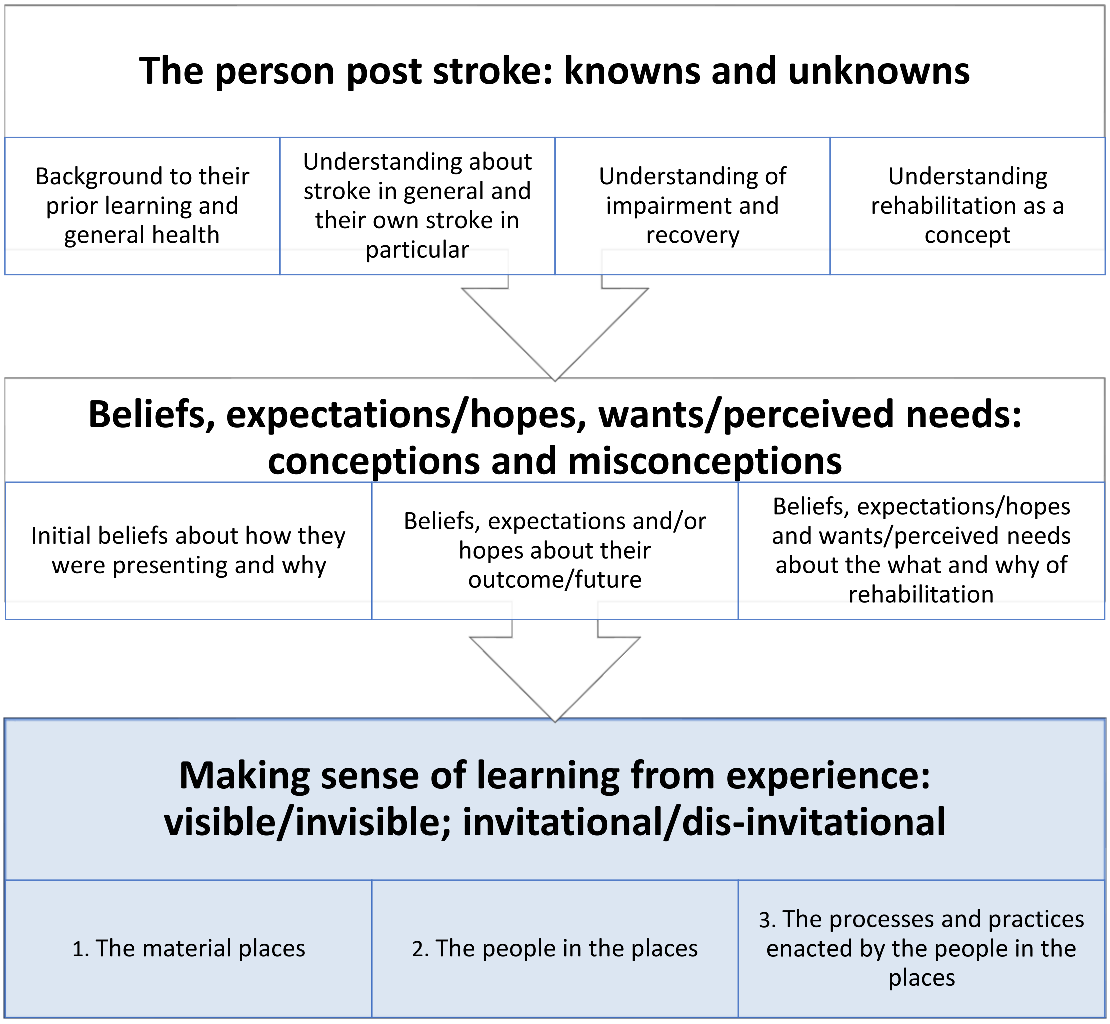


Figure 15 Stage 3 of the foundation to patient learning/sense making

The final finding in this section was that the participants started their recovery with the understandings, beliefs, expectations, hopes and wants that they had in place, and it was on this basis that they tried to make sense of what they were experiencing and learning (Figure 15). This began in the acute setting and continued through their stay in the rehabilitation unit to home. As they encountered these places and situations that were new to them, what the participants brought with them influenced what they looked for and what they saw and did not see – i.e., what was visible and what was invisible to them. It then further influenced what they felt about what they saw and experienced – or failed to see and failed to experience. This was appraised as being either invitational, and therefore welcomed, wanted and helpful, or dis-invitational, and so not welcomed, wanted nor helpful. Invitations were when things felt right and made sense, and disinvitations were when things felt wrong and did not make sense.[2] These invitations/dis-invitations could be big or small and were sometimes enacted intentionally by the staff on the unit with the processes that they operated, and at other times unintentionally. Irrespective, they had an impact emotionally on the wellbeing of the patient participants and their families.

Although they were very much tied in with one another, this seeing, appraising, and learning about aspects either being invitational or dis-invitational, was directed towards: (1) the material places that the patient participants were in; (2) the people in those places, and then (3) the processes and practices that were being enacted, or not, by the people in the places (Figure 16).

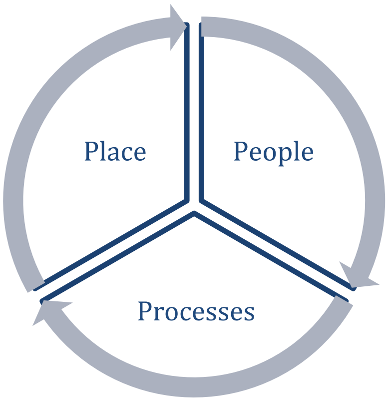


Figure 16 The interaction between the place, people and processes for participant sense making

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[2] The terms invitational and dis-invitational are used widely in the text. More detail will be offered in the discussion chapter, but to provide context at this stage, these terms have been drawn from the work of William Purkey and colleagues who introduced the term Invitational Education (1978). This approach is built on the premise that learning results from the messages that one receives and attends to and how these are interpreted. People are therefore less influenced by events *per se* than how they perceive them. Within the structure of invitational theory, five elements are recognised: care, trust, respect, optimism, and intentionality. The aim of these is to provide the teacher with a consistent stance so that they can fulfil their primary goal of summoning the learner into the learning. Through this, the learner can see themselves as able, valuable, and responsible.

To structure the remainder of the findings, the following three chapters relate firstly to the acute setting, then to the rehabilitation unit, and finally, to home. This chronological order of what the patient participants and their families experienced has been adopted because learning for them in the early to late subacute period post stroke was an evolving process that occurred through gradual steps of complex sense making. None of the steps can be seen in isolation. Instead, interpretation of the present and later stages is only possible in the light of earlier ones. Focus will be placed on what they saw and how invitational or otherwise they found this.

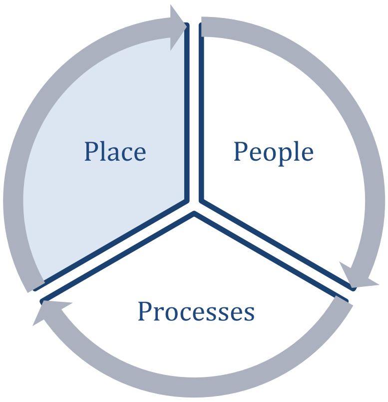
Within each of the chapters, the findings are presented first in relation to the participants' experiences and sense making of the material place, then of the people, and finally of the processes and practices. This structure has been adopted because, with complete consistency across the three different places of the stroke pathway, the participants felt that they were either in the right place with the right people who were doing the right things for their learning related to their recovery, or that they were in the wrong place with the wrong people (or no people) who were not doing the right things. The chapter on the rehabilitation unit is the largest section as this was where most of the fieldwork was conducted.

Chapter 8 Findings III: The Acute Hospital/Setting

Although the aim of this work was to explore learning in the early to later subacute stage post stroke, through discussion with the patient participants what became clear early on was how this learning was strongly shaped by what had been experienced in the acute setting. The two could not be separated and so this chapter presents their reflections on this time.

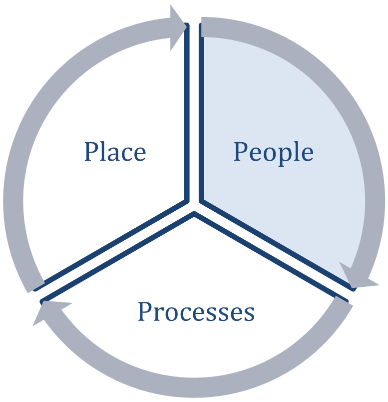
Once stabilised medically, the patient participants were transferred to the wards. Barring Liz and Steve who were transferred to cardiac wards, the rest moved from the emergency department to the stroke wards. From what they reported as they talked about the stroke event itself, for those who retained enough consciousness, their sense making and associated learning began at the point of their stroke occurring. It was with this background of already thinking about and trying to make sense of they were experiencing that their interpretation of the acute setting (the place), the people in the place, and the processes enacted by the people in the place began.

8.1 Sense making of the place



The patient participants saw and experienced two stroke wards in a standard district general hospital. They reported that both were busy, with bays of five to six patients who were regularly coming and going, and who were often quite unwell. This resulted in the wards being noisy, not restful, and therefore largely dis-invitational places to be. Because of both the busyness and the nature of the other patients, sleep was often difficult, with disrupted nights and, for some, episodes of frightening disorientation. All saw equipment that would be expected in a hospital, but only some remembered seeing a chair by their bedside to sit out in. Although they were not much enjoyed, from purely a material space perspective the wards largely looked and felt like what was expected to them as patients, and made sense in as much as they were like any standard hospital ward.

8.2 Sense making of the people



The people in the acute setting comprised mainly nurses and nursing assistants, who the participants saw, like the ward itself, as always being busy. For Stewart in particular, being told to wait for a few minutes only for the person to return a long while later was very frustrating and deeply dis-invitational. Many of the nurses were reported as being transient, with some being seen just once. Both of these aspects, the busyness and lack of continuity, left the participants feeling that they were largely not seen. Indeed, they were not sure that the staff even knew their names. Although a number of the participants were in the acute setting for several weeks, for most, relationships were not formed with the nursing staff.

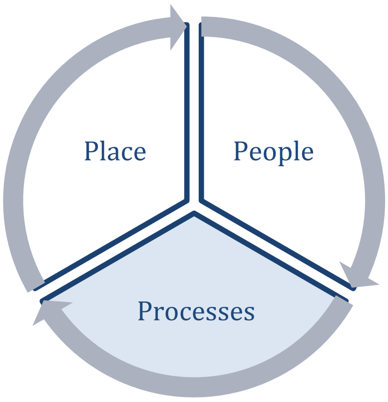
> ***And can you tell me about the nursing staff and what they encouraged you to do, what was their role when you were there at [acute setting]?***
> *I think it was just generally passive, to be frank, I mean they were not involved … I am trying to remember whether they used my first name or second name, I think that they did try and call me by name, but it wasn't always successful, at least to the extent that I can't remember. (Stewart)*

The participants saw and experienced the medical staff as enacting their role in ways that were broadly what they expected based upon previous encounters. In particular, some medical staff showed more interest in and commitment to communication than others.

> *One day he [the consultant] just walked in and he was almost backing away before he had even met Steve, and I thought hang on a minute, and luckily I am like I am because I wanted the best for Steve … we have a few questions, and it was like you hardly even looked at him, come back and [laughter], but I had to be prepared for that, there was quite a lot of, if you're gutsy enough to do it then you're ok, but I do worry about people who wouldn't have, they would have waited all morning for the consultant, one nurse said could I get in at half past eight one morning to see the consultant and we saw him at ten to twelve, and then it was fly by, hang on a minute [laughter] no, we've waited for this, and we want you to explain what going on, so when you push they'll explain, but it's not good that you have to push. (Steve's wife)*

With the hospital feeling so big and busy, the sense making from the participants was that general rather than personalised care was the only option for most of the staff. There was limited connection and, for most, no particular feeling of being nurtured or valued in any way. Patients were, though, fed, watered, and kept clean, and this was enacted in a broadly kind and caring way. As with the material place, although not remembered with any overt warmth and not what was wanted, the actions of the nursing and medical staff largely aligned to previous interactions with healthcare and healthcare staff. By the end of their stay on the wards, the participants had learned what the nursing and medical staff would offer – although this was not what was always hoped for, felt that they needed, or really desired.

8.3 Sense making of the processes and practices



What impacted most significantly on the participants was the lack of visibility of practices or processes being carried out to enable their recovery. This was different from what they believed, initially expected, and later on, just hoped that they would receive. Importantly for the participants, they reported that there was either no, or insufficient, therapy input, with most time being spent in bed doing nothing. The wards were felt to be places of passivity and not activity, with the participants talking about not being challenged, pushed, or even asked to do anything at all: *"I didn't even have a chair when I was first there, they did get me out after about 2 weeks … we were just lying in bed [laughter] and they gave you meals and they encouraged you to feed yourselves and things like that if you were able to but, they were under pressure, they didn't really tell us to do anything"* (Paul). It seemed to the patients that there was no structure to their recovery and no one in charge of organising it. Although they acknowledged that they were not expert in rehabilitation, the participants felt that spending long days in bed without a chair to sit out in and with no clear plan for therapy must be wrong and it was not what they believed, expected, or wanted, to be doing.

Although physiotherapy was provided for some, this was perceived to be ad hoc, often bed based and seemed to end almost as soon as it had begun. Conversely, being helped to stand by the therapists was hugely invitational and made sense, as it matched what they expected and wanted to be doing. This gave them a sense of what their expected and/or hoped for outcome might be. There was no certainty that it would be repeated, though, and with the feeling that they were dropping down the list with every new patient admitted, all the participants had the sense of the ever-growing likelihood of not being seen: "*There was no notion that they would come again tomorrow … and then this disturbed me because I realised that if I was going to make any progress then I was going to have a steady and systematic application" (Stewart).* Not having a routine and not knowing if the therapists would come back was profoundly dis-invitational and distressing.

> *Martin's wife: He was getting so frustrated.*
> *Martin: I was, wasn't I, because I said that with a little bit, well with a lot of help, I could probably start to walk again, 'cause it gave me an insight into what I could do, and I couldn't stand being in bed all day … They said they hadn't got the staff … you know … and then of course someone new comes in, so they had to concentrate on them and then you got further back in line.*

The patients reported that every day spent in bed felt like a day lost, a day when they were getting weaker, and a day further from having anything like the life that they had before and wanted to get back to. They talked about being trapped – not just physically by the effects of the stroke, but by equipment, such as the blood pressure cuff and bed rails, and by the absence of a chair by the bed or a wheelchair that they could use to go off the ward. They also felt psychologically trapped by the endless waiting for help, by not knowing if the therapists would ever come, and by the promise of a place in rehabilitation but with no confirmed date when this would be.

Weekends were especially hard as there was no prospect of therapy on those days. It was at these times that the situation was most distressing and when the participants really questioned what they were doing there and concluded that they would be better off at home. With every day spent in the acute setting, feelings of safety and support diminished and the sense of fear about their future grew. What the participants believed and expected should have been a period of regaining skills and function and moving forward, was anything but. Instead, they felt that they just existed, waiting indefinitely for whatever might come next. With the prospect of success fading and the certainty of failure growing, feelings of hopelessness followed. Expectations of recovery changed to mere hopes, before even these started to fade.

> *Oh, I had mood swings, I was feeling down, really down … I did have moods, some days I just didn't want to know … that's where the hospital let down, because I said look, I really don't think I'm right in the head at the moment, you know, mood swings and that, and three times I asked to see someone and still it never happened … I was a bit annoyed about that [pause], so … but I was pretty depressed at one time. (Paul)*

> *Martin's wife: and you were getting frustrated because you weren't getting enough physio, he gets very, and he really wants to get on.*
> *Martin: I didn't want to sit in bed, it's so soul destroying when you know that with a little bit of help you might be able to do, you know I wanted to take part in things to get myself better, I was just laying, I knew, you know I've lost quite a lot of muscle mass, you saw how jittery I was. (Martin and his wife)*

This deep sense of frustration was problematic not only for the patients but also for their families. Steve's, Martin's and Stewart's wives in particular reported that their husbands would call home repeatedly asking for someone to listen to them and act on their needs. When all else failed, the patients begged to be taken home and even worked out the bus routes so that, if no one came for them, they could get home themselves.

> *Martin's wife: Very frustrated and I could see it and there was one weekend.*
> *Martin: I actually text you one weekend, get me out of here.*
> *Martin's wife: he text me to say get me a wheelchair and take me out of here, I'm going to get the X or Y [numbers] bus, because he knew if he could get on the bus he could come to where I am … he could go home … weekends used to get to you because there was no physio, there was nothing and all they had to do was sit there all the time and that's what you were getting annoyed about and I could feel the build up from the Saturday and it was going into the Sunday and by Sunday night, you were just like up on the ceiling, you were just getting so fed up with them.*

This was exhausting for all. For some of the wives, having almost lost their husbands once from the stroke itself, the sense of fear was made worse by the knowledge that their husbands did not feel safe. Whereas for Stewart's and Steve's wives, the limited visiting times afforded much needed space when they could justifiably not offer the level of support that their husbands were looking for, others wished to be there to ensure that their relative did not come to any harm by, for example, having to wait for care or not receiving medication on time.

The invisibility of any planned curriculum of doing and the lack of perceived predictability and intensity of input profoundly affected the participants' reflections on outcome expectations. With each day spent on the ward, many of the group moved from anticipating a successful and full recovery to a growing sense of disappointment and the associated learning of failure. They saw an incongruence of goals: their desire was to get up and going but the aim on the ward seemed to be just to provide basic care and keep them safe until discharge. The lack of enabled effort, with only limited therapy, meant that they were not able to gauge their own ability and potential to recover. What the participants came to perceive was that the purpose of the acute setting was wrong and so there was no reason to be there. It seemed to them that the acute setting was a place to diagnose stroke but, beyond that, there was little curriculum for skill or knowledge content learning, and seemingly no planned curriculum of social or emotional learning (although this latter aspect was certainly occurring as their sense of well-being plummeted). Their appraisal of outcome, and thus learning, was that they had not achieved the activity or function that they expected or hoped for. By the end of their stay in the acute setting, they were uncertain about who they were, with previous roles no longer seeming possible, and a growing unease emerging about how they could again be the person they wanted, and expected, to be. While some patients managed to keep going, others lost hope and any drive forwards. Feeling defeated, they withdrew and could not push anymore.

> *I thought if I wanted to, I could lay here and be like that, but I don't want to be like that so it was just anxious, being anxious and the fear, I didn't want to go backwards, no, sometimes you can actually want to die, I think sometimes, I don't know why, but I just sometimes got this feeling that if you really want to you know pack up, you know and not do nothing then you know, you're not going to come back from it, or it would be really difficult to get back from it, that's what I was feeling, is that a bit deep? (Martin)*

8.4 The acute setting as a place of rehabilitation and recovery – right place or wrong place?

Looking back at their time in the acute setting, the participants had mixed feelings. Many reflected that it had saved their lives, for which they would always be grateful. While the input of nurses and therapists was valued, the marked misalignment between what the participants expected and what they received meant that the acute setting did not make sense and felt like the wrong place to be for recovery. The unpredictability and uncertainty of the acute setting were exhausting. In addition, the participants felt responsible to not only push to get what they needed, but that they were also responsible for realising their own future, as this did not appear to be in anyone else’s hands. Combined with the sense of being trapped, these feelings caused growing frustration and sadness. Although some of the participants and relatives recognised the acute setting was a hard place to provide care, with patients at their most dependent and, despite their lives having been saved, least grateful, the system as a whole was generally perceived to be at fault. All aspects felt too stretched and therefore unable to offer the support that the participants felt that they needed. Although from what they reported, this model of care was equally frustrating for the staff involved, there was anger at the system and the lack of input, which was something that, as patients, they were not able to control. With no clearly visible curriculum of recovery and what little input there was not making sense, the acute setting felt “soul destroying”. Just as a day in school with no lessons might be perceived as a day without learning, so the participants felt that a day with no therapy was a day of no learning and no recovery.

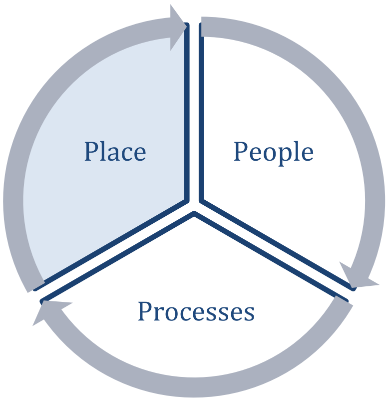
The uncertainty about how long the stay in the acute setting would last heightened the fear of long-term failure of recovery. By the time they left, many of the participants had little or no expectation of recovery and a high expectation of failure. During their time in the acute setting, therefore, they had moved along the continuum from expectation to mere hope of recovery – and even of that, they were not sure. Since the outcome was so important, the emotions related to lack of achievement took them to a very dark place. A number mentioned extreme low moods and there was an over-riding anxiety that, whatever happened, they could never go back. Almost without exception, all participants were fearful of something happening that would necessitate them returning to the acute setting and experiencing it again.

It is important to recognise that the acute setting was not witnessed as part of the data gathering and therefore what has been reflected in this chapter are the experiences and thoughts of the patient participants. It may have been that the clinical judgement of the team about readiness for rehabilitation was different from those of the patients but what is reported is how this episode was perceived. Understanding the sense making and associated learning about the acute setting is important as this shaped how the patient participants then experienced the next stage of recovery. This was in the rehabilitation unit, which will be explored in the following chapter.

Chapter 9 Findings IV: The Rehabilitation Unit

How the patient participants and their families experienced their time in the rehabilitation unit and the learning that they did there was, at least at the start, relative to their time in the acute setting. At the point of transfer, the beliefs of many for both the immediate and longer term were very uncertain. While they did not completely believe that they would not recover at least enough to lead life in a way that was similar to how it was before, they could not see how this recovery might occur. A number arrived at the rehabilitation unit with a strong feeling of failure and the certainty that if it was like the acute setting then they would not be able to cope. With the exception of Steve and Jim, who still held strong expectations for recovery, most of the patients were holding on to only fragile hopes. All though wanted to be at the rehabilitation unit with the promise that it offered of properly starting their rehabilitation and recovery. As it turned out, their apprehensions were soon replaced by joy and relief at the improvement in their function which was still longed for but certainly no longer expected.

9.1 Sense making of the place



What the participants saw was a place that, inside and out, was well kept and welcomed them in. It was calm and attractive, with nice grounds and gardens, which added to the feeling of it being less like a hospital and more like home. Indeed, there was much discussion about the unit not looking like, and being seen as a hospital, for, although it had staff in uniform and hospital equipment was visible, it was more relaxed and did not have a hospital feel. In contrast to the acute setting, which had all the visible symbols of illness, the participants felt that the rehabilitation unit was like a place where people were well and just needed help to get better in order then to get back to life: *“I think for me the environment does make a difference on its own, I mean just, it was pleasant, I can’t, they did make an effort with the garden, the day room, it doesn’t feel like a hospital, it’s not home, but it’s a step towards it, so it does give you a sense of wellbeing doesn’t it, compared to [acute trust], a big industrial place.*” (Tim)

Most participants had their own room, where their space was respected. Being able to shut their door so that people had to ask to come in was, for most, invitational and enabled them to gain a sense of control: “*This is much nicer, obviously [the acute trust] was just in a regular ward; I had no idea what this place was like, I had never heard of it before, didn’t know it existed, and there is a tele there and a door and my own window, it is fantastic, yeah*” (Paul). This was a domain they could influence, where they could make some decisions about and, with a bit of asking, could make even more their own by personalising it with pictures, bedding, and other items from home.

> ***And does it feel more like an environment that if you are going to spend some time in, it’s a more helpful environment?***
> *Tim: Oh definitely, yeah.*
> *Tim’s wife: We’ve bought some plants and some cushions from home, just for me of course [laughter], I’ve got my own mug, it feels more normal doesn’t it.*
> *Tim: it does, as normal as it can be really.*

They learnt that having their own space, which they could invite people in to or not, conferred safety, security, and stability. Whether shared or single, the room was theirs and they had the predictability of knowing that it was going to be their space for the duration of their stay, without the upheaval and risks of the unknown involved in settling into somewhere else.

Participants who experienced the shared rooms generally did not mind them, reporting that they liked the company and being able to help others. On arrival, they did not expect a single room and they did not therefore look for it or see the shared space as being dis-invitational for them. A number recognised that having their own space was successful, and invitational, because they had visitors/family during the day. Without them, it would have been a lonelier, more dis-invitational, place to be. As Tim and his wife reflected about a fellow patient, whose wife did not drive and could not visit often, a shared bedroom of like-minded others with whom he could have some humour and banter would have been ideal: *"because you know, and [fellow patient] for example, you know when his wife couldn't come, we sort of had him come in a sit with us because you could tell he was lonely … and I just think if you were without a partner, without visitors, being in your own room is awful.".* Others, such as Anne, Rachel, and Tony, however, liked their own space, even if visited only infrequently.

From a practical perspective, having their own space meant that participants could escape to their room during the day when they needed to rest, and they were able to sleep better as it was quieter and more restful than a shared ward. Having their own room thus provided a place to retreat to when they needed some time away. This was paramount for a number who found the cognitive, and physical, demands of rehabilitation exhausting. It also enabled a couple of the participants to feel physically safe when other, more challenging, patients made the communal areas difficult to be in. Both Liz and Tim, who were considerably younger than the others on the unit, were especially aware of this:

> *My oldest son came to see me and my friend came to see me … we went into the dining room to have lunch … and um [laughter] one of the patients was kicking off, asked my friend for a fork or spoon or something and then he was just aggressive, I don't know she gave him the wrong thing or something, and um it was not embarrassing because um, but you know for them to be, and then he was just arguing, he was with the nurses, you know what are you doing, but terribly sad, but um you know then we went outside and walked around the garden. (Liz)*

For Tony, the risk was not from patients but from the volunteers who, in a well-meaning spirit, corralled patients into activity groups that most were keen to avoid. His fear of having to join in was such that he chose to hide in his room all day to guarantee avoiding any group activities. Even though it would have passed some time, this aspect of learning was welcomed by very few and reflected how the participants largely did not expect to be doing activities like craft. Most had no interest in things that they could not see as being visibly linked to their understanding of recovery.

Overall, the group had somewhat mixed feelings about the communal areas such as the day room and the dining room. They all commented that these spaces were much nicer than they expected: they were both physically pleasant and, thanks to the charity affiliated to the rehabilitation unit, nicely equipped. However, whether they were enjoyed, and considered to be invitational, was largely shaped by the other people on the unit, who could make a space but also ruin it. Mostly, this depended on whether the patient participants felt any sort of bond or association with the other patients and wanted to spend time with them or not.

> *Well, he and I sparked each other off, we you know, we would sit in the dayroom there and I would say things and he would say things and people would think you are being very rude, but no we're not, all said in good humour and fun you know, and it really was a, two old buddies together, I haven't found that replaced with anyone else yet. (Roger, speaking about his association with another patient who became a friend on the unit)*

Whether the participants wanted to spend time with other patients was partly age-dependent, with the younger participants reporting being overwhelmed and saddened by the sight of so many impaired older individuals. Although circumstance had brought them together, there was little that was attractive about spending extended periods with people with whom one felt no real bond – they would not choose to spend day after day with people the age of their parents.

> *Tim: I think for me because I was the youngest one there it was difficult because a lot of them were … old blokes who I probably wouldn't have socialised that much with them anyway and some of them, you know when you have a stroke it affects everyone in different ways, but some of them were clearly struggling mentally as well.*
> *Tim's wife: And that was difficult for us.*
> *Tim: So, there were a couple of them who you were physically avoiding really you know, so…*

> *Tim's wife: The communal eating didn't work for us in the end, we did try because we could see that was what they'd like, and we did do that for about the first five weeks and then it just, a change in clientele made it just really detrimental, it wasn't beneficial for us at all, but we did, we did make the effort to.*

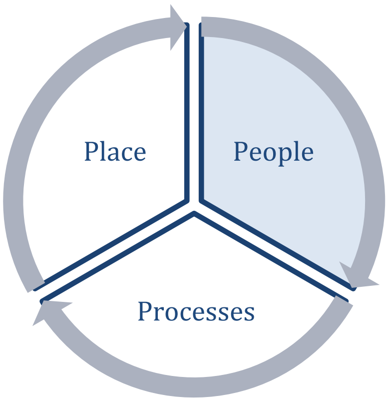
Despite the communal spaces being nicely designed and very well equipped with leisure and therapy-based activities, for most, there was little in them that was, from their perspective, invitational. There was little or nothing that the participants saw that they linked to recovery, or that was important or desirable enough to entice them into the spaces if others present were not people who they found it easy to be with.

The one place where this did not apply was the therapy gym, which was entirely invitational. Most of the group would have happily spent most of their days there, only going to the ward to eat and sleep. This space was invitational because it contained what looked to the participants like the right sort of equipment, with the right sort of activities going on, so that it made full sense and felt like the proper place to be to recover from their stroke. This difference between the gym and the ward meant that there was, for many patients and staff, a clear divide between the two spaces. The gym was the place where they expected to be helped to recover, whereas the ward was not. They therefore saw the gym as doing this but were not looking at the ward as a recovery space and therefore did not see it: "*There were some ups and downs but overall, the concept of rehab is, the reason you are here is to do the physio and do the occupational therapy and then downstairs to get looked after, get fed, to look after you" (Tim).*

Overall, the rehabilitation unit afforded a space away from the busyness of the main hospital where the participants felt they were getting closer to home. Having few expectations before they arrived, almost everything about the physical place exceeded what they were looking for. There was thus nothing that was dis-invitational about the building and gardens. Both the unit as a whole, and the therapy gym in particular, looked and felt invitational, confirming that they were in the right place for their recovery. Being visibly less medicalised than a hospital, the unit said to them that their days of inactivity were over and now the rehabilitation that would help them move forward would begin. They could leave behind the acute setting, where they had been so unhappy, and be in a place of stability that looked and felt like the right place to be. When so much had changed, it was a place where they felt some normalcy and even some pride. They mostly felt comfortable inviting people in and, importantly, had control to be able to show them out. They felt very fortunate that such a rehabilitation unit existed near where they lived and were desperately keen for it never to be shut down as it offered something so important that they felt that all should be able to access.

> ***And then thinking about seeing this as a rehab place, other than perhaps seeing a doctor?***
> *Don't lose it, will you.*
> ***What?***
> *Don't lose this place … if you want me to write a letter, I'll write a letter, you mustn't lose this place, it gives so many people the opportunity to get their lives back, it's vitally important, and I didn't even know what this was, I just had it as a rehab, right so if it's a rehab, there must be extra things I can do there to try to get my road to recovery quicker or the quality better you know, I didn't even know. (Martin – spoken with huge passion)*

9.2 The sense making of the people



The most invitational qualities that the group believed the staff should have, and therefore looked for first, were kindness and that they should care about, nurture, and value them. Kindness was key to interactions being invitational, and its presence or absence was commented on in some way by all. Although they were cared *for* in the acute setting, this was not necessarily in a way that they felt cared *about*. They thus talked with relief about how, from the point of arrival, they had the feeling that the staff at the rehabilitation unit came towards them as patients and, even more importantly, as people. The humanity of care, as well as the normalcy of being treated as one would treat others, was powerfully invitational. This aspect of being seen as a person rather than a patient marked, for some, the divide between the ward and the gym. For them, the style of care and manner of communication on the ward conferred a feeling of being seen as ‘a patient’ whereas in the gym they felt like they were being seen and valued as ‘a person’.

> ***Are there any key qualities that you would say, that’s essential for?***
> *Tim’s wife: Well, you go first because I know what I would say.*
> *Tim: Positivity and a kind word really.*
> *Tim’s wife: Kindness, absolutely, all the way, kindness, all it takes you know, it’s funny how the tiniest thing that you think, ooh, it can really knock you … it’s not that anyone’s particularly done it wrong but it shows you how fragile you really are, that if it’s going OK and you’ve got your little positive steps, but it doesn’t take much to knock the apple cart, you know.*
>
> *I ring the bell and a nurse comes so it’s not just the one whose name’s there, everyone is willing to help you, everyone will do their best and that’s the difference [long pause and more tears] the staff are here to make you better which is what you want, they’re as keen that you should get better as you are so whatever they can do they will do [pause] sorry I get a bit emotional because the kindness shown. (Roger)*

Being with staff who were kind and who cared, there developed consistent, reliable, predictable, and warm relationships that were hugely invitational, and which were very important for feeling safe and secure. Although almost all staff were valued, four consistently stood out – two healthcare assistants, a nurse, and a physiotherapist. At key times, these people first noticed the patients and their families and saw need from within them; they then listened with care to their concerns; and finally, having understood what they were thinking and perceiving, they provided what was needed when their understanding and vision of both the present and the future were most challenged.

It was important for the participants and their families to build bonds with people like these individuals, who were clearly engaged with their situation, who took a personal interest in their recovery, and who invested energy in them. The most invitational people were therefore those who did not see them as being a nuisance but instead showed interest and care as opposed to disinterest and indifference, or even outright hostility. This last, hugely dis-invitational, occurrence was rare but not unreported.

> ***Are you able to tell me a little bit about what role you feel the nurses have played in helping you with your recovery?***
> *Well, some of them are very good, A [HCA] in particular takes a personal interest and some are very enthusiastic about my recovery … one or two of them are absolutely splendid in terms of getting involved and getting up to speed with where you are, what you can do and what you can't do and others are not so …They're enthusiasm and pleasure and the fact that there is something that they are part of, I mean, A [HCA] said to me when she saw me walking, she said 'we want all of our patients to walk' which was a good attitude … and I think that that's a long way from some of the nurses who look at the patients as absolute nuisances, which indeed they are. (Stewart)*

Through these relationships, which made profound sense, the patients felt supported, enabling them to buffer, at least in part, against the adverse circumstances they faced. Many of the group reported that, when they started their recovery, they did not imagine it would take so long and so never expected that they would need to build relationships with staff. One of the invitational aspects of the rehabilitation unit was how these relationships were achieved. Being with staff who knew their names and recognised their specific needs made them feel that they were not alone. Being treated as adults and not just as patients enabled them to be visible, heard and known. They were asked what they wanted, and this was listened to and acted upon. Importantly when they called out, either verbally or non-verbally, this was recognised and the right help and support were given. Through feeling safe and secure in their relationships, the patient participants were able to predict and plan so that life felt a bit more stable and the unknown a bit less frightening.

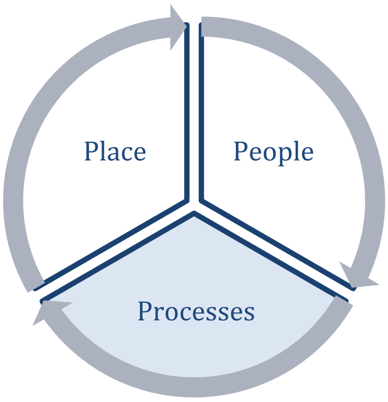
Alongside kindness and caring, the participants also looked for the staff to have enough time and resources, as well as specialist knowledge and skills, to do their jobs effectively. The clear display of capability and competence further enabled the participants to feel that they were in safe hands. After the anxieties and distress of the acute setting, the wives, perhaps more than the patient participants, needed to see this so that they had the confidence and peace of mind to trust and to step away. They could only feel safe when they could be sure that their husbands were safe.

> *No, no, but there's some people that you make a natural connection with and immediately, I could go home that day knowing that you were fine, I didn't always feel like that … I want to know that I can go home, and someone is going to check in on him, you know and not just, which is partly why from the beginning I wouldn't leave him because I didn't feel that there was that care … that way, I could get through it because I knew he was in good hands. (Tim's wife)*

The patient participants recognised that they were not experts and did not know what to do to get better. They therefore needed the guidance of staff with specialist knowledge and skills: *"You just don't know really what to do because you are not the professional in the medical sense you are recipient of treatment being given to you"* (Roger). This point was repeated often, perhaps reflecting the anxiety from the acute setting of needing to drive forward their own recovery but being unable to do so. The participants worried that if it was left to them to work out their recovery, there was the risk of not doing the right thing or learning bad habits that would compromise their end outcome. They felt that it was their responsibility, instead, to listen hard to the experts and follow what they said. For some, including Martin, Paul, and Jim, this came with the unfortunate consequence of self-blame, ascribing lack of perceived progress to being their own fault for not listening enough or inadvertently doing the wrong thing. There was a strong need to know that there was someone in charge who would take their recovery in hand and would operationalise the system so that it worked. The patient participants wanted to be involved in their recovery but they did not want the responsibility of having to work out what to do and how to drive it forward.

Overall, the participants were very grateful for the care they received from many of the staff at the rehabilitation unit, which exceeded what they had expected in its kindness and skill. They were thankful that responsibility for their recovery was taken on by competent professionals and not left to them. This was hugely valued because it felt so right and made so much sense. By the same token, as will be seen later, its cessation was problematic.

9.3 The sense making of the processes and practices



Central to what was lacking in the acute setting but visibly present at the rehabilitation unit was a planned curriculum. This section will consider the processes of the curriculum by looking at the role of: (1) the ward and the wider unit environment; (2) the timetable; (3) the therapy sessions, and (4) independent exercise practice (Figure 17).

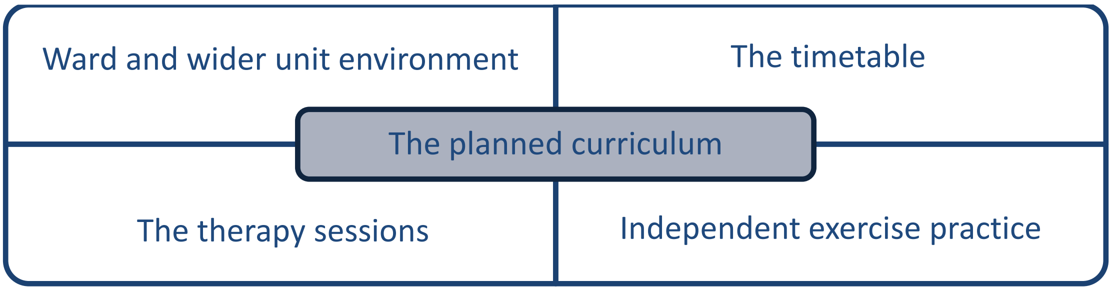


Figure 17 Four facets of the planned curriculum

9.3.1 The role of the ward and wider unit environment in delivering and enacting the planned curriculum

The invitations that caused the participants to feel that the rehabilitation unit was the right place to be for their recovery started even before they arrived, when the ambulance drivers told them they were going to the best place to get better. On arrival, they were greeted by patients and their families familiar from the acute setting, which conveyed immediate messages of welcome and of people being pleased to see them. Being taken to their own room, which was almost entirely unexpected, given a cup of tea and, especially for those who arrived cold and late in the day, tucked into a warm bed, all gave strongly invitational early messages of this being the right place to be, among people who cared and were kind.

> ***When you came here, what sort of orientation did they do, did they show you around?***
> *A bit of a tour, they explained what it was [pause] first thing they did was make me a cup of tea.*
> ***Perfect***
> *No, it meant a lot. (Paul, with real feeling)*

What was also very invitational, was being looked in on during the first night, which gave Jim in particular the feeling of being held and supported. Conversely, Anne's first night was somewhat dis-invitational, as she was not orientated enough to be in a room on her own and did not know that there was a buzzer to press when her calls for help went unheard.

For all participants, these first impressions, both invitational and dis-invitational, were remembered and could be recounted vividly throughout the six-week stay and beyond. The arrival of most patients went well. However, Tim and Liz were both greeted with initial uncertainty about whether they could stay: it was not clear if Liz's medical needs could be met and Tim whether there was a bed for him. In fact, Tim and his wife had made a number of hospital transfers already, all of which had been stressful and some unsuccessful (they had previously been twice taken to a different hospital with the same name). Nearly being sent back to the acute setting by the receptionist because he was not expected almost produced a reaction from Tim's wife that she said she was not sure she could be responsible for. The actions of the staff on both occasions were not intentionally dis-invitational but were made so by the importance to Tim and his wife of being at the rehabilitation unit.

> ***Are you able to tell me about that arrival here?***
> *Oh it was hideous … so I started to lose my rag at that point … the lady upstairs she said … his name's not down, the ambulance people were saying we'll have to go back to [acute trust] and I was saying, I was ready to kill someone at that point … that was a hideous moment, so transfers have been disastrous, generally transferring of any type has not been good for us and has been unsupported in the worst possible ways, emotionally that was huge for us, because Tim's there on a stretcher, come out of the ambulance, I'm with the receptionist and she's saying we're not expecting you … it was awful, emotionally, at a time when for us, it was personally made worse, from the transfer from [acute trust] it took 30hrs and at this point, getting out on a hoist from the bed on to a stretcher twice, one late at night, at midnight and secondly at 11 the following morning … but … that was like a tidal wave when you are in that process, because this was like the promised land at that stage, we had just got you out of [acute trust] half an hr ago and then they were saying, oh no bed; for me that was huge because at that point, I just want him somewhere better and you know, we were standing in reception and no bed. (Tim's wife)*

While the timing of arrival was not something the rehabilitation unit controlled, it was crucial to the perceived invitations/dis-invitations. Because the participants were often at their lowest at the point of transfer, many described feeling saved by their arrival at the unit. Transitions from the known to the unknown were reported by a number of participants as being stressful and disorientating. This included movement between the wards in the acute setting, between hospitals, and eventually between hospital and home. Knowledge of a place provided some degree of safety and so transfer to the rehabilitation unit, although strongly desired, still carried the uncertainty of moving into the unknown and needing to build understanding again from scratch. With so much riding on it, first impressions – both seeing and feeling – were very important, as both the participants and their family members had few emotional or energy reserves left.

Having a fixed six-week stay was then also both invitational to some and dis-invitational to others. Roger, Jim, Anne and Rachel, for instance, felt as though it was going to be too long, while Martin, Tim and Richard, who had already spent about this length of time in the acute setting without making any progress, thought it would be far too short: "*Because when … they said that you'll be there for a minimum of six weeks, six weeks, I can't even walk properly, you know how am I going to be able to walk, you know if I've done that in that time, how the hell is six weeks going to do?" (Martin).* In the initial days and weeks, the six-week length of stay was though broadly invitational as it provided some stability and certainty. Towards the end, however, Martin, Tim and Richard, in particular, felt that they had more recovery to make. A clear end date could thus build high levels of anxiety. This was not fully seen or understood by the staff, who knew, but did not communicate, that there could be an extension to the length of stay. Indeed, although an extension was being planned for Tim and Richard, these plans were not shared with them in such a way that they understood, and so their anxiety and fear were allowed to grow. The participants were too afraid to ask, as it was better not to know and to continue to hope, rather than have the negative outcome of discharge confirmed.

> *I think its reassurance that everything will be all right, really, because at the beginning, I think I said to you, how at the beginning of [rehab unit], how stressful I found it because Richard wasn't progressing because he wasn't well and I thought oh gosh, he's only got another three weeks left and however is he going to be able to come home, I found that really … like a big countdown; that was the worst time … the six week time limit I did find very stressful, they did explain that it could be extended but I very much got the feeling that it had to go to the trustees and that sounded like, oh, they're not going to agree anything. (Richard's wife)*

In general, communication, whether intentional or unintentional, was sometimes perceived as being invitational and sometimes dis-invitational. Key instances of invitational communication were when non-verbal body language of distress was read and support offered, or when family members were listened to as adults with fears and needs to be met.

> ***Are there any particular qualities of an individual that you think make them a good person in that role, are you able to say what makes an individual?***
> *I suppose [Nurse's name] dealt with it immediately, or as quick as she could, you know, just the fact that she said come round to the nurses station, she brought me round to where she was, it wasn't across the desk and she listened and she dealt with it and we dealt with it together, she was very clear with Steve as to why he needed to do this, even though again, he was still challenging. (Steve's wife)*

Unintentional dis-invitational communication often related to plans and timings of activities not being communicated, resulting in periods of uncertain waiting. Being vulnerable and waiting when dependent, with no capacity for control, was a frightening situation, as Stewart conveyed by citing a poem that had great resonance for him.

> Now, he will spend a few sick years in institutes,
> And do what things the rules consider wise,
> And take whatever pity they may dole.
> Tonight, he noticed how the women's eyes
> Passed from him to the strong men that were whole.
>
> How cold and late it is! Why don't they come
> And put him into bed? Why don't they come?
> Wilfred Owen 'Disabled'

Both patients and relatives understood that waiting was often inevitable, but this did not take away from how distressing and dis-invitational it was, and how every step forward in confidence could easily be reversed by one action or inaction, or even just a casual turn of phrase. Stewart's wife recognised that learning to be dependent was the hardest learning her husband had had to do.

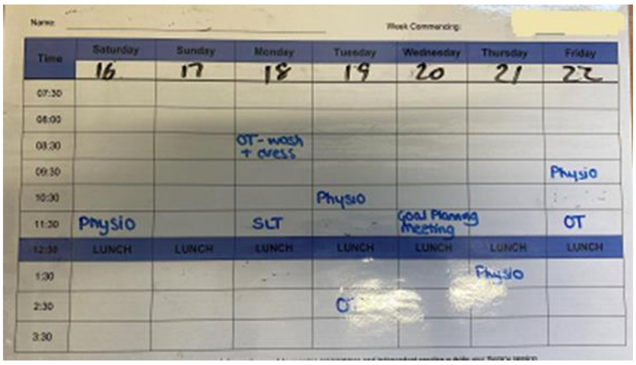
Trusting and believing and, in turn, being trusted and believed were hugely invitational, conferring a sense of control, responsibility, and independence. Having a purpose and direction in life, as well as being seen as unique, are key features of being who we are, and both small and large actions that reinforced these qualities on the ward were very important. It was invitational to the patients that, within limits, they were able to dictate and enact their own daily routines. They saw the rules that were in place as relaxed and sensible, designed to keep them safe but not to constrain them. Support for self-care was generally provided until the participant felt both physically and psychologically ready to take on the daily tasks. A couple of incidents of unsupported night-time care showed the vulnerability that lay just under the surface and how frightened many participants were. However, these were some of only very few intentionally dis-invitational acts and, as such, they stood out. Being given independence was a visible and invitational message of being trusted and through this came the learning that one could trust oneself a bit more. It also enabled the participants to impose some order on the perceived inefficiencies of the system, which had been deeply frustrating for some as they had not previously been able to fix or influence them in any way. No longer would they be trapped in bed fearful of missing an early therapy session when they had been given the freedom to get up, showered, dressed, and breakfasted by themselves.

9.3.2 The timetable: visualising the planned curriculum

One of the practices of the Unit that was most visible and, for many, most invitational was the use of a written daily timetable. This instilled a strong sense that both the place and the people were operationalising, what felt to the participants, like the right ways of working that would enable them to achieve the outcomes they still hoped for but no longer fully expected. A large part of feeling safe and supported was conferred by being able to see a curriculum of learning and associated success criteria. Both of these were valued and made sense to the participants. The curriculum thus matched the instinctive sense the participants had that they needed to be doing something in order to get better.

> ***You mentioned right at the beginning … about the timetable … are you able to explain to me a little bit more about why that's important to you particularly?***
> *Because when I was at [acute trust] in particular, I didn't see any sign of remedial work on the horizon in any organised fashion, as soon as I came here, the very hour I arrived, that went on the wall [the printed timetable] and that gave me reassurance that at least someone's got this in hand, which indeed they did, we have stuck to that programme pretty rigorously. (Stewart)*

The personalised timetable that each participant received consisted of a fairly scrappy A3 laminated sheet with ruled lines for the seven days of the week, with the therapy sessions for the week written in pen (Figure 18).



Name:

Week Commencing:

Time	Saturday	Sunday	Monday	Tuesday	Wednesday	Thursday	Friday
	16	17	18	19	20	21	22
07:30							
08:00							
08:30			OT - wash + dress				
09:30							Physio
10:30				Physio			
11:30	Physio		SLT		Goal Planning Meeting		OT
12:30	LUNCH	LUNCH	LUNCH	LUNCH	LUNCH	LUNCH	LUNCH
1:30						Physio	
2:30				O			
3:30							

Figure 18 Example of patient timetable

The participants received their first timetable within a day or two, of arrival. Thereafter normal practice was for it to be put up on a Friday afternoon, detailing the sessions for the forthcoming week. While timetabling was used to enable both patients and therapists to plan their time, being given their timetable on the day of their arrival gave a strong message to the patients of being expected and valued as well as the reassurance of regular therapy input. Crucially, the clear structure and routine set out by the timetables was rarely deviated from.

> ***Yeah, that determination to keep going … and when you came here, you saw physios most days?***
> *Yeah, I think that I got here on the Saturday, and they took me up for an assessment on the Sunday right away and they realised that this side was slightly stronger, and I could pull myself up and they gave me a few bits to do to see what I could and couldn't do, it was the second day, and then I got the thing [timetable] and started. (Paul)*

Although they could be scrappy, with old entries barely erased and new entries unclearly written in too thick pen, these timetables were extremely important to patients. They represented a clear symbol of commitment of staff to a systematic and organised pattern of delivery through which the patients could hope to get better. They thus took away the patients' anxiety of whether and when anyone would come to help them recover. Just this one piece of laminated paper allowed them to relax, removing responsibility for driving forward their recovery and putting this, instead, into the hands of expert others who they perceived were much more likely to achieve success. What had dwindled to mere hopes of recovery, thus began to grow towards expectations once again.

The timetabling process itself was carried out by the therapists alone and the absence of nurse or other ward input affected the messaging as nothing was noted that visibly related the schedule of recovery to any ward-based activities. Occasionally, for patients with very specific needs, daytime rest sessions were written up, but this was the exception rather than the rule. The only aspects of rehabilitation that were therefore made overtly visible to patients were the therapy sessions. On reflection, the therapists thought that the timetable could probably be used more and wondered whether, by just including formal therapy sessions, it sent the message that these alone constituted rehabilitation and that the rest of the time was just sitting and waiting. This was not far off the understanding by the patients, who did not see learning as occurring during the whole day but only within specified time slots. Because though, they did not clearly recognise its invitational importance, the staff wondered whether, if they did not have a timetable at all, patients would be less dependent and would take the lead in organising their own day. In the end, however, they thought that this would probably be unlikely, and so timetables remained.

> *Senior nurse: And again, it's a long day and you want to know that you are doing something*
> *Physio: And I think it's nice for the visitors as well to see that they are busy*
> *Senior nurse: Yeah, what they have done, because the patients might not be able to tell you, but just see what the plan, what they get here, it's nice to visibly see what is going on*
> *Physio: It's interesting, we've had this discussion about whether people should or shouldn't have timetables and you know, do you actually get more repetition in if you aren't giving someone a timetable and therapists just going on to the ward and seeing them and encouraging them to do things, it's kind of what works better in getting the repetitions in really … it kind of feels like it works well for some and not others and some prefer just to be able to come up to the gym.*

9.3.3 Therapy Sessions as part of the planned curriculum

Seeing therapy sessions on the timetable mattered so much to the participants because they promised to address the weakness that was, for most, their primary concern. From everything that was offered by the rehabilitation unit, these sessions were the key thing that patients saw as making sense to them for their recovery, and so they pinned all their hopes on them. By the time they arrived at the rehabilitation unit, the patient participants had started to understand the effect of their impairments, which most articulated as being weak and not being able to walk. Although there were many other things that they could not do, this was the primary signifier of the dependent position that they were in and what they most wanted to be able to correct. There was great pain and sadness in the acknowledgment that this incapacitation was the reality and might stay so. The only life that they could, or wanted to, envisage at this early stage was still one where they were able to walk. They did not want to see any other type of life, and to an extent, could not really see any other type of life. At least at the start of rehabilitation, therefore, recovering walking was recovering overall.

> *It suddenly hit me when my brother phoned from Scotland … and he said, as everyone does how are you and I said I can't walk, [tears] I'm sorry, I don't think he fully appreciated what that meant and it was only later that I think it sunk in, sort of, the idea of you can't walk [more tears], what will you do if you can't walk, I don't know, maybe I'm wrong, but I just had this feeling of quietness when I first said to him, I can't walk. (Roger)*

Correlatively, as they settled into the rehabilitation unit, it very soon became clear that what the participants wanted and valued most were their physiotherapy sessions. The other activities that they did over the rest of the day, such as washing and dressing, were largely invisible and not recognised as linked to recovering. To the participants, these activities did not have the same sense making as doing exercises in the gym. In their pre-stroke life, they were not activities that they linked in any way to skill acquisition or maintenance. Although they saw ward-based everyday activities as things that they needed to learn, their understanding was that washing and dressing was a task to get clean and ready to face the day, eating was a task about satisfying hunger, and the many possible leisure-based activities, such as reading the paper, were about not being bored. None of these were seen as activities that were related to improving motor, cognitive, emotional, or social skills. The ward was seen as the place where they were cared for while waiting for therapy sessions and, to an extent, the design of the timetable and the messages given by the staff and wider systems reinforced this impression. For example, the participants understood the role of the nurses in rehabilitation as being to get them ready for therapy. Although it was recognised that the physiotherapists needed the support of the ward staff, they nevertheless had the most appreciated role: *"At [rehab unit], it was pretty good in as much as they did the job of getting people ready for the transfer to the physios, so to that extent it was very good." (Stewart)*

Physiotherapy was most valued not because it did anything better than, or even very much different from, the others but because it was the one activity that the patients expected to be doing and that led most visibly to the desired outcomes. It therefore made most sense. As a result of a historical divide that seemed to persist mostly because of convenience, the physiotherapists largely focused on the lower limbs and walking, the key goal for all of the patients, and the occupational therapists on the upper limbs. Recovery for most of the participants followed the common pattern of greater lower than upper limb return, such that all bar Richard, were mobile when they left but a number, including Martin, Tim, Adam, Tony and Jim, had residual upper limb impairment. This difference in outcome was not unexpected for the staff but it was for the patients, whose prior expectation was that both would recover at the same rate. No one having told them differently – or at least no one having told them in such a way that they could understand – they had no reason to think otherwise. As it was, in interpreting differing degrees of recovery, the patient participants assumed that the two professions must be doing something different, with the physiotherapy approach working and the occupational therapy not. The approach that the physiotherapists took made greatest sense in as much as everything about what they did looked like gait rehabilitation. What patients did within their sessions felt like exercise to strengthen weak muscles in order to walk, which is what they wanted so much to be able to do again. Occupational therapy on the other hand did not really make sense as it was not close enough to what the participants conceived they needed or wanted to be doing with their upper limbs. They did not feel like they were doing exercise to strengthen weak muscles and so they could see little purpose in it.

> ***And you see the occupational therapists as well do you, what types of things do you do with them?***
> *Tony: She's the one that has the balls, knock the balls backwards and forwards, um gripping, that's right, put a towel on the table and um, go round, dominos (prompted by wife).*
> ***And would you ever think about going to do those types of exercises by yourself?***
> *Tony: No, no, I mean, they're, they're, I don't want to say that they are too menial, but they are not the sort of thing that you would get up and do yourself really…*
> ***And have they given you any exercises to do on the ward?***
> *Tony: no not really.*
> *Tony's wife: Putty.*
> *Tony: Oh, I've got putty there, terrible thing.*
> *Tony's wife: It's no good saying that, that is the exercise.*
> *Tony: It's not really what I call exercise at all.*
> ***What would you think is exercise for that arm, what would you be doing with it?***
> *Tony: Well, I don't know, stretching it a bit more, moving it around a bit more, and not with a bit of putty.*

Physiotherapy/gait rehabilitation also had the advantage of presenting the opportunity to enact many of the best practice principles for learning.[3] Unlike the upper limb sessions, where the content often appeared to have little relevance and the outcomes seemed unobtainable, the lower limb focused sessions operationalised aspects such as deliberate practice, spaced versus blocked learning, and the provision of immediate feedback of success. A further feature of physiotherapy sessions that was valued highly by the patients was that they were pushed further in them than they thought they could go, but in a way that was well scaffolded, did not exceed their ability, and felt entirely safe and supported: "*Well, I'm doing things which I*

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[3] Best practice principles for learning aim to incorporate principles of motor control, motor learning and skills acquisition into rehabilitation practice (Muratori et al., 2013).

wouldn't dare otherwise, every day that I do physio, I do something different, never err, it's never the same twice." (Anne).

Physiotherapy sessions were clearly planned, with a definite purpose and direction. They were conducted in relative silence, with just a few verbal instructions, giving the participants space to attend to, and focus on, what they were doing. With a reduced cognitive and psychological load, the participants could put their attention into the learning itself, consolidating gains in small increments through assimilation. Most importantly, the sessions produced a positive end outcome, with the participants leaving almost every one feeling that they could do something more than when they arrived. Attainment of success was linked by the participants to their own effort which, in turn, led to a powerful sense of control. For the sessions focused on the upper limb, however, this was not the case. The participants felt that these were, at times, rather chaotic and unstructured, with one activity after another appearing unachievable or not really working. As a result, they often demanded a high expenditure of mental and physical effort to no productive end.

> ***Right, in what way does it [physio] help with your recovery?***
> *Tim's Wife: and it wasn't fluffy, that's why it worked … the way, [physio named] was very good at making sure that, he would say enough without, I don't know, you knew what was expected of you, but we found in OT [occupational therapy], it was try this, try that, this equipment's broken but we'll try it anyway, you know it was … which bit are we doing and that might be because um after the event you realise that there's so much more to be done with the arm than, we've learnt being uneducated in physiotherapy.*
> *Tim: A lot of it was very frustrating, it was very passive, and I couldn't do much and it was like, it was endless trying to move the cones, and I just couldn't do it and move the hand, and I was like, it didn't feel very, I don't know, it didn't feel like you were achieving very much.*

The occupational therapy sessions were also felt to be focused around doing low-level, trivial activities with little purpose or relevance. The lack of positive feedback and the imbalance between effort and result, meant that the participants soon became frustrated and lost faith in what was being done, which was then very difficult to build back from.

Feedback received from the physiotherapists was rapid, positive, and hugely invitational. It was also, at times, revelatory when, in a session where they had not anticipated it, the participants were able to take their first few steps. Having feared that they might never be able to walk again, taking their first steps was deeply emotional. These sessions had wide visibility as they were videoed and sent to family across the world.

> *Well [physio name] in particular has sort of grabbed the thing a bit; I was using the … pulpit one day and doing quite well with it and she walked into the scene and suddenly grabbed me and put me into a wheelchair, took my hand and we stood up and we did that sort of shuffle down the corridor there … so I think that [physio name] intervention was a big, big breakthrough in terms of psychologically, we recorded that … and we WhatsApped it to all the family, it boosted them tremendously, because the concept of me walking before that in any form was totally strange and unimaginable. (Stewart)*

It was also these sessions that could bring them to tears – something which certainly Martin's wife reported that she had never seen from him before. The recognition that they were moving ahead at every stage and never going backwards was not achieved from anything else that the participants did over the course of their day. Indeed, not only did the upper limb sessions never have such moments of revelation, they had few moments of regular positive feedback at all. Instead, the opposite feeling of not getting anywhere was typical, reinforcing all the other doubts that the patients had. Overall, physiotherapy built a certainty which occupational therapy, with its focus on gaining recovery in the upper limb, did not. Patients wanted their effort to produce the desired outcome and they got this from physiotherapy alone. The powerfully invitational nature of the physiotherapy sessions, with their positive feedback and clear improvement, meant that the participants favoured time with them. As Roger put it, what he had learnt most in his early weeks of rehabilitation and his physiotherapy sessions was that there was hope after all.

In the sessions focused on the lower limb, learning occurred through stages of assimilation – building in small incremental steps on a reasonably stable foundation such that the end outcome was not very dissimilar to the original. This type of learning, although not without effort, was not negatively emotional nor physically too demanding. In contrast, the participants who did not achieve upper limb function were not able to learn through assimilation as building on their existing schema of arm use was not possible. Although this was not formalised or overtly facilitated in any way, a number of the participants were slowly having to learn through processes of accommodation, in which they needed to let go of, and break down, their old schema and build a new one of a less functional upper limb. In contrast to learning through assimilation, this type of learning was emotionally exhausting as it was not learning that they wanted to do.

In making sense of these differences, the participants believed that the physiotherapists were doing something very right that the upper limb sessions were not. What they were receiving in physiotherapy matched what they expected and had confidence in, and so they felt that they could trust the physios in a way that could not trust the others. Accordingly, they wanted 'physio' on their arms. Although they did not do anything wrong, upper limb focused sessions, by contrast, were just not invitational. Indeed, they became actively dis-invitational, with a number of participants being quite critical and blaming sessions for the lack of return of arm function. By the end of their six weeks, a number mentioned that they preferred to be busy on the ward using their affected upper limb, keeping their rooms tidy and helping less able others, as they felt this was better than formal upper limb sessions.

> *Yeah, mostly the physio more than the OT because I sort of worked that stuff out on my own, picking cups up, and I was able to do it, definitely more the physio, not dropping someone in it, but I have got a lot more from the physio.*
> ***And from the nurses on the ward, what would you say that you got from them?***
> *[long pause] General care really, they have looked after me.*
> ***And do they encourage you to do your walking and push you to be independent if you can do it?***
> *Not really no, if I walk out here [his room] without a stick, they are on to me, they are on my case [laughter], yeah, they have been really good, but they haven't really made me do anything in particular. (Paul)*

Once improvement started to occur, what the patients did in physiotherapy felt attainable. As a result, their confidence grew so that they believed they might achieve their desired outcomes. They saw value and purpose in the process of learning, with a clear sense of the success criteria of walking further, faster and without aids. This was not the case for all the other elements of their rehabilitation day. Emotions linked to physiotherapy were powerful in that they were almost universally positive and activating, and included often intense joy, hope and pride in what had been achieved and what might still be achieved. With this, expectation for continued improvement grew.

Key to physiotherapy, therefore, which was different from other aspects of rehabilitation provision, was that the planned curriculum closely matched both the desired curriculum and that received. This planned curriculum was largely content, or skills, related and aligned to the short-term aim of enabling the patients to return home. The clear purpose of building functional activity made sense to the participants and aligned with what they felt that they needed and wanted. As two of the participants who had both been teachers reflected, the aim of working in rehabilitation and the satisfaction that staff must gain, was to help the people get to their next stage of life – not to keep them still but to reach the next rung of the ladder and open the doors for them to send them on in a better state than when they had arrived.

9.3.4 Independent Practice

The material place of the rehabilitation unit was felt by all to be very pleasant. Thanks largely to the charitable organisation attached to the unit, the grounds were attractive, while inside there were a surfeit of leisure-based activities and therapy-based equipment. The dayroom, for example, had computers, a piano, puzzles, a fish tank, an exercise bike, and a Nintendo Wii™. Barely any of it, though, was used independently by patients. The only thing that they did with any regularity in the dayroom was read the daily newspapers that were provided. This space was open all day and night, but few patients went there for any length of time on their own initiative to make use of what was on offer. The same was true of the therapy gym.

Although having more restricted hours, this operated a fairly open-door policy outside of scheduled sessions. Even so, despite it being the place the participants said they enjoyed the most, hardly anyone went there by themselves to do independent practice. Although it offered numerous activities, and patients knew that they needed to practice to achieve recovery, it turned out that the environment of the rehabilitation unit was not enriching or invitational for self-practice at all.

There was therefore very little translation from the supported therapy sessions to independent exercise. When asked why, a number of the patient participants suggested that it may have been because they were inherently lazy and that they needed to be pushed, cajoled, and supported to go forward. They thought that they would do more if the activity was shared, especially with staff, rather than done alone.

> ***And practising down here by yourself and practising in the gym by yourself, practising with the therapists, do you notice if there are any differences, more of less enjoyable times?***
> *It's not as enjoyable doing things on your own, you know, there's a bit of banter, I get on with them all up there, so it's nicer working with someone, but it's just something that you've got to do, working on your own, I realise that bit I don't enjoy it as much, I would much rather do it with others … that part of it is soul destroying, but I just have to do it. (Paul)*

Learning and practising were what the patients had to do but not what they wanted to do. For those with residual deficits, there was also no sign of an end point when it was clear that they could stop. Doing independent exercise therefore necessitated having not only the energy and will but also the belief that they needed to do something and that this would lead to clear positive outcomes. In most cases, however, this was lacking.

Importantly, in addition to these factors the participants needed to be actively and overtly invited into the activity. They needed to know what to do, and to have the confidence of how to do it. Very few participants had exercises that were written down and kept somewhere they could find them. When questioned, hardly any said that they would know what to do, especially for their upper limbs. They were also anxious that they would do something wrong that would negate the hard work of the physiotherapists and set them back. The greatest apprehension for those who had grasped the idea of independent exercise was that they would miss something or do something wrong that would necessitate a return to the acute setting. On balance, it therefore seemed better not to do, for fear of having to go back. While they were still in rehabilitation and had the security of guided sessions, the known of the current condition, even though not desired, was safer than either the unknown of the future or the known of the past.

When trying to determine what the rehabilitation unit could offer to encourage more practice, the participants reported that they would have liked more structured activities within their day. However, they struggled to identify what these might involve other than exercise, as this was really the only thing that they could see and believed that they needed to do. What they wanted was invited, structured exposure to the enriched environment of the therapy gym. This behaviourist approach to learning demanded the least of them and allowed them to concentrate their limited reserves of energy on trying to master the day-to-day instructions of the activities in hand. As was clear from both report and observation, even following the simplest tasks in their therapy sessions required a significant cognitive effort from the patients. There was little acknowledgment of this cognitive effort by staff, however, nor much attempt to develop it. There was also hardly any integration of alternate learning strategies that might have complemented the behaviourist approach and prepared the participants and their families for greater independent ward-based practice or for discharge, when the exposure to the enriched environment of the therapy gym would stop. If they wanted to do any independent practice, therefore, it was largely up to the participants and their families to work it out.

> *I think um, I think I’ve been lucky because [wife] has written down or videoed just about every single exercise that anyone had ever done, we have a whole library of stuff to reflect on but I think, you know, had we had not made that concerted effort to absorb I think because of my stroke, my memories to absorb is not what it was, so again I’ve been lucky, I’ve got [wife] doing that for me, if I was doing it on my own, I think I might have struggled, I mean just before I left [rehab unit], I realised, oh my god what am I going to do when I get home, because I*

> *asked [physio] what exercise should I be doing and he showed me a few but I had to be proactive to get that from him, it would have been nice to have been shown this is what you do every week. (Tim)*

One process that had the potential to promote greater independent practice was the open-door policy for relatives/family members to observe the different therapy sessions. As Stewart's wife, who was a retired social worker, commented, it took courage to expose oneself so much to observation of practice. This policy proved to be very invitational to family members, emphasising their involvement in the rehabilitation process. The role of the relatives in these sessions was, though, largely observational with little information given to enable greater carry-over of practice. This absence of information giving was particularly problematic for family members who either could not join sessions or, like Steve's wife, chose not to, feeling that their relative might value time and space on their own. With very little written guidance on independent practice, there was no way of knowing what had occurred and if there was anything that should be done between sessions to progress recovery. Even when sessions were observed, it was the responsibly of the family to write down or video what occurred, with very little provision of guidance for self-practice.

> *And I suppose my only … suggestion would be, especially somewhere like a neurological place where, you know Steve has got short term memory issues, I didn't know what was happening in some of the sessions; I sat in on a couple but it wasn't always appropriate for me to be in them, so I wouldn't know what had happened, and I would say oh how was speech and language therapy and Steve would go, um which one was that, that would be the one with [named SLT] and he would go, um, I can't remember what we did, and so I didn't know then how I could help Steve, if Steve had any homework to do, or exercises, and it was like oh, how do we help. (Steve's wife)*

The willingness of patients and their family members to learn therapy activities for self-practice was thus not harnessed to improve outcomes. Instead, although the therapy staff said they would like the patients to do more independent practice, it seemed they did not really believe this would happen and did not know how to achieve it.

While there was no intention to make the patients dependent, few strategies were used to counter this. The consequence was that they remained frightened and/or unsure. The learning was unlike anything the patient participants had done before and the stakes were very high, so they sought the guidance of experts who would help them get to where they wanted to be. With the therapists, they felt able to do things that they would not have known to do or had the confidence to do alone, so gaining the belief that with supported guidance things could change.

9.4 The rehabilitation unit as a place of rehabilitation and recovery – right place or wrong place?

In contrast to the acute setting, which had felt like the wrong place for learning because of the invisibility of doing, the rehabilitation unit felt like the right place because of the clear visibility of a planned curriculum that the participants were looking for and actively invited into. The thrill of learning and gaining greater activity/function that the participants experienced was a strong motivator and so they were generally keen to invest effort in their rehabilitation. At least for the lower limb, the learning/rehabilitation outcomes and success criteria were clear and made sense in that they matched the expectations and desires that the participants and their families held. Having come from the acute setting with low expectations, from their physiotherapy sessions they learnt that they could do not just more than when they arrived but more than they had initially dared to hope. Once improvements in walking started to occur, confidence grew such that they believed once again that they had a reasonable chance of achieving their much-desired outcomes. Indeed, nearly all the participants achieved the end outcome of being able to walk.

What the rehabilitation unit delivered largely matched the expectation of the participants to be doing things that they valued in a regular and systematic manner that they had some control over. Learning thrives in environments where the people and the practices that they operate are invitational. Being welcomed, supported, and cared for in their rehabilitation is what the patients hoped for and generally received. In turn, these invitational acts built feelings of safety, support and trust, although these could still be quickly knocked down by dis-invitations.

A key invitational aspect was trust and belief in others, where participants had some autonomy but were under the care of others who had overall control. They then felt safe and supported to step out, literally and metaphorically, into their new world. Being in the rehabilitation unit, and in the gym in particular, provided the knowledge and skills about what to do and the support and confidence to do it. Without this guidance, the participants were clear that they would not have made the progress they did as they would not have known what they ought to be doing. The interest shown in them as individuals and the praise received on doing something right was hoped for but not, at least at first, expected. It was, though, greatly valued and highly motivational. As they all articulated, because none of them had any experience of rehabilitation, they needed to be with people who knew what they were doing and would enact a visible curriculum that would help them achieve success criteria. Without this invitational support, they did not have the confidence to push on into the unknown alone.

The place itself, with its fully equipped gym, sent positive messages to the participants that they were in the right place for the learning needed for recovery. They also felt that they were generally in kind, safe and competent hands, with staff who were prepared, knew what they were doing, and came towards them in their care. In addition, the people in charge seemed to have a plan such that things would happen in a structured and systematic way. Having confidence that the right things would occur at the right time and in the right way helped provide much needed stability and settled a large part of the anxiety of uncertainty from the acute setting. However, most of the participants were not interested in doing activities that they did not see as linked to their beliefs about recovery. As highlighted at the end of Chapter 7, despite its wealth of facilities the place was not as enriched for them for self-practice as it seemed initially to an outside observer. Having not gained or been given any other understanding, what they almost exclusively focused on was physiotherapy and its associated exercises, which most wanted to be supervised and supported. There was, therefore, fairly limited use of the gym outside structured sessions and extremely minimal engagement in independent exercise. The participants wanted to be where they saw the greatest invitations for activity and recovery and where they felt most welcomed, and they wanted to do what they felt made the greatest sense and the greatest difference to their recovery. All of this amounted to wanting to be actively invited into structured physiotherapy sessions, of which they would take as many as they could.

Although the main focus of the visible curriculum was on the day to day, by the end of their six weeks most of the participants had started to think ahead to the medium term of weeks and months. One of the main struggles with the acute setting was not being able to see a positive future. This was different for the rehabilitation unit, where the improvements, at least in mobility and some aspects of self-care, occurred fairly linearly. Most felt safe with their progress and expected this to continue. Importantly, in the rehabilitation unit they had started to regain some sense of who they were and of the value of their unique personhood. Consequently, the participants generally left this stage of their recovery with reasonable confidence about the future. The emotional dimension of learning acquisition had developed from the positive gains made in learning content. As shown in the next chapter, however, this link became problematic in the home environment once the provision of regular therapy stopped.

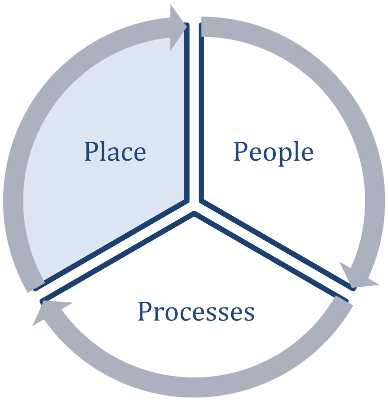
Chapter 10 Findings V: Home

Just as understanding the acute setting helped explain the learning that took place in the rehabilitation unit, so too understanding the unit helped make sense of the learning that some of the participants did at home. Where the sense making of the rehabilitation unit was done in light of the acute setting, home was seen and interpreted in relation to both there and the rehabilitation unit.

In the transition from the rehabilitation unit to home, the patient participants broadly fell into three main groups: (1) those who returned home much as they had been before their stroke with little absolute need for ongoing rehabilitation; (2) those who returned home with impairments but who were outwardly accepting of these and were not seeking active ongoing rehabilitation; and (3) those who returned home with impairments and were anxiously seeking ongoing rehabilitation for what they felt were unmet needs. How they interpreted home was very much shaped by which of these groups they fell into.

As with the other transitions, a great deal was riding on this final transfer home. After their positive experience in the rehabilitation unit, most embarked on it with some uncertainty but also optimism. At this point on their roller-coaster of emotions they were at a relative high, and so it was with expectations rather than just hopes of continued recovery that they returned home. As will be explored below, however, these expectations were realised by some more than others.

10.1 The sense making of the place

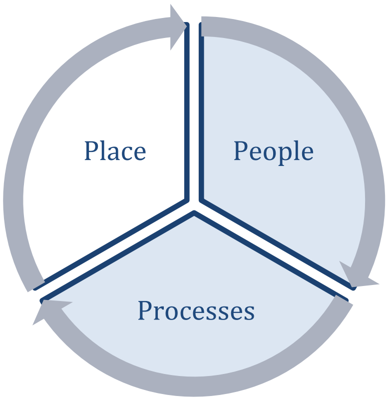


All of the patient participants were pleased to return to the familiarity of home. For a number, though, being at home reinforced the signs of limitation and dependency within their everyday living in a way that they had not felt while in the rehabilitation unit. This was especially the case for Paul, Stewart, Gordon, Jim, and Adam for whom home was unexpectedly dis-invitational in certain respects. A raised toilet seat or a perching stool, for example, would reiterate their sense of restriction, providing a visual reminder of how their circumstances had permanently changed. Stewart commented that where in the rehabilitation unit he was a glass three-quarter full person, at home he felt like a glass three-quarter empty person. When he was in the rehabilitation unit, he did not have the sense of disability and permanence that he felt back at home. Although he knew that he had done very well in his recovery, exceeding his expectations, he was not sure this trajectory could continue at home. Indeed, it was only at home that a number of the group became properly aware of the significance of their stroke in their life history and fully realised that they were no longer the same person that they were before. As Stewart said, it was on being at home and experiencing his new life in that familiar space, that stroke actually became part of his identity and as such, even though he had recovered very well, his life had closed in on him.

> *It's been more or less as I thought it would be but what I also discovered coming back home with all of the equipment around and my somewhat reduced capacity … I'm 85% but I miss the 15% … so it's imposed on me the notion that my life's now a bit more restricted, whereas at [rehab unit] I was making progress every day and thought, didn't think my life was restricted, but now I realise that I've got restrictions in my life that I've got to be aware of … and also I have been able to take a view on the stroke and realised it was a big event in my live and has been woven into my life history in a way that it wasn't before; when I was in [rehab unit], I had had a stroke but now I'm home I realise that I've had a STROKE [strong emphasis placed on this] … that knowledge has embedded itself in my personality in way that it hadn't before … my wider field has closed in a little bit and I'm aware of that. (Stewart)*

> *Gordon: Umm…apart from that, strokes a pain in the arse.*
> *Gordon's wife: you're being recorded [laughter].*
> *Gordon: It is because it affects so many things*
> *Gordon's wife: It does, so many things, it changes your life.*
> *Gordon: I've got to accept that for the rest of my life I'm going to have, not a disability but a partial disability, it will probably never be 100%.*

10.2 The sense making of the people and processes



At the end of their inpatient stay, most of the participants were referred to the community therapy team. For some, this was to consolidate the learning they had done in the rehabilitation unit; for others, with more marked ongoing deficits, the expectation of the participants and their families was for the acquisition of greater learning content. As with the other stages of their stroke journey, the participants had no experience of rehabilitation at home and had little understanding about what community therapy would look like. Indeed, some, such as Tony and Anne, were not even sure why the referral had been made as they could not picture what the community team might do.

As the community team was based at the rehabilitation unit, communication with the inpatient team was strong. This greatly helped Tim and his wife, who had the opportunity to meet the community therapist prior to discharge. Since no previous transition had gone well for them, they were apprehensive about returning home. Knowing that a physiotherapist was coming to help them continue their recovery, and being able to visualise who it would be, was thus very invitational and supportive for them.

The number and nature of the therapy sessions was not clearly articulated prior to discharge. While the participants knew that the provision of physiotherapy would not be the same as in the rehabilitation unit, none had asked when it would end. In the event, some therapy was given to all the patient participants but, as in the acute setting, it was unpredictable in its delivery and stopped, for most of them, too soon. What took its place was the visualisation of a long future without knowledge of how to continue to improve. The amount of input provided was what the service model allowed but it was not what was expected and did not match what the participants believed they needed.

Even though no unrealistic promises had been made, for those with ongoing deficit and who were seeking more recovery, the limitation on the number of sessions made no sense. Going from daily therapy in which they were guided along the path to travel, given exercises and activities to do, and enabled to see progress, to receiving almost nothing was a stark transition. Those with ongoing deficits, in particular, were neither expecting this nor ready for it. Since, to that point, the understanding of recovery had been linked to therapy input, the drastic reduction of therapy not only made no sense to the patient participants but caused fear, sadness and sometimes anger.

Paul's only contact with physiotherapy at home was to be discharged, which made him so angry that he insisted it be done at his house rather than at the rehabilitation unit where he had been asked to return for an outpatient session. His interpretation of the rationale given to him for being discharged was that his high-level walking was considered such a good outcome that he did not need any more input. This, however, contradicted his belief that he now needed physiotherapy for his arm. Since he linked his slow upper limb recovery with the type of therapy he had received in the rehabilitation unit, he did not want to continue to be seen by OTs at home as he did not see their approach as leading to the improvement he desired. For him, as well as for others, without physiotherapy it was impossible to see how they were going to improve. This was most difficult for those, like Paul, with ongoing upper limb deficits who, in the absence of any discussion of prognosis, timelines for recovery or the future, did not believe that they had reached their end outcome but felt at a loss as to what to do.

> ***And if you could redesign the after, what do you think would really suit you for, if you had the perfect, if you could ask for anything to help you with your recovery?***
> *[Quickly] Definitely more physio … because I said that I wanted to walk out of [rehabilitation unit], they concentrated on my leg and I didn't realise this at the time but, yeah, I would love some more on the arm, more so than the OT, to me OT is common sense you can do silly little exercises at home any time, but the physio bit you can't always do on your own, you need help, well I found that anyway.*
> ***What would you like them to do, if you were directing the physio, what would you like them to do, what help would you like from them?***
> *[pause] Anything would be nice, to be honest, you know, I've listened to what they say and I've done all those exercises, but when I saw that physio over at C, at this surgery thing, and he was sort of had me laying down and pulling the shoulder and pushing the joint, obviously you can't do that yourself can you … but I just wanted him to look at it and make sure there was nothing. (Paul)*

The participants who still wanted to progress were frustrated, in part, because few felt they had been given any strategies for progression or any structured programme of exercises to do at home. It became clear to them that time alone was not furthering recovery but was, instead, lost time that could not be regained. Where home exercises had been provided, they were mostly for the lower limb and mobility, not for the upper limb. This matched the experience on the unit, where little attention was given to teaching the participants and their families about ongoing recovery at home. As discussed above, on the rehabilitation unit the planned curriculum meant that independent practice had never gained visibility and the patients had not been sufficiently invited into it. Having not developed understanding of any benefits to be gained, it was not something they felt confident in or competent at.

The small number of visits from the community team meant that they too did not make visible or invite the patients into an exercise practice space where they could progress their improvement at home. The patients thus did not have any visible curriculum to be doing at home. Tim and Gordon were exceptions in this respect because their wives had pushed hard for a curriculum to go home with. As a result, they managed to sustain their exercise practice. However, they were both very clear that they would not have done so without the strong support of their extremely committed wives. It was their wives who had first invited them into the independent practice space and then kept them there. For Tim and Gordon, as for the other patients, the prospect of exercising alone held nothing invitational at all.

Paul and Adam had tried to exercise independently but by their final formal conversation, both were at the point of giving up. Paul had tried to carry on with the few upper limb exercises that were written down for him but saw no progress and so quickly lost motivation. As in the rehabilitation unit, many of the exercises felt remote and unrelated to what he wanted his hand/arm to be able to do. Upper limb exercises such as pushing a cloth across a table or trying to cut up putty did not align closely enough with using a power tool or fixing a shower head – especially when the effort seemed to go nowhere and the outcome did not match expectations. Having abandoned these exercises, he then tried to work out for himself what to do based on what he remembered from his inpatient stay and his general knowledge about exercising. This was, however, much easier for the lower limb than for the upper limb, where he felt completely at a loss. Finally, having failed to drive improvement through specific exercises, he tried to gain improvement through increased everyday use of the limb but found this went nowhere either. In the end, despite huge effort and determination, with no alternative learning strategies to draw upon, he gave up.

Adam’s structured therapy had ended on completion of his second round of upper limb group sessions. He was clear that without the guidance of someone interested in his progress and the modelling from others that the classes provided, he would also be unlikely to carry on exercising at home. In contrast to his everyday world, where his residual deficits were not understood or supported, the group gave him both a sense of worth as an individual and the visibility from others of a potential future outcome. It was through exercising with support that he had seen some small success and he did not believe he would achieve this alone.

When the patients were asked what they would like most to help them exercise now that they were back at home, the response from Paul, Adam, and Gordon, independently given, was to be able to use the gym in the rehabilitation unit again and, when there, to have someone to report into. Because the gym was empty for some of the day and much of the evening, they thought it would be possible to use. When there, they would like to be checked up on and guided in the right direction. Without any clear progress, the exercises became stale and uninteresting so that, especially for those who lived alone, the effort seemed futile. The patients longed for the gym and found it hard knowing that there was something out there that they felt would make all the difference but that was not available to them. The most invitational aspect of their recovery was the therapy gym, which was associated with nothing but good memories. It was the place where, after every session, they had felt a powerful sense of progress that, having experienced nothing but frustration trying to exercise at home, they longed to feel again.

> ***If it was the perfect world where we could offer you anything, what would be your perfect, what would be the ideal things for you, what would be your?***
> *I would have liked more use of the gym, if they could organise an open session.*
> ***This gym here?***
> *Yeah, a lot of the time it is empty, all that nice equipment and its empty, I've had to join a gym um at considerable expense bearing in mind that I'm earning nothing …, if there was a way, if you could cost, people could come and use it, on a set day have an open session for 2hrs a day, once or twice a week, it would be worth, I mean I would drive from B, it takes 40mins to an hour to get in but it would be worth it for two hrs, an hour twice a week … surely they could spare the gym for an hour or two, it's largely empty, you would just have to reschedule the odd person, when I was in here, they used to go home at 5 o'clock and they would kick you out, whereas that place downstairs [the ward] operates 24hrs, I couldn't sleep there because of noise or whatever, I would have come up at 2 in the morning as I'm used to starting early … there's cameras in there so its secure and everything … so when they go home at 5 the place is shut up, its unusual really, all that equipment sitting there and not being used for 12hrs a day. (Paul)*

10.3 Home as a place of rehabilitation and recovery – right place or wrong place?

As a number of the participants reflected, it was on getting home that the true impact of stroke and its consequences became apparent to them. While they were warmly welcomed into the rehabilitation unit, minimal help was given to leave the community there and, equally, little help was given to join any community at home. The affirmation of competence that was offered in rehabilitation unit was sought but, especially for those without spouses to offer it, not received at home. Particularly for those with ongoing impairment, their perceived competence no longer matched what they felt that they needed at home. With no one to guide them, the wider rules, practices and traditions of living life after stroke were not made visible and meant that at least in the first instance, they joined an empty community of someone post stroke.

That they were discharged from the community service on the premise of lack of more learning content was distressing for a number of the participants. Not only did they still want more learning content, but there were also other aspects of personal and cultural learning that they were not necessarily aware of but which they were trying to work through. As they understood it, they were nowhere near the end of their pathway of learning, since the purpose of rehabilitation had not been fully realised for them. With little visibility of both the immediate and longer term, the future was difficult to imagine. It was therefore, at this point of being at home that their identity was really questioned. Without any teaching to establish who to be at home, entry into a post-stroke existence could not be properly achieved. Who they were in the world thus became a real problem.

For most, therefore, home felt like the wrong place to try to progress recovery in the early to late subacute period post stroke. As in the acute setting, there was an absence of doing, and the participants and their families felt that they were again being left to their own devices. Since the rehabilitation unit adopted a largely behaviourist approach to delivery of the planned curriculum, with a focus on learning through exposure, the participants were discharged home with few learning strategies and little knowledge of, or confidence for, independent practice. Further, the small number of visits provided in the community meant that there was no scope to invite them into this mode of rehabilitation. As a result, they were at almost a complete loss as to what to do.

The emotional high and expectations of further improvement that the participants took from the rehabilitation unit to home soon shifted back to the low of fragile hopes. This was similar to how they felt when they left the acute setting, with mixed emotions of anger, anxiety, and deep sadness. They could not understand how the trajectory of improvement over the six weeks in the rehabilitation unit could suddenly come to an end. It made no sense to them that one team of professionals in the rehabilitation unit had had belief in their improving but not another team in the community. They were also at a loss to know how to lead the life that they wanted, with the purpose that they wanted. They knew that they wanted more recovery but they did not know how achieve it. With community visits coming to an end so soon, the participants were faced with the realisation that ongoing practice would be required, which they would have to do alone, and that it would again be up to them to drive their recovery forward. When this did not happen, they faced the anxiety and sadness of not knowing what to do next. The incomplete recovery of those without a plan for supported input demanded further learning and a shift in understanding of their outcome and what their future would be. Misalignment remained in making sense of what the final picture looked like and why.

Intense frustration and sadness were also related not just to the outcome but also to the fact that that many of the patients had tried so hard to get better but it was just not possible. This misalignment between effort and outcome was not fully accepted since it conflicted with previous formal and informal learning situations in which attainment of success was due to effort alone. Self-blame for not working hard enough, not listening and following enough, and not knowing enough about the system to set the right goals, were thus all expressed. In the absence of any other narrative, Paul especially made sense of his limited upper limb recovery by blaming himself for not setting improving upper limb function as a goal in the rehabilitation unit and instead concentrating everything on his standing and walking. He felt that the staff had followed his wishes and worked on his gait but ignored his upper limb. In retrospect, he thought that if he had understood how goal setting worked, he would have set an upper limb goal and his end outcome would have been quite different. From this combination of self-blame and blaming the system/others came a mixture of rolling emotions from frustration to anger and deep sadness. With a successful outcome no longer perceived as possible, and failure thus a certainty, feelings of hopelessness prevailed.

Facing a future of dependency and the inability to live alongside others in the same way that they did before demanded that the patients learn about their altered sense of personhood and self. In particular, not being able to return to previous employment and wider life roles necessitated trying, often alone, to visualise and then put in place what might constitute a new life. During this period of intense personal learning, a safe position needed to be found if defeat was to be accepted. Not all the participants achieved this, however. Because they did not yet believe the end outcome of who they now were, or understand how to be in their new world, some continued to search.

Chapter 11 Summary of the Findings of Study 2: reviewing the objectives for the ethnography

Having a stroke took the patient participants and their families into a new world of which they had little previous knowledge and where learning was from need not choice. This world of rehabilitation and recovery post stroke was a place that they never expected, and did not want, to be. With so much riding on the outcome, though, it was a world that those who still hoped for more recovery did not, by the end, want to leave. It was also a journey of learning and sense making that was experienced with extreme emotional highs and lows. With reference to the objectives identified at the start of this study, this chapter will draw together the main findings and highlight some key points to be developed further in the discussion.

Objectives: To explore

1. **What patients perceive that they learn and how they make sense of this learning in the early-late subacute period post stroke; and**
2. **What it is like to learn and be a learner in the early to late subacute rehabilitation period post stroke**

The learning space into which the patients and their families entered was unfamiliar to them. In order to make sense of what they were experiencing, they looked back to their life pre-stroke – the life that was still visible to them. In the initial stages, the knowns that the participants based their sense making on were that they had had a stroke and that life going forward was likely to be different, in as yet undefined and unknown ways. Their unknowns were about stroke itself, about the process of rehabilitation, and importantly about recovery and what life post stroke might look like. With very little discussion of possible/probable outcome, both the big picture and, often, the specifics of daily learning were felt to be unknown.

When asked what they expected at each stage of their pathway and what they thought they should be doing or learning, the immediate and strong response from the patient participants was that they did not really know. Further questioning revealed how the key conception they worked from was that they struggled to move because they were weak. What they therefore looked for, and found invitational, was a curriculum of rehabilitation that involved learning tangible exercises designed to help them get stronger. It was on this basis that they tried to make sense of what they were learning in the acute setting, the rehabilitation unit, and at home. Whether these places felt right or wrong depended on the visibility of such a curriculum. Sense making of learning was therefore almost exclusively within the domain of acquiring greater learning content – mostly of motor skills but also, to some extent, knowledge.

Because they were focused on gaining greater learning content, the participants did not enter recovery anticipating significant personal or cultural/social learning. At least in the early stages, most had little awareness of, and so did not look to join, any community of practice related to stroke. Since most had not experienced anything like stroke before, they had no reason to do otherwise. Indeed, a number had no awareness that they would need to think about, and work towards, the longer term. Their focus was exclusively on learning for doing, so that learning for belonging, and ultimately for becoming, was not anticipated and not recognised as part of rehabilitation and recovery. Overall, with little visibility of the future and almost no experience to draw upon, most of the participants envisaged entering the learning situation, achieving the content learning, and then exiting. Over time, however, even those participants who recovered well learnt that travelling the pathway of recovering from stroke was neither quick nor easy. They discovered that while progress could be made, it could also stall and stop. Those with ongoing deficit who wanted more recovery learnt that they could not enter the learning of rehabilitation, get it done and leave as they had expected to.

In line with what the participants were looking for, in all three recovery spaces the planned curriculum was almost entirely directed to gaining greater learning content – knowing what, knowing how and, hopefully, being able to. What differed was the visibility of the curriculum and the degree to which it was offered. In the acute setting, while the participants were very keen to engage with a curriculum of recovery, it was mostly perceived as being absent. In the rehabilitation unit, by contrast, they were welcomed and invited into engagement with the curriculum. A sense of competence was largely achieved through positive gains in learning content. In addition, even though the learning outcomes were not fully explicit, what was gained aligned both with what was hoped for by the participants and with what was expected by those delivering the curriculum.

While at the rehabilitation unit, many of the participants expected continuing improvement and a largely complete return to their previous life and personhood. However, for those who could increasingly see that they were going to need to progress their recovery at home, unease built as they did not know how this was going to occur. This became more palpable and more distressing on arriving home, with the reality of needing to progress rehabilitation without enough knowledge or any planned curriculum. The small number of visits from the community team that the system afforded thrust the participants into a constructivist framework of learning that was in stark contrast to the behaviourist approach of the rehabilitation unit. This adjustment could have perhaps been eased with a greater focus on a more cognitivist approach in the unit. Although it is incumbent upon a teacher to hand over the responsibility for learning, this needs to be done through invitational and visible methods that are trusted by the learner. When the scaffolding is taken down, there should then be a solid foundation of skills and strategies of learning in place for the learner to build upon. Learning is the tension point between engagement and emancipation – learners need to be invited in but then eventually they need to be let go. It is thus crucially important for those delivering the teaching to think about how to achieve both and not leave either to chance.

With their beliefs and expectations determining what they saw and found invitational, both the nature of and the outcome from at least parts of the planned curriculum were not visible. Whilst in the rehabilitation unit, because it was clearly visible on their timetables, made the most sense within their understanding of recovery, and was what they looked for, the participants only fully saw the learning-conscious-learning that took place in the planned and structured sessions involving the staff as teachers and them as learners. For those who were given exercises to practise independently, they partially saw this structured planned learning, but they did not really want it, and they mostly did not see the informal learning such as every day washing and dressing that went on as part of normal living on the ward. They knew that they were doing it and could see some small value in learning new routines, but they did not see it as part of their recovery and as something that would help them get better. Overall, therefore, they did not really see the experiential task-conscious-learning that was occurring alongside the planned sessions. It is important for those delivering rehabilitation to be aware that, with little visibility in the curriculum and no discussion to inform the patients otherwise, ward-based tasks such as washing, dressing, eating and drinking were not seen as rehabilitative tasks and were not linked to recovery. Equally, equipment provided for independent practice to promote social, cognitive, and motor learning was not seen or much used. What appeared as an enriched environment was thus not received as such by the participants and their families. Because they did not understand these other dimensions of learning and recovery, the participants were not able to intend them. As a result, when the formal, exercise-based, sessions ended, a number of them felt that they no longer had a curriculum of learning to promote further recovery and, as a consequence, uncertain, and for some, unwanted futures.

Objectives: To explore

3. **Where and how this learning occurred; and**
4. **What factors shaped the level and direction of the learning effort**

The importance of the social situatedness of learning was clear from the participants' strong belief that the places and spaces on the pathway of recovery were very much either right or wrong. To gain mastery of skill, one has to submit to the learning involved. In order to do this, the participants needed to feel safe. Even more than the material aspect of the places and spaces, feeling safe and in the right, or unsafe and in the wrong place, was shaped by the presence of the right/wrong staff who were doing, in the participants' understanding, the right/wrong thing.

In their situation of not knowing, what the participants wanted were people with expertise who could help them to get better. They neither wanted, nor felt able, to take full ownership of their recovery. As well as being vulnerable and anxious, they were exhausted, which added to their sense of wanting someone else to lead their recovery. The staff who were valued most had the cultural competence to understand the patients' positions and backgrounds and to create relationships that provided emotional security through being consistent and predictable, with empathetic communication as well as the ability to perceive and respond to needs. The participants felt that the actions of these staff were done intentionally and, through this, they felt seen and heard.

What the participants looked for, and found most invitational, was teaching that was formal, clear, intentional, visible, and designed for them by others to ease their mastery, with rules learnt and practised later. As with many adult learners, most of the participants were to some degree sceptical, circumspect, and aware of failure. They were, in part, looking for short-term learning episodes rather than wanting, or being able, to sustain learning both all the time and into the long term. A key part of the visibility and 'invitationality' of the rehabilitation process was their timetable. A timeline, even if created by the patient with poor and limited material to work from, is needed to help manage the uncertainty and unknowns of ill-health. It is very hard to wait when one does not know what one is waiting for or for how long. Where for healthcare professionals time passes in just doing their job, for patients it is experienced as lost time and a portion of their lives that is passing. The timetables of the rehabilitation unit supplied important knowns, providing a visible indicator of predictability of input and the sharing of responsibility with others. In doing so, it offered the possibility of a future that the participants wanted and hoped to see. Linking effort with output, they understood that they would need to work to reach their desired outcome, but that it could be attained. They did not believe that they could achieve this alone but needed help to know what to do, and they looked for this help to be provided in a systematic way.

Having never done the type of learning involved in recovery before, the participants had few learning strategies to draw upon. As is common for adult learners, the learning that they expected and wanted to do, wherever and as much as possible, was through assimilation, adding in small ways to what they already had and knew. They were wary of learning through accommodation, which necessitated dismantling the old and building a new, and so carried the greatest risk of the unknown. For the participants without marked ongoing deficits, fitting their new life into their old through assimilative learning was broadly successful. However, this was not the case where ongoing deficit, especially of the upper limb, remained. Without the option of varied strategies, the risks are that the person will either continue in the same vein without the knowledge or confidence to do things differently, or they will stop. Successful learners tend to have a range of learning strategies to draw upon. That the more severely affected participants, especially those with impairments of their upper limb, had only limited strategies available to them was problematic especially when trying to progress their recovery at home. The restricted repertoire of exercises became boring and frustrating, especially when the outcomes were minimal or nil. Not surprisingly, they eventually stopped. It is key for those delivering rehabilitation, therefore, to help learners develop a range of strategies that can be drawn upon in different situations and over time. The curriculum of stroke care meant that the participants were able to develop some strategies to become reasonably efficient with their learning while in the rehabilitation unit, but this did not translate and was not extended to discharge, so they did not have a sufficient range of strategies to draw upon when at home.

Part of the reason why the participants had few learning strategies was that the rehabilitation unit, where most of the planned formal teaching was delivered, followed a mostly behaviourist approach. This emphasised adapting the environment and promoting learning through exposure rather than considering *how* the participants were learning and optimising it. That they were learning and improving was considered sufficient. At least at the start, this behaviourist approach was welcomed, and needed, by the participants who, as novice learners, felt strongly that they did not know what to do and wanted experts to teach them. The limited input they received in the acute setting, and the onus that they then felt to work out what to do for their recovery, meant that when the participants reached the rehabilitation unit they were tired and emotionally very low. They were therefore happy to feel safe within this behaviourist approach. Many spoke of being fatigued and having a limited cognitive capacity, observing that rehabilitation was at least as exhausting mentally as physically. While some patients interpreted this as their own laziness, in reality they were a group of adults who had never envisaged doing anything like what was being asked of them for their rehabilitation. It was thus important, at least at the start, to design learning that specifically recognised this and invited them as learners into the learning space in a safe and supported way. For those with ongoing deficits, who are going to have to transition exercising to their homes, additional and alternative approaches need then to be considered.

Within the behaviourist framework that underpinned the delivery of the curriculum, the most enabling environment and the fullest scaffolding was felt to be provided in the therapy sessions, especially those related to the lower limb and gait recovery. In these sessions, the participants did not have to use too much imagination but instead could learn through assimilation and use perception of the here and now to make sense of what they were experiencing. In contrast to the upper limb sessions, the lower limb sessions fitted many of the principles of successful supported curriculum delivery in that the participants did not have to push too far into the unknown and what they did do had visibility of where the sessions were heading. The task of walking was hugely valued and had great relevance to them, so they had expectations of success. They believed that they could take risks and still be successful, and could act as learners who demonstrated confidence in their abilities to succeed at a task. By being able to see improved performance occurring incrementally in a linear fashion resulting from the input made, they were able to persist for longer and perform better. The lower limb sessions also allowed them to act and thereby gain freedom in a way that the upper limb sessions did not. As they relearnt how to walk, they moved on, both literally and metaphorically, gaining a feeling that they could lead this aspect of their life again.

All of this contrasted with some of the upper limb sessions, where each time the participants returned to square one of not being able to use their limb as they wanted to. It took too much imagination to understand how the exercises or activities could translate to real life, and required too much patience and too much waiting. The task of accommodative learning, dismantling the old and building an unwelcome new, was unmanageable for the participants and eventually they lost faith that they could achieve it – especially when what they wanted was a normally functioning upper limb. Trust derives from an understanding of, and a sense of obligation towards, the collective efforts and goals of those involved, and the participants fully trusted the physiotherapists in a way that they did not trust others. The physiotherapy tasks felt right, producing high activity emotions, and the resulting achievements were right, producing high achievement emotions. Both of these aspects are important for learning post stroke.

As the participants got closer to discharge, there was little sign of any change to the curriculum and mode of delivery, which maintained its behaviourist approach. Although some participants asked for feedback and tried to work out what they should be attending to, little developed to enable this for those with ongoing deficit, whom it was increasingly clear were going to need to carry on navigating a path of recovery once at home. Learning for many of the participants was very demanding, and trying to make sense of everything exhausted them. This was a major topic of both the formal and informal conversations of the research, with long, slow discussions in which the participants worked through why they were experiencing what they were experiencing and what they could do additionally and/or differently. It is therefore important that time is given in rehabilitation to reflection and working through the participants' sense making, especially for participants whose recovery is going to be incomplete and who need to be developing long-term strategies. Although not necessarily appropriate for all, a move towards a cognitivist approach, which emphasises understanding the learner and their learning as opposed to learning though exposure to an enriched environment, could expand the learning strategies of those with ongoing deficit and help their transition home. Building transferable knowledge structures is arguably a harder job in rehabilitation than in some other aspects of healthcare, as it involves teaching patients and/or their families the knowledge and skills that they need to take forward into life. Their learning is therefore not just the technical learning of a specific skill, as might be taught to other patients/carers, with competence that could be signed off. Instead, it involves the development of skills of attending and perceiving so that the person can stay on the pathway of improvement/recovery and not wander, or fall, off. The cognitive or attentional element that is often associated with formalised learning can encourage reflection in a way that informal experiential learning may not. Any available time in the rehabilitation unit, therefore, needs to be used to build these foundations.

What the longitudinal design of this work has highlighted is the evolving nature of the learning that occurs in rehabilitation/recovery and how much patients and their families are impacted by their past, what they experience or fail to experience of their present, and the visibility they have of their future. It was particularly in relation to the three aspects of the place, people, and processes of the curriculum, that the participants looked for, and appraised, alignment and misalignment between what was planned for them to experience (planned), what of this was actually delivered (delivered), what they felt that they should be experiencing (desired), and what they felt they were experiencing (received). Where alignment was strong, things made sense and the participants felt that they were in the right place for their recovery (Figure 19). When there was misalignment, they felt like they were in the wrong place.

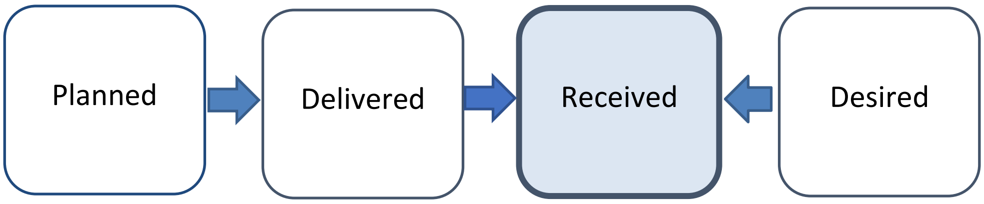


Figure 19 Alignment between what was planned for the patients to experience and what was desired by the patients to experience

It was also on the basis of their understanding, expectations and hopes that the participants interpreted and appraised the outcome of their curriculum – what they could do, who they were with their sense of identity, and how they could be who they were for the life that they wanted to lead. When things made sense, the patients and their families were able to feel safe and could start to step forward, making their way through their rehabilitation and recovery. This was not possible when, however, they did not. Although it was not articulated as learning, the participants certainly did not passively accept what they were afforded by the places, the people, and the processes of the system. These were, instead, appraised and judged against whether they were what the participants believed and expected they should have within their curriculum of recovery and whether they were therefore what they wanted. The contention from the participants that they did not know what to expect from rehabilitation and recovery certainly did not mean that they had empty minds to this. On the contrary, both what the person arrived with at the start of their stroke journey and what they had already experienced, shaped how they felt about the present and what they looked for in the future. No moment along the pathway, therefore, can be seen in isolation as it is always influenced by what has gone before and also shapes what happens next.

11.1 Strengths and limitations of study 2 – the ethnography

Although ethnography is traditionally considered to be a methodology for exploring the culture of peoples and/or a place, the aim of this work was specifically to explore a phenomenon related to a group of people in a place – that of patient learning within the early to late subacute period post stroke. For this, my time was mostly based on the rehabilitation unit, with the intention of trying to capture what learning involved within a rehabilitation context, what it meant to the patients and their families, and what they perceived that they learnt. The intention was not to describe the culture of the place as a whole. As raised in Chapter 5, it is often hard to articulate learning and to know when learning is taking place and/or something has been learnt (Eraut, 2004). A strength of this prospective observational study design was being on site to witness the interactions as they occurred between the people, the places, and the processes. I was able to see and reflect on aspects of learning post stroke in a way that would not have been possible from retrospective interviews/conversations alone, and I would not have arrived at the study’s findings if I had not been so fully immersed on site.

Whether, by exploring a phenomenon and not the culture, this work was not a true ethnography but a qualitative study using ethnographic techniques is a point for consideration. What exactly ethnography is or is not, is much debated. In their respective discussions of this issue, Hammersley (2006, 2018) and Parker-Jenkins (2018) both conclude that what matters is the transparency of the amount and type of data gathered so that the findings presented can be considered in light of these. Although I was not completely immersed in the field, in the way that early ethnographers were, with my involvement within the service over 18 months, and with data collection involving observation, gathering oral accounts and documentary evidence, I would consider this study to be an ethnography.

This time was most concentrated over the summer months, with two consecutive extended periods spent on site observing and listening to the day-to-day activities as they occurred. Returning to site where possible is recommended (Beach, 2005) and doing this allowed me to confirm my initial thoughts and assess the durability of the behaviours observed and sentiments shared. One of the key findings was the strong consistency of voice and this provided reassurance that the initial findings that were starting to be built did not refer only to a one-off occasion or something special or unique about the time of first data gathering. As Hammersley (2006) discusses in one of his critiques of ethnography, descriptions in ethnography are of the moment they are captured, and it cannot be expected that change will not occur. Indeed, change in respect to time and circumstance should be expected (Beach, 2005; Walford, 2007). Gathering data over a prolonged period, therefore, has afforded credibility to the findings by having some generalisability, at least over time.

Being within the service over an extended period also allowed me to start to trace possible causal processes, which was important in trying to understand the phenomenon of learning. A criticism Hammersley raises of researchers is that they often fail to examine the nature of the phenomenon (2019) despite this being a strength that the methods of ethnography he feels can confer (2018). Not only does an ethnographer need to describe, they also need to analyse (Hammersley, 2006). Studying the day-to-day processes and practices of rehabilitation, and seeing and hearing at first-hand what those involved did and said in particular contexts, enabled the phenomenon of patient learning to start to be witnessed and understood.

Aligned to Hammersley's (2006) contention that ethnography needs to involve analysis, Willis and Trondman (2000) in their *Manifesto for ethnography* also highlight how ethnography needs to be linked to theory in all aspects of the process. As part of this, both Atkinson (2015) and Delamont (2016) stress that analysis within ethnography needs to involve reading – especially from sources outside the immediate field. Along with the translation of theory from one field of practice to another, this should better enable the familiar to feel strange. The wide reading that I undertook during the lengthy period of analysis allowed my thoughts to develop and be refined (see further in the next section). This iterative process, led by theory, of backwards and forwards movement between external texts and the texts of the transcripts and field notes, informed the development of novel findings and, I believe, led to the work being richer as a result.

Finally, returning to the field also allowed me to show my commitment to the people and the service. This was important to both maintain the understanding of this commitment by those staff I knew already, and for it to be built with others. Building trust is something that can often be achieved only with time (Emmel et al., 2007; Miller and Bell, 2002), but it increases the credibility, respectability, and trustworthiness of the work in the eyes of those involved (Parker-Jenkins, 2018).

As accounts within ethnography are context specific (Hammersley, 2018), to make sense of the patients' sense making it was necessary to have seen the people, places and processes that were being referred to. Being on site enabled the processes of learning to be viewed contemporaneously, and by having the conversations and actively listening at the time when the learning was taking place, the participants did not have to register what they were doing as learning nor did they have to entirely reflect back. Instead, they could discuss what was occurring in relation to their current situation.

Both listening and observing are important within ethnography, with different commentators extolling their respective virtues. As the objectives of this work were to develop a deeper understanding of what the patients and their family members perceived that they were learning and how they made sense of it, listening alongside observing was important. This involved an exploration of the interaction that the patient participants had with their families, with other patients and staff, and with me. As discussed by Forsey (2010), within ethnography listening is just as important as seeing and engaged listening needs to be recognised with equal value alongside participant observation. Indeed, he reflects that, as in this work, what ethnographers report in their written text often relates more to what they heard than what they saw. Despite the emphasis being placed on the spoken word and the findings being structured around the narrative of the patients and their families, my reflection is still that the work was more ethnographic than phenomenological as the voices could only have been interpreted as they were in light of what was seen and experienced.

Making the decision to provide direct quotations from the participants in the findings also gave value to their voice – something that is considered important within ethnography (Emmel et al., 2007). A criticism raised of the method is how much the final voice of the ethnographer is really that of the participants or not. How much it is their world lived by them that is finally represented, or instead the world constructed by the ethnographer. Despite importance being given to the role of theory informing all stages of ethnography (Willis and Trondman, 2000), a parallel criticism is that studying the lives of the people involved in terms of theory does not necessarily reflect the world as the people who live those lives see it. One important concern is that the researcher may claim a superior voice to that of the participants, a point that is, in part, countered by Hammersley (2019), who suggests that what the researcher chooses to explore is also often of concern to the people involved as well. The hope of this ethnography is that the participants' views of the emic do sit alongside those of me as the researcher, of the etic.

To be confident of this, it is important that the methods employed are rigorous. In order to capture the participants' voice, the conversations were recorded and then transcribed by hand. This process was lengthy, given my limited proficiency, but what this afforded was full immersion in the words – both oral and then written. This process of transcribing, and each subsequent re-listen, took me back to the conversations and I was able to picture where they took place and what context they were in. This picturing was enhanced by aligning the transcripts to the fieldnotes.

These notes were written both on site and afterwards. As I was not fully clear quite what learning looked and sounded like and therefore what I should be observing and listening to, the fieldnotes were mostly in the forms of inscription and noted largely what happened or did not happen (Beach, 2005). As the analysis progressed with its focus on visible and invisible, I noted parallels so that, just as the patients saw what they were looking for, so too was this a risk for me. I also entered the field not as a blank slate but with professional and personal identities (Hoey, 2014). As such, it is important to acknowledge that I was looking with my lens of being a physiotherapist who was familiar with neurorehabilitation. This did, at least initially, influence how I looked, what I attended to, and what I perceived. As my understanding changed over the 18 months of data gathering, I started to look for different things when observing on site and, over time, for different things within the data.

The finding that I am most aware could be read as presenting this possible bias is that about the strength of feeling by the participants towards physiotherapy and their struggles with some of the other professions within the MDT. This was not something that I had expected and it in no way reflects a desire to promote 'my' profession over others. I do not feel that the participants were expressing these sentiments because of my role, and I hope that others reading this work do not feel that I looked more positively on what the physiotherapists were doing compared to any of the other professional group. If anything, it made me reflect on how, because of the propensity for greater lower limb recovery than upper limb particularly post anterior circulation strokes (Paci et al., 2016), physiotherapists, especially if they focus on the lower limb and gait, have an advantage that is gifted to them rather than arising from anything they necessarily do.

Entering the field as a physiotherapist and student educator meant that, if there is such a thing as a neutral researcher, I could not claim this role. Nevertheless, I tried to maintain objectivity as I looked for the strange in the familiar. It is important to recognise, however, that the findings were shaped by me as a researcher new to ethnography, and that other people, with different understandings, a different research question and a different vision, might have seen things differently. The findings, though, were built from the ground up and came from the work and not from preconceived ideas (Hoey, 2014).

Alongside the strengths, there were also some limitations to this work. The data collection was based in just one Trust, in the relative affluence and limited socio-cultural diversity of the Southeast of England. All the participants were white, and the majority were male. They were reasonably socioeconomically advanced, having all worked, and all (bar one) owned their own home. They had a readiness to commit to the work of learning as part of recovery/rehabilitation, with none presenting with post stroke cognitive deficits and all believing that the input they put in would equate to output they would get out. Whatever the influence of these factors, it needs to be recognised that this homogenous group all experienced their journey of rehabilitation and recovery in a very similar way. Indeed, one of the interesting points was that although the data were gathered from participants who, in the main, did not overlap, they almost all said the same things in the same words. It may well be, though, that a different group of people would have experienced the pathway differently. It would be important therefore to replicate this work in other settings to determine how much the findings could be extended to others.

An additional aspect of homogeneity was that all the participants had had a stroke. Because the rehabilitation unit was for people both post stroke and with other neurological conditions, it was felt that it would be hard for the staff to separate out in their discussion learning related to people post stroke and that for other forms of acquired brain injury (ABI). Both groups were therefore included within the eligibility criteria. The nature of who was admitted to the unit over the data collection periods meant that no one with other forms of ABI was recruited. That the findings were, as a result, focused just on stroke adds strength to the transferability to this population, but limits the extent to which they can be extended to others with sudden onset, vascular, neurological conditions.

As is normal for qualitative research, the group was also relatively small. This was always the intention, as it allowed for relationships to build over time and for the participants and me to get to know each other. It was through these warm and trusting relationships that I was able to gather the depth of data that were collected. As recovery and learning are both extended processes, there was certainly benefit from being with a smaller group of people for a longer period of time.

Although I was warmly welcomed on to the unit by the patients, their families and the staff, I was an outsider entering and leaving the field. While this position had its strengths, as I was not involved in either the delivery of patient care or the politics of the unit, in my declared role as physiotherapy researcher I was watching practice and therefore this may have influenced how the participants behaved and what they did or said. Being known to some of the staff in the unit before the research began and spending extended time there may have diminished this dimension of being an outsider. However, as with all qualitative research, it needs to be recognised that, to an extent, the more formal interactions were constructed because the people were part of the research.

As a way of lessening my role as an outsider, and as a form of thanks for allowing me to be there, I offered to teach about stroke, recovery, and rehabilitation, to any of the professional groups as part of their professional development. This could be to individuals or small or larger groups, and on any topic of their choosing. The offer was mostly taken up by the nurses, which allowed me to build further trusting relationships with them. Although I had aimed to keep a relative degree of detachment, as a consequence of this involvement I was seen by some as an expert in the field and so my expertise was sometimes solicited as part of ward practice and delivery of care. This was often a complex situation to negotiate: I did not want to refuse to help when the patients and staff were helping me, but I had to stress that I was not part of the care delivery team. I also did not want to appear obstructive in not sharing findings while on site data gathering when these were being solicited so that they could lead to early implementation of different ways of working to enhance patient care. The desire from the staff at the rehabilitation unit and wider neurological services to continually improve and develop their services meant that they gave generously to the research in the hope that the findings could influence their patient care. In commentary about ethnography, it is recognised that it can be difficult to stay detached when the participants want more from one as the researcher (Emmel et al., 2007; Parker-Jenkins, 2018). As described by Emmel et al., (2007), it can often be the exchanging of one valuable resource for another, but I was aware of the challenge of being both a critic and ongoing participant observer (Bell, 2019). To minimise the impact of this, reflexivity and the positioning of self are key (Brookfield, 2009), and I would say that by the end and my exit from the field, I was a nominal member of the community being researched.

Chapter 12 Discussion: The rehabilitation curriculum and the processes and places of its enactment

This overall research started with the premise that to optimise recovery post stroke, people need to practise at sufficient intensity (Lohse et al., 2014). For this, they need to know what to do and therefore often need to receive some form of instruction or teaching. Poor education leading to patients not knowing, understanding, or remembering what they have been taught limits adherence to health management plans (Coulter and Ellins, 2007, Institute of Medicine (US), 2004). In contrast, effective therapeutic patient education has been shown to have significant beneficial effects on health outcomes (Lagger et al., 2010; Simonsmeier et al., 2022). Within therapy sessions, the delivery of education is reported by therapists as being integral to, and forming an extensive part of, their practice (Caladine, 2013; Rindflesch, 2009). However, this is realised in a way that is often inconsistent, passive, and based largely on what the therapists think their patients need (Foster et al., 2012; Hafsteinsdottir et al., 2011; Hoffmann and Cochrane, 2009).

What this ethnography has shown is that in the early to late subacute stages post stroke, amid all the uncertainties and unknowns they experienced, what the patient participants looked for, and wanted, was rehabilitation that was clearly visible and invitational to them. This involved not just content that they believed in and wanted but content delivered in a place and by people enacting processes that aligned to what made sense to them. As so much depended on this for the participants and their families, their emotional wellbeing was strongly influenced by the alignment of what was planned to what was delivered, what was received, and what was desired (Figure 20).

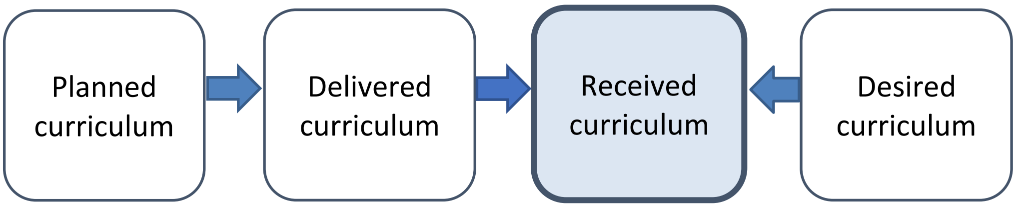


Figure 20 Alignment between a planned curriculum and the desired curriculum

Like formal education, rehabilitation is assisted and purposeful learning that arises from facilitated guidance that has been designed by others for the purpose of consciously promoting the achievement of the learning. Both are based on some form of teaching and are educative learning rather than learning just through the accumulation of experience. Within formal education, to guide the structure, delivery and content of this learning, there is often a curriculum based around a clear statement of intent detailing what the endeavour is setting out to achieve.

The participants in this work were looking for just such a curriculum of guided, structured, and systematic activity to help them to recover. Where this was visible, they felt the system was safe and invitational, and that they were in the right place for their recovery. Where it was not, and there seemed either to be a limited or no curriculum, they felt very much that the system was dis-invitational, and they were in the wrong place. Aligning the process of rehabilitation to a more formal curriculum, like those in education, has not been considered before. It offers a structured and comprehensive way to view, and articulate, both the different elements that people receiving rehabilitation post stroke are looking for and what those working in the field plan and deliver.

A curriculum is more than just its stated syllabus of activity (Prideaux, 2003). First, it should be underpinned by a statement of values and purpose that aligns with the content and details what the learners should get from the learning (Grant, 2018; Prideaux, 2003). It then needs to lay out how the delivery will be organised, how the outcomes will be assessed and finally how the curriculum overall will be evaluated and by whom (Grant, 2018; Prideaux, 2003). Thinking of what is currently offered within rehabilitation post stroke as a curriculum that can be clearly articulated allows both those planning treatment and those receiving it to know what is being aimed at. If this is not made explicit and visible, there is a risk that the understanding and expectations of the learner will be different from those of the teacher – a misalignment, producing a lack of belief and trust that, as was seen within this study, can become problematic for both sides.

Traditionally, educational curricula have been structured around the needs of the organisation or those delivering it. More recently, however, the focus has been placed on enabling curricula that are structured around the learner, putting the person, and their needs, at the centre (Kift and Nelson, 2005). These curricula focus on designing environments that humanise the learning experience. To do this, it is essential to know about the learner. The findings from this work showed that an important part of this is exploring what the patients and their families understood about the process of rehabilitation and what they expected to get from it, as this determined what they looked for and how they appraised what they received. If what was provided aligned with what they expected, then things made sense. Misalignment, however, resulted in a lack of sense (Figure 21).

This chapter will start by, first, reviewing the important considerations to be aware of about the patient, as the learner, at the centre of the curriculum. It will then propose possible purposes for rehabilitation and their links to content, before looking at the teaching and learning in the delivery of the curriculum. Finally, the chapter will end by considering how the participants evaluated the curriculum in the three different places of the acute setting, the rehabilitation unit and home – if indeed they saw a curriculum being present and enacted in these places at all.

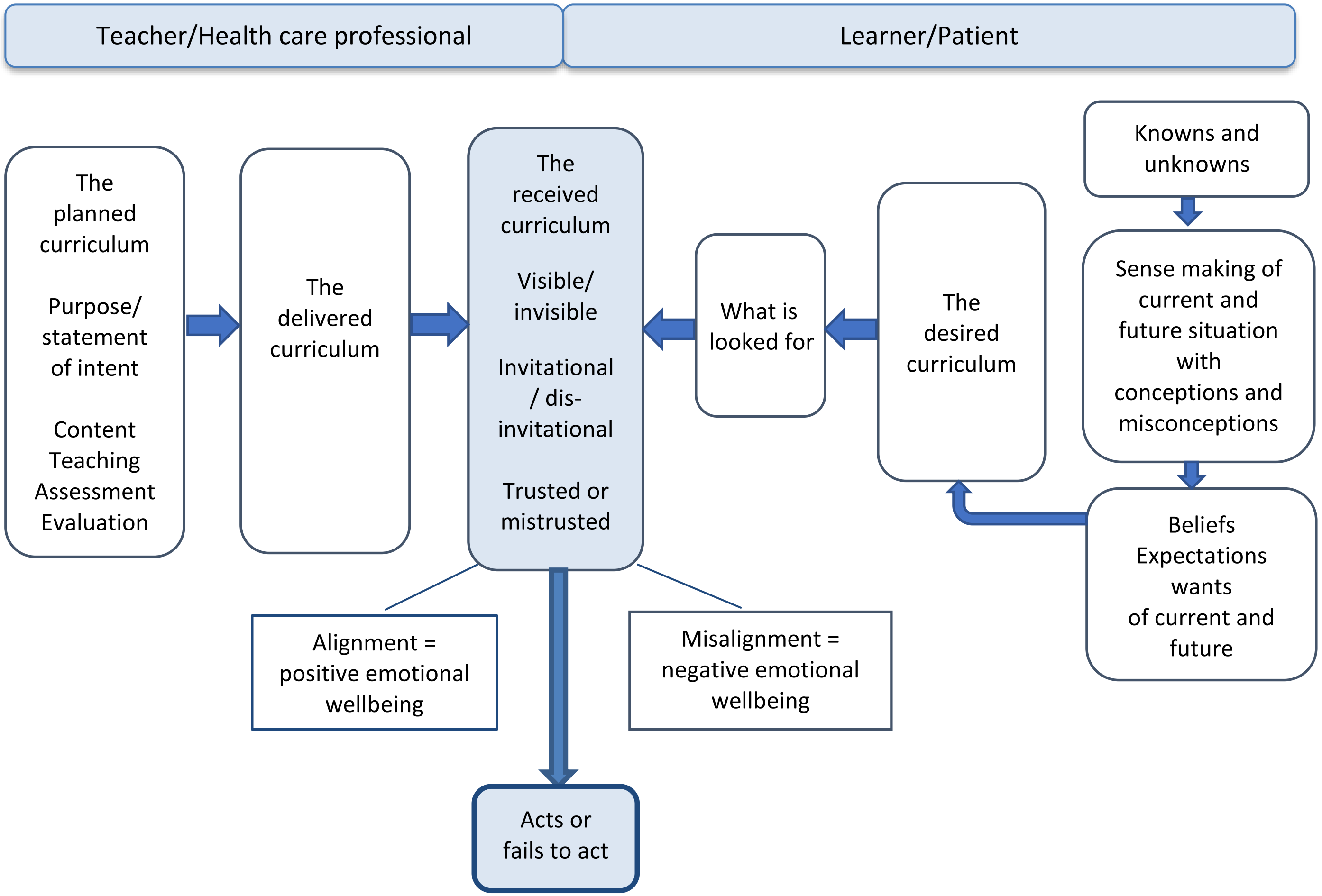


Figure 21 Visualisation of the sense making of the received curriculum in rehabilitation post stroke

12.1 The patient as the learner

When designing a curriculum based around the learner, the first questions to consider are: a) who are the subjects of the learning within the curriculum; b) how did they arrive in the position that they are in; and c) what, in the specific situation, is their contract to learn? These opening questions are important because although learning and education/rehabilitation are not the sole preserve of the learner, the role of the teacher/health care professional being integral and irreplaceable, it is the learner who ultimately needs to carry out and enact the learning. Those delivering the teaching cannot roll out a curriculum irrespective of the recipients with the hope that the planned learning will occur (Biesta, 2017; Dumont et al., 2010; Illeris, 2017b). Instead, they need to account for both the wider experiences of the learner and the context of the learning. To be able to help the people doing the learning, it is important to know who they are (Grant, 2018).

In this work, the people who were doing the learning were the patients post stroke and their spouses. The patients were adults who found themselves in the situation of novice learners needing to learn without ever having anticipated doing the type of learning that was being asked of them. Rehabilitation post stroke was therefore an enforced learning episode which came at a time of life when the participants largely did not want to do the learning and practising that they now needed to do. Although adult learners may want to be actively learning, or feel that they have to be learning, they often do not want to be in formal learning situations at all (Illeris, 2003b). It was in this contradictory position that most of the participants found themselves – desperately wanting to be recovered but at the same time, especially if not invited and supported, either not feeling able or not really wanting to do the learning involved.

Although they were newcomers to recovery post stroke, the participants did not enter the learning situation as blank slates. Instead, like most novice learners embarking on new learning, they came both with knowns and unknowns and, correspondingly, conceptions and misconceptions about their learning situation. On this basis, and through the subsequent sense making of their current and future situation, they developed beliefs and expectations that gave rise to wants and desires. Although it was not as straightforward as this for the participants involved, if teaching and learning are placed within a constructivist framework, the processes are considered to start from what the learner knows already and to proceed to where the person wants to be (Hattie and Yates, 2014).

As Ausubel stated back in 1968 in an early work written on the cognitive view of educational psychology: “If I had to reduce all of educational psychology to just one principle, I would say this: The most important single factor influencing learning is what the learner already knows. Ascertain this and teach him accordingly.” (p. 163). At least initially, most learners, including the participants in this research, try to fit their new learning into their old understanding. If the new learning is going to succeed, therefore, it is crucially important to recognise at the outset what this old understanding is.

In his commentary on the learning sciences, Sawyer (2008), suggested that: “One of the most important discoveries guiding learning sciences research is that learning always takes place against a backdrop of existing knowledge – students do not enter the classroom as empty vessels, waiting to be filled; they enter the classroom with half-formed ideas and misconceptions about how the world works.” (p.6). In the OECD document, *The Nature of Learning* (Dumont et al., 2010), this point is extended by showing how information can remain confused and incomplete: learners often fail to perceive the relationship between pieces of knowledge, so that they simultaneously hold correct and incorrect understandings without noticing the contradiction, simply using whatever feels right within a given situation. Teachers, and designers of curricula, need to know what these conceptions and misconceptions are so that, as was shown throughout this work, they can understand what the person is perceiving, thinking, understanding, and believing about the situation they are in. From this, the teachers can understand: first, what the learners are looking for and what is visible to them; secondly, how invitational or otherwise the learners find the teaching; and finally, whether the learners trust what they are experiencing or not. It is these factors that will determine what the learners do or do not do.

In considering the aspect of visibility/invisibility, two elements of thinking from two very different worlds, unrelated to stroke or even health, are pertinent. The first is the oft cited phrase ‘You cannot be what you cannot see’ (Wright Edelman), which although stemming from the completely different context of American civil rights and the Children’s Defence Fund, seems to have great resonance for people trying to recover from stroke. The second, this time from the world of art appreciation, is the work of John Berger, and in particular his book *Ways of Seeing* (1972), in which he discusses how seeing establishes our place in the world. What Berger emphasises is that what we know, what we feel that we understand, and what we believe, affect how we look and therefore how and what we see. As the human eye can only see one thing at a time, what we select to attend to centres this chosen aspect for the beholder. He points out that we only see what we look at and that what we look at is the active choice of the seer.

The importance of seeing and perceiving to education and learning has been previously noted. In his writing on invitational teaching/education, Purkey (Purkey and Schmidt, 1990) places the perceptual tradition alongside self-concept theory and the democratic ethos as a key underpinning element. The perceptual tradition maintains that how a person behaves is the result of how they see and perceive the world (Purkey and Stanley, 1991). People construct their understanding and make their choices based on what they see and their subsequent interpretation of this rather than, necessarily, on the reality of the facts. In relation to everything that is delivered within the current curriculum of rehabilitation post stroke, it is therefore important to consider what the patients and their family members are looking for and why. What is visible to them and what is invisible? Does this align with what they expect to see and are therefore looking for? And does it align with what those delivering the curriculum think they should be seeing? Ultimately, these questions will determine how the person makes sense of the situation that they are in, whether they find it invitational or not and, from this, whether and how they act.

In line with the saying ‘You cannot be what you cannot see’, with their limited visibility of the future, the participants were largely building towards the only life that they could see and the one they desperately wanted, which was life as it was before their stroke. This picturing of, and desire to return to, pre-stroke life has been described previously by others (Mckevitt et al., 2004, Salter et al., 2008; Satink et al., 2013). Learning in this early-middle stage was about trying to go forwards in order to go backwards, to how they had been before their stroke. With nothing else visible, the only plan for being or becoming for the majority of the patients was their old life, and it was this that they largely drew upon to make sense of what they were experiencing.

The problem with directing learning effort to what was in the past is that we lead life not for the past but for what follows in the future, with the present being the in-between of the already had of prehension and the not yet of aspiration (Ingold, 2015). As Ingold writes, at any moment in life, one is both fully prepared and yet utterly unprepared (2015). A similar point is raised by Steen Nepper Larson in his conversation with John Hattie in their book, the *Purposes of Education* (2020): we live in the tension point of the now, which is directed to an unknown future that is already beginning and is influenced by a historical past that is not yet over. This complex point of now has previously been described in relation to the biographical disruption resulting from stroke by Caroline Ellis Hill with her Life Threads model (Ellis Hill et al., 2008). These threads of life represent the continuity between past memories and future plans that are so important for emotional wellbeing. The challenge presented by the disruption of a person's life narrative was evident from the participants, who found themselves, at their early stage of stroke recovery, trying to use their imagination to move into a mostly invisible future while holding on to their perceptions of and groundings from a past that was visible, understood and, for them, yet to end.

These findings suggest that it is important for people engaged in designing and developing the teaching of rehabilitation to understand the complex positionality of stroke survivors and the sense making that results from it. This will help them to understand the different expectations and wants the patients have from the process of learning and what they are looking for from those delivering it. People have varying degrees of openness to new experiences and/or dispositions to learn and make different judgements on the value of investing in the learning effort. A person's behaviour is based on their perceptions and every person behaves in a way that makes the most sense to him or her at a particular moment (Purkey and Stanley, 1991). Learning through initially attending, then perceiving and finally sense-making requires the active involvement of the learner. However, because people in the position of the participants are often limited in what they can attend to and perceive, they are selective and tend to focus only on what they perceive is relevant to their needs and makes the most sense at that time. Having a curriculum that is visible and clearly articulated should allow them to see more clearly the otherwise largely invisible future they are aiming at and the pathway to get there.

In this study, the participants were motivated to learn, but they learned based on what made sense to them and what they believed in. It is this that helps explain what they felt and what they did, or did not do, as part of their rehabilitation and recovery. As Jarvis states (2009), it is the whole person who learns, so by understanding the person and their understanding, beliefs, expectations/hopes and wants, teachers can better understand the why of behaviour and, from there, the what. Without this knowledge, what healthcare professionals, as teachers, deliver within their curriculum of rehabilitation may not make sense to the learner, may not match the perceptions, beliefs, expectations and wants that they have, and therefore may not lead to actions that have the best chance of resulting in a successful outcome.

12.2 Underpinning values and purpose – what the learners should get from the learning

Curricula need to be based on a statement of intent or vision (Grant, 2018). As stated by Tyler in his seminal work from the late 1940s on curriculum design, “it is very necessary to have some conception of the goals that are being aimed at. These educational objectives become the criteria by which materials are selected, content is outlined, instructional procedures are developed and tests and examinations are prepared” (Tyler, 1949 p.52). From this, the structure, content, and process can be derived and defined.

The term ‘to rehabilitate’ dates from the middle of the 1500s and means to make fit again. Other terms that can be used include restore, reinstate, redeem, and reclaim. This end outcome is commonly reflected in descriptions of rehabilitation and recovery such as this, from the first stroke roundtable collaboration: “Rehabilitation reflects a process of care, while recovery reflects the extent to which body structure and functions, as well as activities, have returned to their pre-stroke state” (Bernhardt et al., 2017 p.445). Taken literally, it may be that equating the term rehabilitation to restoration and making fit again, is one of the drivers for what people look for and what they expect the purpose, or goal, of rehabilitation to be. It may also be one of the problems for perception of outcome, with the group of participants who were still searching for more recovery not feeling that they were restored, reclaimed, or made fit again. Stone and Papadimitriou (2015) suggest that a better derivation for rehabilitation is not from the verb *habile*, meaning to be able/ to be fit again, but instead from the verb *habe* or *haber*, meaning to have. They talk about rehabilitation being the re-having – for example, the re-having of oneself. This way of thinking, the having or re-having of oneself, aligns with the work of the educational theorist, Gert Biesta, who has written extensively on the purposes of education. He talks about there being not one but three inter-related domains, or ‘gifts’, of education – the gift of qualification, the gift of socialisation, and the gift of subjectification (2010). All of these are relevant to rehabilitation, aligning with the three aspects developed from the meta-ethnography of learning to be an expert, learning who to be in a community alongside others, and learning who and how to be as someone living with a health condition such as stroke.

Rehabilitation for qualification was the gift that was most evident for the participants in what was delivered. In respect to both purpose and content, it was also most immediately what the participants wanted, what they saw, what was most invitational to them, and what made the greatest sense. The assessment and evaluation components of a curriculum, the participant goals and the metrics gathered, were all set in relation to rehabilitation for qualification. This was the domain that, at least in the short term, those delivering the rehabilitation and those receiving it concentrated on as the key gift. In line with previous research which has shown that people post stroke look for greater functional outcome (Barker and Brauer, 2005; Luker et al., 2015; Wiles et al., 2002), at each stage of the stroke journey the participants desired greater content learning – higher levels of motor skills and knowledge and therefore higher levels of qualification to act in a competent, skilful, and knowledgeable way. It was this aspect that was most closely linked with the participant's emotional wellbeing, with real joy when content was gained and intense disappointment when it was not. For many people with motor deficit, the syllabus of a curriculum of rehabilitation is not likely to be complete and trusted unless this purpose of learning for at least some greater qualification is included.

Again, supporting the findings of others (Pereira et al., 2021; Sarre et al., 2014; Theadom et al., 2018), the desired content and purpose of learning for the participants with ongoing impairment changed over time, away from a sole focus on learning for qualification and content acquisition to learning for participation in the community as someone post stroke. With a longer-term perspective, and the realisation that stroke would always be part of them, their learning shifted from learning-for-having to learning-for-being/becoming. These are two different types and reasons for learning that can sit alone or together (Sfard, 1998). Learning for the acquisition of more motor function was a desire that none of the participants ever lost but some gained the awareness of needing to learn also about participation in life. In just the same way that they sought teaching for their acquisition-based learning, so did they for participation-based-learning. Since this was as complex a task as acquiring new learning, the participants did not feel able to work it out completely for themselves. When this teaching for becoming was not forthcoming, the associated emotional learning of disappointment and distress was just the same as for the lack of continued help in the acquisition of greater learning content.

Reflecting this shift to learning for participation, the second purpose of education Biesta (2010) refers to that should be visibly present in a curriculum is socialisation. This encompasses the socio-cultural aspect of learning and therefore the ways of being for the person so that they can competently navigate their world (Biesta, 2010). Competence in action is, though, not defined by the individual but by the existing community. Membership of one's community, the importance of which has been recognised by people post stroke (Anderson and Whitfield, 2013; Haslam et al., 2008; Kruithof et al., 2013), is based on the demonstration of that competence (Wenger-Trayner and Wenger-Trayner, 2015; Biesta, 2006; Vitello et al., 2021). It is not just an individual characteristic but something that is recognisable by other members of the community. Peter Jarvis (2012), in his writing about learning in a social sphere, talks about learning occurring in the tension field, the interaction, between the individual and the social, and how the more the person is involved and engaged in this interaction, the greater will be their learning possibilities.

When arriving at new borders within a learning landscape, learners have to choose whether to cross those borders and then commit to learning the history, traditions and general ways of working of that new learning space or not (Wenger-Trayner and Wenger-Trayner, 2015). A key gift of education and, in turn, of rehabilitation, is therefore to design a curriculum that helps the learner see that there is a border to be crossed and then actively invites them, as newcomers, into the socio-cultural aspects of their new learning space – the insertion of the newcomer into the existing order (Biesta, 2006). Moreover, the syllabus of the curriculum then needs to help them stay and learn. Giving learners the opportunity to locate themselves in the customs and practices of a new situation is important because it is here that learners are challenged to consider how others see them and it is therefore here where identity sits (Biesta, 2012; 2021). Learning is not just about the individual but about their relationship with others both within and outside the learning space. The domain of socialisation therefore demands that the curriculum of rehabilitation helps the learner answer the question: who am I in this world?

Following from the question of identity, the last gift of education proposed by Biesta (2010; 2020) relates to *how* I am. Learning should enable an individual to exist in the world as subject in themselves rather than an object for others – what he calls subjectification. The purpose is therefore to give the person their freedom to act or refrain from action – to exist, with purpose, in and with the world alongside others. Whereas socialisation refers to relationships and how people see us, subjectification relates to how others act on what we do, which, in turn, allows us to be subject and not object. Implicit to existing is acknowledging one's uniqueness as irreplaceability

– how I exist and what no one else can do in my place (Biesta, 2020). The key questions Biesta raises here are: when does it matter than I am I? When does it matter that it is me rather than anyone else? What responsibility falls to me as me, and do I take this up or do I walk away from it? Drawing on one of the findings from Martin et al (2015) of the need for people post acquired brain injury to be a friend and not just have a friend, this sentiment seems to have particular resonance in that it is only when we are in the world alongside others as subject and not object that we can exist. If we withdraw from the world, or are partially withdrawn from it by stroke, then we may exist just for ourselves, which is a poor way to exist, if indeed it is a way to exist at all (Biesta, 2020).

Biesta recognises that the term subjectification plays on the double meaning of the word subject – to be a subject means to be the origin of action, but as individuals we originate things for other people to then take up what we have begun. If we are to exist in the world therefore, we are subjected to what other people do with these beginnings, which is outside of our control. In this aspect of his work, Biesta draws particularly on the political philosopher, Hannah Arendt, and her work on freedom and what it is to be human – what she called the ‘human condition’. To be free, she argues, is not an internal construct about having the will but an external construct of being able to do and to act – the freedom to be able to act in ways that are new, unpredictable, surprising, different, and human. “Men are free—as distinguished from their possessing the gift of freedom—as long as they act […] for to be free and to act are the same” (Arendt, 1961 p.151). Particularly pertinent for those who work in rehabilitation, she states that labour (tied to the human condition of life), work (tied to the condition of worldliness) and action (tied to the condition of plurality) are what make up the human condition – the three fundamental activities of our being-in-the-world (Arendt, 1958). Although she recognises that we often think that we do not want to labour, labour gives us purpose, fulfilment and meaning. Labouring is important because we toil to get to a place of happiness which, alongside safety and security, is of the highest value. We live in a labouring society and how we define ourselves and ascribe value to our lives is very much orientated around what we do.

Without labour, lives would be trivial and if we are separated from labour, perhaps by stroke, then we can lose both meaning and public significance.

Different from labour, work, with its more specific focus on the manmade and the artificiality of fabrication and production is also important, as finally is action (including speech) as this is ultimately how humans disclose themselves to others. Through action, we distinguish ourselves from others as unique beings and in this way generate human relationships. It is action that for Arendt really distinguishes humans from other species who also have to labour and work. Action, she says, enables us to distinguish *who* we are as opposed to labour and work, which distinguish *what* we are. Whereas we are similar in what we are, we are very different in who we are. Actions individualise people and give them a recognisable identity and meaningfulness as someone who matters in the world. This loss of identity and meaningfulness was, indeed, keenly felt by some of the participants whose could not act in the way that they wished.

To act can require courage in stepping away from the safety and security of what is already known. It is through acting, however, that individuals are noticed, talked about, and become unique and purposeful. Actions thus make individuals meaningful. Two central tenets of action are freedom and plurality. The beginnings that we make need to be taken up by others so that they can be judged and acknowledged, and through this made meaningful. As Arendt says at the beginning of *The Human Condition*, it is crucial to realise the 'fact that men, not Man, live on the earth and inhabit the world' (Arendt, 1958 p.7). It is by virtue of plurality that each of us is capable of acting and relating to others in ways that are unique and distinctive, contributing to a network of actions and relationships that is infinitely complex and unpredictable. In action and speech, with their revelatory quality, Arendt maintains, individuals reveal themselves as the unique beings they are and disclose to the world their distinct personalities.

Translating this to rehabilitation and curriculum design, the participants post stroke who were challenged to labour, work, and act, were confronted with the question of their freedom and whether, and how, they could be the humans that they wanted to be. As Tim Ingold (2015) states, humans must do what they do in order to be who they are, unlike animals who must be who they are in order to do what they do. In the acute setting particularly, the participants talked about being trapped and unable to act, so that their sense of self was curtailed. This changed in the rehabilitation unit. There they were not only helped to act but were with staff, other patients and visitors who could take up these actions and respond to them. A number of the participants expressed sentiments of uniqueness, with a sense of irreplaceability through, for example, their ability to assist others less able than themselves. From this, they were able to build a sense of subjectivity from their original position of being just an object. At home, however, faced with the reality of labouring, working, and acting but without much support or the presence of others, the sense of being an object dependent on others returned. Their learning was thus that they were not able to be the I that they wanted to be.

Previous qualitative research with individuals post stroke has identified a number of these aspects related to qualification, socialisation, and subjectification. Using the framework of these three ‘gifts’, though, makes it possible to think in a more concerted way about the purpose of rehabilitation and the learning involved in recovery. It could be used to determine what needs to be included both in a statement of intent relating to rehabilitation post stroke and in the actual content – the syllabus – of the curriculum. Although gaining greater qualification will likely remain the most visible purpose in the early to late subacute period post stroke, for life after stroke especially, the domains of socialisation and subjectification are important purposes for the curriculum of rehabilitation to make visible and actively start to address. Learning who am I and how am I, how I exist and lead my life, how I respond to and engage with what I encounter in my life so that I can be meaningful are important outcomes that a curriculum post stroke should, at least in part, afford.

12.3 Delivering the purposes and content of the curriculum

Learning is a balance between imagination and perception – the creative alongside the cognitive and ordered (Ingold, 2015). A learner needs to be helped to see the former and be given support for the latter as they step out, literally so for people post stroke, into the unknown. Since the world of stroke was foreign and strange, it meant that, as Roth states more generally about learning and the unknown, it was “invisible and therefore cannot be visualized, envisaged, and aimed at.” (Roth, 2011 p.viii). Because of this, the participants felt what others have expressed, that it made no sense to build their recovery blindly without a plan (Roth, 2011). This was especially so when there were other people who had the plan – the curriculum – and knew what to do. Instead, the participants wanted to learn from those whom they believed and could trust to enact this curriculum in a caring, systematic, and predictable way, so that they could gain the content and achieve the purposes they expected or hoped for. They wanted support from others in order to find the forbearance and patience to wait for the world, and to respond to all the challenges it put forward. This is important for any learner but especially so for adults.

Teaching adults is different from teaching children. This is not because they necessarily have fundamentally different ways of learning but because the relationships are different (Rogers, 2003). Although an adult may have a lot to gain from learning, they often also have the awareness that they have a lot to lose. The submission to the unknown that is required of learning is not normally associated with adulthood, especially in respect to re-learning skills mastered in childhood. The participants were therefore faced with the challenge of how to balance the rights, responsibilities, and hard work of being an adult, a student, and a patient (or family member of a person post stroke) – what Carl May has termed ‘patient-hood’ (May and Mead, 1999 p.62). Where there is not normally a problem with the congruency between student and child, there can be between student and adult, with a potential discomfort in how these roles sit together. The result is often the presence of learning defences, which enable the person to hold on to their old perception of self (Illeris, 2016). Although the overall gift of a curriculum of learning is a new way of seeing, this may also necessitate, at least in the early stages, the unwanted gift of letting go and then forgetting. Once one knows the world as a knower, one can no longer see it fully as a non-knower (Roth, 2011). As adults, even more than children, come with history, they need to go through processes of unlearning as well as learning, with the additional complexity that in finding one's new identity, there is no way back (Biesta, 2006). The effectiveness of a curriculum therefore depends upon how the learner positions themselves, but equally on how the teacher positions themselves within complex adult-adult horizontal and healthcare professional/teacher-patient/learner vertical relationships (Rogers, 2003). Learners need to know how the staff as teachers have constructed themselves in their role and teachers need to know likewise of the learners.

The term education has two potential derivations – either from the Latin word *educare*, which means to mould or to shape, or *educere*, which means to lead out or lead someone forth (Ingold, 2015). Although these are in many ways opposed processes, the reality was that the participants wanted and needed the delivery of the curriculum across the stroke pathway to do both. To a limited extent it did, but not always in a way that made sense to the participants as learners. Importantly, what both processes share is that they refer to someone helping someone else to learn. This reflects that education is less about the individual than about the human relationships, the interactions, between the someone as learner and the someone else as teacher. This student/teacher relationship forms a unique pedagogical space (Hinsdale, 2016), termed 'relational pedagogy' because learning often happens in and through relationships and these relationships need to precede actions. For the participants, the presence or absence of these relationships was the catalyst to successful or unsuccessful learning. When there, they provided firstly the physical and psychological support needed as the person submitted to the learning and enabled them to buffer against the many challenging and adverse circumstances they experienced. Following this, they provided the expertise needed to help the participants gain their content mastery.

This finding about the importance of the teacher, although complex, is well recognised in education-based learning. In his meta-analysis of the over 800 studies that existed at the time, Hattie (2009) discusses the role and expertise of the teacher as the single biggest in-school influence on the outcome of student learning. This reflects Purkey's comments in his writing on invitational education that the classroom teacher is the most important element in establishing the culture of the classroom and the learning that results (Purkey and Stanley, 1991). Invitational teaching denotes being and doing with, and not to, the learner, with the best teachers being those who develop learning environments in which the learners feel comfortable, understood, and supported, and where the learner has been actively invited in to learn (Purkey, 1978). This echoes both the sentiments of the participants, who felt very strongly that advancement in their learning and recovery was due to the people who provided this invitational support for them, and the existing literature on the importance of the therapeutic alliance for people post stroke. Although this construct derives from the field of psychotherapy, there are parallels with education, including the importance of personal connectedness, trust and the alignment of common purpose, as well as the participants feeling valued and cared for (Bishop et al., 2021; Lawton et al., 2016). Within education, where there is high support there has been shown to be a lower threat to the individual, which is increasingly important the more vulnerable a learner is (Roorda et al., 2011). When they feel invested in by teachers who are attentive, encouraging and have the right expectancies, learners are more likely to invest back in the teacher and the resultant learning is very much a product of the interaction between the two (Purkey, 1978). What the participants valued were the staff who cared about them as learners, and whom they could trust to navigate the recovery path with them rather than leaving them to do this alone. In order to feel safe and confident to submit to the learning and step out into the unknown, the participants wanted guidance and rules as well as to be actively invited.

The aim of teachers and teaching in delivering a curriculum, is to invite their learners, through both verbal and non-verbal cues, to look forward and see the future more clearly (Purkey, 1978). Where this occurred, the actions and words stayed with the participants. They reflected for them an important aspect of teaching, which is receiving the gift of an aspect of the truth. Although recognised as a complex area, with much written about the importance of hope post stroke (Bright et al., 2011; Soundy et al., 2014), by being given truth some of the participants' uncertainties were reduced and they were helped to see and think differently, with their own personal revelation and understanding. This awareness that was so important to the participants aligns with a key gift identified and discussed by Biesta in his defence of teachers and teaching. This gift – the double truth of giving – is one of three that he proposes (2021). According to Biesta, teachers need to give people the truth and then help them achieve belief in this truth. The first of these two tasks, the giving of the truth, he suggests is relatively straightforward. The second part, going further such that the person takes on that information as the truth, is harder but vital. As was seen, for this to occur, it was fundamental that the information, embedded as it was in the wider curriculum, made sense. Without closing the horizon of hope, the role of teachers, once a relatedness and trust has been established, is therefore to put the truth in front of the learner. They then need to invite and support them first to see this and then to do something with it so that the person can start to understand differently and see this new understanding as true and meaningful. Unless the truth is brought within their scope of understanding, learners will see what they can see and what they want to see, until they reach a point where they are forced to see differently.

The importance of this giving, and the challenge involved in it, was shown over and over in this research, with some successes but also failures. How much they were given the truth, how much they were invited and helped to hear it, how much they believed and how much they accepted, took the participants to the highest and lowest of places. Following both the principles of invitational learning and the strengths of the therapeutic alliance, to help learners manage these complex emotions, teachers need to know their learners and create for them positive learning opportunities and environments that are full of warm, consistent and predictable relationships into which the truth can be inserted.

Having first enabled the learner to feel known and safe, and then invited them into some truths, teachers can go on to build on this and fulfil the next gift of teaching highlighted by Biesta, which resonated strongly with the participants who mentioned it often as being hugely invitational. This is to give learners what they did not know to ask for – their moment of revelation or transcendence that went beyond that which they could have known or could do themselves (2021). For Biesta, the teacher does not just facilitate the process of learning but offers a curriculum that takes learners to a new place that they would not have had the confidence, knowledge or, for people post stroke, ability to risk going to alone. As previously identified, formal learning is constructed by others for the purpose of consciously assisting the learning. It is educative learning rather than learning simply through the accumulation of experience by exposure of the person to the world. Although it is important to be mindful of dependency, without a visible, structured syllabus of content, there is the risk of placing too much emphasis on incidental learning and learning through doing, so that the learning may not happen at all. As Biesta discusses, just allowing people to experience things within their existing situation does not necessarily give the learner the opportunity to learn more than their own situation (2021). A key task therefore for those delivering a curriculum of rehabilitation is to give the person more than they asked for, or could know that they could ask for. This should enable the invisible to become visible so that the learner can move from the unknown to the new state of the known.

The final gift a person can be given by a teacher within a curriculum of learning is themselves. Biesta aligns this to the third of his purposes of education, to give a person their 'subjectness' and their understanding of what they will do with who they are or have become. With this gift, teachers can give understanding to a person of how they are, how they will exist, how they will lead their life, and how they will respond to the challenges that come their way. Part of the pedagogical responsibility of the education gesture is to dissatisfy or disappoint the students by not allowing them to remain passive (Biesta, 2017). The task of the educator therefore is to refuse the student the satisfaction of not having to be a subject and instead to invite and help them into this role so that they can take on their freedom. This does not involve taking on all of the responsibility for the learning, but it does mean that learners cannot leave it all to others.

In his writing on education, the anthropologist Tim Ingold talks about the process of humanifying – discussing how, as humans, we are constantly becoming and are never finished (2015). The role of the teacher is therefore to help a person in their becoming by gifting them more than they could have achieved alone. Although, from the patient's perspective, this was the role that they wanted and that gave them the most emotional ease, the teaching involved in delivering a curriculum is more than just *educare*, or instilling knowledge or skills. It also involves *educere*, the leading out of the person into the world so that they can be taught by the world. People in the early to middle stages of stroke needed, and eventually wanted, both. Their immediate desire was for a curriculum and a teacher whom they could be taught by and who could help them back on to the pathway that their stroke had deviated them from. For those without ongoing deficit, this was enough. Those with ongoing deficit, though, who needed to keep on navigating a recovery pathway of continued becoming, needed a teacher who followed a curriculum that firstly invited and helped them on to the right pathway, and then taught them what to attend to and how to attend to it, such that they could stay on track and continue to move forward with recovering.

12.4 The places and processes of enactment of the curriculum of rehabilitation

A curriculum has most value when it is relevant and responsive to its local context (Grant, 2018). The final part of this chapter will therefore discuss the enactment of the curriculum of rehabilitation in the three different learning environments and also offer comments on how the participants evaluated them. The discussion will first explore the therapeutic landscape generally and the role of place in facilitating health (Gesler, 1992), and then look more specifically at the material places of recovery, the built pedagogy, to ask whether these constrained or enhanced patient learning.

The second of the two key processes identified by Illeris in his learning triangle as being inherent to all learning is the interaction between the learner and the social, cultural and material environment that they are in (2002). Learning takes place in, and is influenced by, the space and place, with the person interacting with their environment and the environment with them such as to influence the learning that takes place (Luz, 2008). Learning acquisition is therefore situated in and determined by the time and place in which it happens. Importantly, use of learning, or learning for participation or being, is also situated, as new content achieved in the process of acquisition needs to be put into use in the necessary/desired context. The learning environment is therefore fundamental to the delivery of the curriculum and the learning that results.

The built environment of rehabilitation spaces has been an area of quiet interest in the literature since the 1990s. Although environmental factors are not specifically mentioned in the current stroke guidelines, studies exploring ward design have highlighted how the physical environment is potentially an important factor in stimulating both cognitive and social activities among patients (Lipson-Smith et al., 2021; Shannon et al., 2019). This includes the ambient environment (such as lighting, noise levels, and air quality), architectural features (such as the layout of the hospital/ward), the size and shape of rooms and the placement of windows, and the interior design features (such as the furnishing and artwork). People live their lives within the built environment, and in the ICF the category of environmental factors 'makes up the physical, social and attitudinal environment in which people live and conduct their lives' (World Health Organisation, 2001). The space can thus influence both how care is provided and the patients' health outcomes (Ulrich, 1991). It is suggested that to promote wellbeing, the physical environment should be designed to support patient care by providing a sense of control, access to social support, and access to positive distraction.

The pathway of recovery for the participants comprised an inpatient stay in two formal institutions, the acute hospital and the rehabilitation unit, and then discharge to the informal institution of home. The first of these places, the acute setting, was experienced by the participants, without exception, as being very much the wrong place for their recovery. The lack of visibility of, and invitation into, enough or any curriculum of rehabilitation, took the participants to an extremely low place emotionally. They were desperate to be there so that they could get better and go home, but with no or minimal signs of structured input they could not see how this was going to occur and greatly feared that it would not.

In his book, *Asylums: Essays on the Social Situation of Mental Patients and other Inmates*, Erving Goffman (1961) described the inmate culture of what he termed ‘total institutions’. In his work, these were American prisons and psychiatric institutions of the mid-twentieth century. He described the inmates of these closed communities as being exiled from living, with time being wasted, taken from life and not to be got back. He wrote of an awareness of dead and heavy hanging time – a dead sea in which little islands of activity appeared that helped to withstand the stress but whose insufficiencies added to the sense of deprivation (1961). Although the institutions described by Goffman were, of course, deliberately incarcerating, and the time the inmates were there was much longer, the sentiments were not so different from those of the patient participants when describing their experiences within the acute setting. They also talked about loss of identity and role dispossession, of time being wasted and valuable recovery being lost, and of occasional therapy sessions being given, which raised their hopes but then dashed them as they did not know if such sessions would be offered again. Whilst on the acute wards, the patients looked for anything that they could call a curriculum of recovery and a learning space for this to take place in. They especially valued being taken to the gym area rather than doing exercises by the bed, seeing being out of bed as a learning/recovery space and being in bed as the opposite. Interestingly, considering Goffman’s work was partly done in prisons, the patients also talked about feeling trapped and imprisoned within the assigned quarters of their bed. Here, just as Goffman describes, they had the notion of being ‘good patients’ who were ‘dull, harmless and inconspicuous’ (1961, p.164).

With no timeline of when they would be transferred and not always knowing which rehabilitation facility they were being transferred to, for the patient participants in this study, the concept of self was the preserve not of them as people but of the institutions themselves. This deprivation of liberty, which was supposedly for their own good, seemed to them to be doing them no good at all. For nearly all the patient participants, the impact of the stroke, and everything it had changed, was exacerbated by the impact of the place, with the lack of a curriculum and associated interaction related to recovery taking them to a very low place emotionally. Although it was recognised that this way of being was not the intention of any individual but a limitation of the wider system, how the patients described their time in the acute setting had great resonance with what Goffman termed ‘disculturation’ (1961, p.23). Instead of gaining function through recovery, their time on the ward led to demoralisation, and perceptions of skill deterioration and role dispossession. As a result, they felt less rather than more empowered to make the most of their next stage of rehabilitation. The kindness of the care meant that they did not experience the mortification described by Goffman, but they certainly described a loss of freedom and sense of curtailment of self at a time when they desperately wanted to be regaining the self that they had lost.

In contrast to the acute setting, the small, purpose-built design of the rehabilitation unit afforded the participants a safe invitational space for a more visible curriculum to be enacted. The attractive and well-kept aspect of both the indoor and outdoor spaces reflected the love and care the staff had for the place, which in turn conferred messages about the love and care that was afforded to the people in the place. It was a space that showed that it had the needs of the patients and their families, as learners, at its heart. Similar to the features described by Purkey and Schmidt (1990) for invitational schools, the rehabilitation unit was a warm, caring, intimate and responsive place, where the participants were known and valued, and where they felt safe in their identity as someone recovering from stroke. Whereas in the acute setting, the participants were striving to survive both physically and emotionally, the visible symbols of predictability and stability of the rehabilitation unit meant that they could start to thrive. Although traditional total institutions were often stigmatised as being settings of social control and incarceration (Curtis et al., 2007; Wood et al., 2013), they were recognised as also offering a secure space to ‘be’, and a space where long-term residents could engage in therapeutic pursuits. As described also by Suddick in her work based in a stroke unit (Suddick et al., 2021), both the physical and symbolic barriers to the outside world meant that whilst the patient participants were in the rehabilitation unit, they felt that they were in a safe space that held them. On their arrival, when at their most vulnerable, the unit opened its doors and acted as a strong container that welcomed both them and their families in, wrapped them up and held them until, at the end of their six weeks, it released them. Key to the perception that the rehabilitation unit was the right place to progress their recovery was the feeling that they were both physically and psychologically safe, and that it made sense to be there.

This relationship between safety and growth is well established and what was observed and heard during the study was very much in line with the work of Maslow and his writing on the hierarchy of need (1962). Although not without its critics, this model of needing a foundational layer of safety from which one can grow seemed to have real resonance in stroke recovery. In his book *Toward the Psychology of Being* (1962), Maslow talks about how moving forward towards mastery can only take place on a foundation of safety and that to step out into the unknown is only possible with the knowledge that there is a safe and secure place to retreat to if needed. This aligns with the work of Tim Ingold, who, in his writing about education, describes how mastery comes only when one submits to the learning. To practice a skill is to feel one's way forward – following a trail with imagination, improvising as one goes along in an unformed world where one has to be patient and wait for things to fall into place (Ingold, 2022a). As has been discussed throughout this work, despite the rehabilitation unit having symbols of a more visible curriculum, learning for the participants still involved engaging with what was unknown and strange. As novice learners, with limited visibility of the long term and little within the curriculum to address this, rehabilitation was very much about pushing out into the unknown which, with so much to gain but also so much to lose, could be frightening.

From a perspective of built pedagogy, the safety and security of the space was conferred both by the unit overall and by the more personal places of the bedrooms. Across the group, there was much discussion about the pros and cons of having single rooms. The territoriality this conferred provided somewhere that was demarcated, defensible and respected by others. For many, their room was their personal place of safety. They could be found easily by their therapists and so would not miss any of the sessions that were so hugely valued; they were safe from other patients, who could be erratic, challenging or with whom they just did not connect; and, for one patient in particular, they could hide from the volunteers and their groups. Safety also came through having a place to retreat to, away from others, where the participants could rest and sleep, which is what many felt that their body needed. For most, the gains of peace and privacy outweighed the losses of loneliness, but it was recognised that this was so only because most had family and friends who could visit regularly and for substantial periods. Although they confer privacy, single rooms have been criticised as patients are less physically active when alone and not seen. In their work '"It's Lonely": Patients' Experiences of the Physical Environment at a Newly Built Stroke Unit', Anaker et al (2019) discuss the same contradiction as was experienced in this research between single rooms allowing privacy and giving a sense of control whilst, at the same time, creating the potential for loneliness. The door to their room, though, provided the participants with a clear divide between their own space and the communal spaces, which was valued by all. Having a space that they could, to an extent, make their own enabled ownership and belonging, and gave a sense of stability and of having settled, so that there would be no more uncertainties of the unknown related to place and space.

Beside the bedrooms, the rehabilitation unit was seen as having two other distinct zones: the therapy gym and the communal areas of the ward. Each of these three areas was viewed differently in regard to enacting a curriculum and enabling recovery, and each engendered its own feelings and emotions. These zones spanned the continuum from the formal, structured, and teacher-led didactic learning space of the gym to the informal space of independent, self-directed, unstructured learning that was the ward. The patients and their families saw the gym and, to a very small degree their room, as learning spaces, but this did not apply to anywhere else, including the communal areas of the ward. In theory, environments need to be clear and easy to navigate, and to be designed in such a way that they are naturally used and encourage use (Ellis and Goodyear, 2016). What was notable was that the design of the communal areas in the rehabilitation unit followed the best practice principles as set out in the International Health Facility Guidelines (TAHPI, 2018), with each space having a reasonably unique identity and the rooms given different types of visual character; good landmarks, labelling and sight lines in the corridors; and within the bigger rooms, smaller and more intimate spaces to sit and meet. Research related to the built environment of inpatient stroke rehabilitation suggests that they are often relatively deprived (Anaker et al., 2019; Clarke et al., 2021). The spaces in the rehabilitation unit were, however, very far from this, being well furnished with both overt therapy related equipment such as exercise bikes, and leisure-based activities including books, computers, jigsaws, and a piano. Despite this good practice, though, the spaces did not give the necessary clues or, importantly, invitations, as to how they could be used for incidental or informal content learning and, with few of the elements being visibly linked by the patients to their recovery, they were only minimally taken up. Although they appeared to be enriched environments, the spaces of the rehabilitation unit were mostly not invitational enough and so, not being linked to recovery, did not make enough sense to be used for independent practice. To an observer's eye, the rehabilitation unit looked anything but a deprived environment, but in trying to understand more about places feeling right or wrong, what became apparent was the reality of what the patients and their families saw and did not see of the spaces they were in and why, based on their sense making, aspects had visibility and 'invitationality' to them or not.

Perhaps part of the reason why they were not visibly places linked to rehabilitation and recovery was the presence of the gym. In the same way there is a classroom for teaching, knowing that there was an obvious space for learning in the form of the gym meant that the participants did not need to see learning taking place in any other space. Just as a child at school would not consider the canteen or the other social areas as places of learning, so the patients disregarded most spaces other than the gym. They knew that their room was meant to be a place of some learning but in discussion none volunteered that the day room, the dining room or the gardens were spaces that were in any way part of their learning or recovery. A large part of feeling safe and in the right place was through the visible sign of the gym as the key place for the curriculum of recovery to be enacted. As recovery was so tightly linked in the participants' understanding of a syllabus based around exercising and improving strength, achieving this was not aligned with any space other than the gym. This did not make the other spaces unimportant, but they were not perceived by the patients as places that would enable them to get better.

To be more invitational, the informal spaces could have been planned in ways that more closely aligned them to the curriculum rather than just being nice places to be.

As described by Ellis and Goodyear (2016) in relation to schools, this might have included spaces that helped the participants as learners prepare for the therapy sessions and then consolidate afterwards. If there had been this coherence, it might have been easier to make the transition of learning between the two. In reality though, what the participants wanted was someone in the spaces, providing clear invitations to enter and then to be there to share their learning with. People enacting processes of teaching were therefore always going to be more invitational that any space or equipment could be alone.

Interestingly, one point of discussion raised by the patients that encompassed the uncertainty about the use of the space was that the rehabilitation unit both did and did not feel like a hospital. The nurses looked like nurses and there were elements of equipment that were linked to hospitals, but the atmosphere and day-to-day working of the place meant that it felt more relaxed (too relaxed for some). Although not itself home, it was certainly a step closer to being at home. Novel names were offered to capture this aspect of the unit, such as it being a super-clinic, and all agreed that it was not a hospital. Indeed, the participants referred to going back to the hospital when talking about the acute setting. Similar to the debate laid out by Gubrium and Buckholdt in their book *Describing care: Image and Practice in Rehabilitation (1982)*, the participants in this research discussed the relative merits of the hospital image, the school image, the nursing home image, and the sanatorium image. While no definite conclusion was drawn, they reflected what Gubrium and Buckholdt noted: that at different times a rehabilitation unit is all these different things to different people. How this is actualised in the design of the building will depend very much on the constraints of the space, but there are no doubt interesting design considerations to sit alongside more tradition features such as those put forward by Lipson-Smith et al (2019).

In contrast to the rehabilitation unit, home was a complex, and often problematic, space for following a curriculum of learning. In a way that was less the case for the inpatient spaces, home was linked to the difficult relationship with self and identity, regarding both the physical space and the items in it, as well as the activities that took place there (Karasaki et al., 2017). Whereas the rehabilitation unit was geared to learning for acquisition, and was therefore reasonably straightforward, home involved learning for being and to be in a place, which is a harder form of learning to do (Ellis and Goodyear, 2016). Home was therefore the place of recovery that most challenged identity and subjecthood. It led some to question who they were and how they were to be who they were. For a number of the patients, there was continuity from pre-stroke; for others, though, home was quite a different place to be. In contrast to being an inpatient, where the patient's role was clearly one of learner/ receiver of therapy input, at home part of the challenge was working out when they were enacting their role of just being and leading life and when they were enacting their role of being a person trying to recover from stroke. The very limited curriculum offered at home meant that there was minimal content to address these purposes of rehabilitation.

Whereas the acute setting and the rehabilitation unit were, in theory at least, designed for recovering/learning, home was not, and for a number of the patients it was not clear that one space could work for both living and learning. Similar to some of the challenges of learning in workplaces, learning will not necessarily be the priority at home if other more home related things need to be done or are desired. Home is much more than just the building. It involves many other factors, including the personal relationship that one has with the place. As Illeris (2017b) points out from his work exploring learning in the workplace, workplaces have priorities other than employee learning that tend to take priority, and so learning is often accidental, happening by chance if at all. This incidental learning has been defined by Marsick and Watkins (1990, p.6-7) as "a by-product of some other activity, such as task accomplishment, interpersonal interaction, sensing the organisational culture, or trial and error experimentation". It is neither intentional nor planned and due to lack of time, space and qualified input, can often be narrow and without much foundation or context (Illeris, 2017b). If the curriculum of learning at home is set up to be largely through incidental or informal means, then the environment needs to be modified so that the desired learning is most likely to occur. This approach to enriching the curriculum is always risky as the learning may not occur and/or may stop occurring if the environment changes. It also depends entirely on what each individual person takes note of in the environment and learns from. As was seen from the inpatient settings, however, learning through incidental everyday activities had no visibility to the patients, which then carried over for many at home. While this accidental learning may therefore be enough for some patients, it was not so for others who, if they were able to sustain exercise at all, sought the structure and systems of a gym, with all the visibility and invitational messages that these conferred.

An additional challenge for home was that the one space was having to act for work, resting and playing. It was thus for many much harder than the rehabilitation unit, where these activities were separated between gym and ward. There was nowhere at home to escape to and then to return from to carry on with everyday living – nowhere like the social environment of the rehabilitation unit gym which was so strongly linked to feelings of getting better and recovering. In their rapid review, Oakman et al (2020) explored the impact on both physical and mental health for the general population of working from home and identified a number of systemic moderators, including the demands of the home environment, the level of organisational support and the social connectedness external to work that all influenced mental health in particular. Although not shown consistently across all of the papers within the review, lower levels of feedback and greater role ambiguity were shown to lead to increased levels of anxiety and exhaustion, and a key role was shown for colleague support and communication. Stroke survivors who are discharged home and prescribed a programme of exercises could be understood to be ‘working from home’ in the same way as the participants in the Oakman et al (2020) study. The implications for practice drawn from Oakman et al (2020) suggest that stroke survivors at home need organisational support involving regular reliable and consistent communication, formal and informal co-worker support, technical support, and boundary support management – none of which were evident in trying to promote independent practice at home. This last aspect picks up once more on the work of Hannah Arendt (1958) and the focus that she places on plurality in the human condition. Other than for two of the participants, who had extremely supportive wives who would practise with them, doing exercises at home lacked invitation and produced feelings of loneliness and pointlessness.

Although in essence a space of safety and control, if they were alone and had no visible curriculum of recovery, home did not hold the participants in the same secure way that the rehabilitation unit did. Instead, it left some once again feeling vulnerable and uncertain about what the future would bring. In contrast to inpatient units, which are spaces of transition (Curtis et al., 2007), home is a space of permanence that should promote a feeling of continuity and belonging. However, it did not feel like this for all. With the limited formal input that the system provided, the participants were having to adopt a cognitive approach to compensate, but without having the necessary foundation or skill development from the inpatient settings. Rather than being enabled to submit so that mastery would follow, home necessitated trying to put mastery first with the hope that the body would submit to these commands and follow. The greatest limitation of this was that the commanding required a knowledge and visibility that the participants did not have.

In his work on visible learning, Hattie (2009) discusses how, in developed nations, there are many more variables that impact on outcome within a school than there are between schools. This suggests that factors such as the built environment, although important, are less impactful than other factors such as teaching, teachers, and the curriculum (Hattie, 2009). Similar points are also made for higher education by Lansdale et al (2011). The participants in the study felt that the environment did matter but found it hard to articulate in what way. While it is important, therefore, when designing a curriculum, to recognise that learning environments need to confer opportunity and extend the possibilities for learning, as seen very clearly from this study, in itself a place/space is unlikely to be invitational enough to draw the learner in and engage them with learning. Instead, through people and proceses, it needs to overtly invite the learner in and then work actively to keep them there.

12.5 Concluding thoughts

In many respects the thoughts and quotations offered in the findings were not new – indeed, although not using exactly the same words, very many of the aspects observed and sentiments expressed by the participants have been reported in other qualitative research reflecting on the early-middle stage post stroke (Ellis Hill et al., 2009; Eng et al., 2014; Janssen et al., 2022; Last et al., 2022; White et al., 2015; Wiles et al., 2002). This is perhaps to be expected, as the stroke unit/pathway where this work was situated was chosen as a typical example of stroke care in the UK. The contribution from my research is to consider what these findings mean specifically in relation to patient learning and the associated process of education. Recognising that this learning is embedded within a wider curriculum of rehabilitation provides a way for the process of education to be more clearly articulated and, importantly for the emotional wellbeing of patients and their families, to be visible and make sense.

Returning to figure 21 proposed at the start of this discussion (p.226), the world that the participants entered post stroke was unfamiliar and strange. They were therefore, largely learning into the unknown. What was most visible was what made most sense to them in this context. The understanding that they arrived at the learning with largely determined what they expected, and wanted to see, i.e., their desired curriculum. It thus further determined what they looked for, what they saw and experienced, whether they found this invitational and therefore whether they trusted it, i.e., their received curriculum. Structuring rehabilitation within a formalised, clearly articulated curriculum would make visible what those planning the delivery want to be seen and would mean that these aspects would be less likely to be missed, especially if they are dimensions of rehabilitation that are outside the typical patient/family understanding and sense making. By doing this, more opportunities could be gained by both those delivering and those receiving, with greater alignment of understanding between the two.

Chapter 13 The development of a theoretical model to underpin learning in rehabilitation

The aim of this penultimate chapter is to offer some personal reflections and to draw together considerations on the meaning of the findings from both study 1 and study 2. These are presented as the development of a theoretical model that could help further understand patient learning. It finishes by offering some clinical implications, suggestions for future research, and thoughts for dissemination.

13.1 Reflection on the process of analysis and development of an interim model of the importance of safety for learning in neurorehabilitation

As discussed in my reflection at the end of Chapter 4, I embarked on this PhD thinking that if teaching/prescribing of exercise was better understood and methods improved, then better adherence and improved outcomes would result. With the completion of the meta-ethnography, my thoughts had moved away from teaching being the key component to patient learning being the more important element that needed to be understood. This led to the exploration of adult learning presented in Chapters 3 and 4 and the attention given to patient learning in the ethnography.

During much of the analysis for the ethnography, my focus stayed on learning, with deeper exploration of learning theories and writings on the learning sciences – in relation both to adult learning and education/school-based learning. It was really only towards the later stages of analysis and with the reading of authors such as Gert Biesta, that my focus moved once again back to the importance of teachers and teaching. As a number of authors whose work I have read and cited in this thesis have noted, although the relationship between learning and teaching is not straightforward, one cannot think about one without the other. In getting to this stage, I travelled through a number of interconnected lines of thinking to try to best understand what the findings were showing about the phenomenon of patient learning within a rehabilitation setting. Although I did not complete a full analysis of all the data with each new framework/line of thinking, there was a considerable amount of rethinking and repackaging/rearranging of the findings at each stage.

I did not embark on the analysis with a pre-determined framework in mind but started by loosely looking at the data in relation to Illeris' (2002) three dimensions of learning. What came through most strongly was the relationship between the content and incentive dimensions, in particular how this related to participants' moods and how these were strongly linked to their perceptions of what they were receiving and whether they were making the progress of recovery that they expected. What was very apparent from this was the consistency of views and voice about the places of rehabilitation being sites for gaining learning content and therefore either right or wrong for their recovery. This led me to think about the importance of place, and to the work of people like Ervin Goffman on institutions. At this stage, I had tentatively retitled the work 'The places and spaces of rehabilitation'.

In trying to work through what it was about the places that made the participants feel they were so right or wrong, I encountered William Purkey's (1978) work on invitational education. Within this, he talked about the importance for learning of his 5Ps – place, people, policies, programmes, and processes. With the importance of kindness being an insistent theme from the participants, I focused my thinking for a while on the people as the most important element. Eventually, however, I settled on it being the people enacting the right policies, programmes, and processes that was key for the participants. This led to a revised analysis of the work exploring how the participants' experience could be understood in respect to the four domains proposed by Purkey (1978) of intentional and unintentional invitations and intentional and unintentional dis-invitations.

In doing this, the concept of the visibility or invisibility of the policies, programmes, and processes was developed. The notion that, based on their understanding, people look for certain things and see certain things, but do not look for and therefore do not see other things was felt to be important in making sense of how the participants experienced what they were receiving. These aspects of invitational and dis-invitational and visible and invisible, and what they conferred to the participants, then led me to explore the importance of safety, both physical and emotional, and the notion that learning thrives in environments where people feel safe. This resulted in a further analysis of the transcripts and the development of a pictorial image of a triangle of steps, all building from emotional safety at the bottom (Figure 22)

It was when considering safety in more detail and really trying to understand what, more than anything, allowed the participants to feel safe, that I arrived at the concept of the curriculum of rehabilitation, and how this was profoundly invitational when it was clearly visible. Although neither the staff nor the participants referred to it in these terms, when the patient participants had a notion of where they were heading, what the purpose of the intervention was, and that this was going to be provided in a structured, predictable way, they gained a great deal of emotional security. Focusing on the curriculum thus put some of the onus of understanding back onto the teachers and the teaching but in a different way from how I had envisaged at the start.

The movement through these different stages has been strongly guided by reading a variety of literatures, some of it related to health but much of it ranging more widely. What interested me most was how much resonance there was across fields and how there were so many different aspects of theory that had not been previously applied to understanding health, patients, rehabilitation and recovery. In fact, this work has only really just scratched the surface of the many different directions that could be taken in this regard.

Being a novice researcher to ethnography, I felt on many occasions that others with greater proficiency would have worked through their different ways of thinking much more efficiently than I did. I felt that I often arrived back close to where I had been several stages before, and therefore questioned if all the steps had been necessary. However, I believe that in the end all these steps added to the project, and they were ultimately necessary to reach the destination. It is my hope that the reader feels likewise.

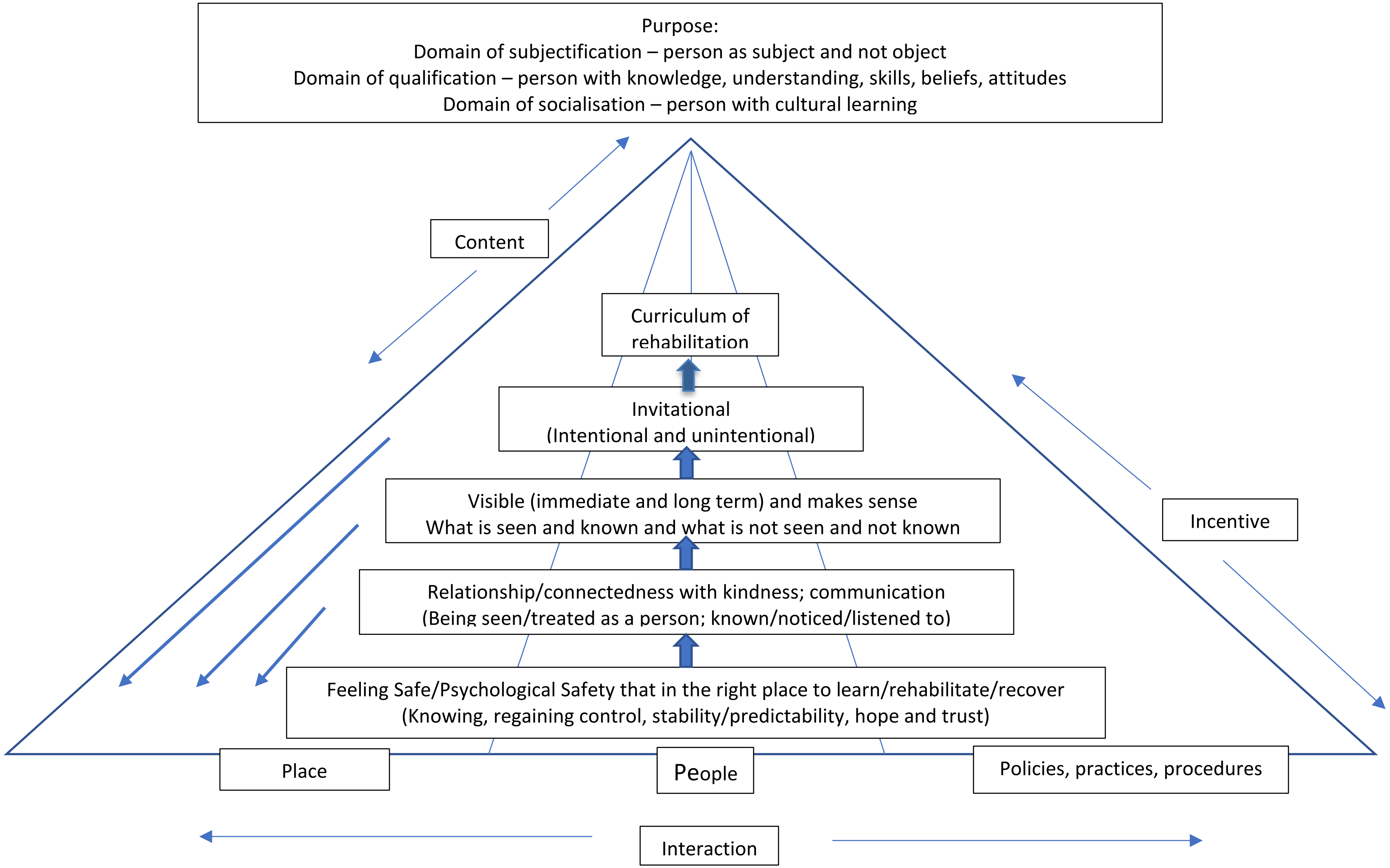


Figure 22 Working model to represent a triangle of steps underpinning learning post stroke in a rehabilitation setting

13.2 Development of a learning theory and schema for rehabilitation

As introduced at the start of this work, poor education and information giving that results in patients not knowing, understanding or remembering advice has been shown to limit adherence to management plans. Of interest to me was whether learning at a point of life disjuncture, such as that resulting from stroke, posed unique challenges that had not been fully understood but which might impact on receiving education as a patient and therefore also influence levels of adherence. Prior to this work, limited research about learning and being a learner had been undertaken to determine whether the theoretical assumptions about adult learning, and even learning more generally, applied when the need for learning was imposed by ill health as compared to learning from choice.

This work has started to address some of these unknowns. This was done firstly through study 1, the meta-ethnography of existing research relating to exercise prescription, and secondarily through the ethnography within a rehabilitation setting. What was noticeable about the findings from both studies was how similar they were. Where the ethnography focused on the broad construct of rehabilitation post stroke but in a narrow field of just one site, the meta-ethnography concerned the narrower construct of prescription of exercise but for a range of different conditions, in different settings, and at different times. Because of the similarity, it was possible to use the findings from the ethnography to add further depth to the developing understanding of the phenomenon of patient learning derived from the meta-ethnography. As a result, the three themes arrived at from the meta-ethnography were expanded by including a further three elements that are encompassed within the processes of patient education and learning: (1) The person (the patient as learner), (2) who was learning something, (3) for a reason, (4) from someone (the healthcare professional (HCP) as teacher), (5) who was teaching something (the guidance received), (6) somewhere (Figure 23). As the educational theorist, Gert Biesta states (2020), people do not just learn but learn something, for a reason, often from someone – that is, teaching and learning, and likewise rehabilitation, have content, purpose, and relationships.

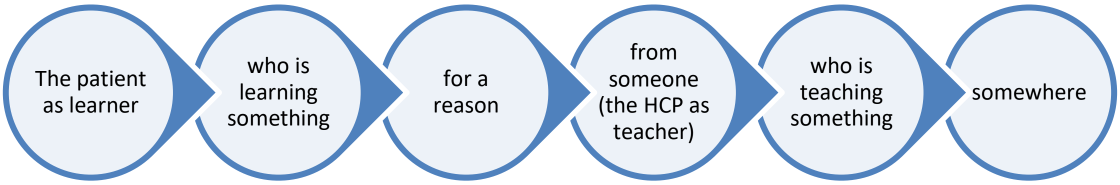


Figure 23 Six elements encompassed within patient education/learning

The short sections below offer some further reflections in relation to these categories to build on those introduced at the end of the meta-ethnography.

13.2.1 Further learning/reflection about the patient as learner

This body of work started with my simple belief that if as healthcare professionals working within rehabilitation we thought differently about the process of, and support given for, the prescription of exercise, then more successful learning and adherence to treatment would result and improved outcomes would be achieved. What this work has shown me, however, is both how much more complex the relationship is between teaching and learning than is suggested above, and also how very human the processes are. Both education and rehabilitation are interventions into someone's life. As Biesta states about education, it is 'motivated by the idea that it will make the person's life better, more complete, more rounded' and, he suggests, 'more human' (2006, p.2). Rehabilitation generally, and physiotherapy specifically, could be expressed in similar terms, with being 'more human' reflecting the ability of the person with a health condition to act in the way that they wish so that other people can take up and do something with this acting such that the person achieves the sense of both uniqueness of self and purpose.

At the outset, I had not fully appreciated the implications of learning as a patient being from need rather than from choice. Patients are often in the contradictory position of having to learn to help their recovery but, because the pathology was imposed upon them, not really wanting to do the learning at all. To compound this, they are also often having to learn at a time of life when the investment of effort needed for the formal learning is not usually required. Prior to undertaking this work, what I had not fully acknowledged is that learning as an adult is different from learning as a child and that these differences need to be recognised, with places, people and processes adapted accordingly. Although learning for adults may confer many gains, with the need often to undo the old before moving forward to the new, there can also be an awareness of losses. What was common to both studies was that the participants had little or no experience of the learning situation they found themselves in. Starting one's learning from scratch with feelings of not knowing about either one's current situation or what one is learning towards is an uncertain and frightening place for adults to be. Learning defences are therefore commonly seen, and are only taken down when the sense making, invitation, and trust are in place.

Building from this, what I had also not considered previously is how much learning can be a risky activity to which one has to submit with no surety of the end result. To learn means to furrow a path. It is a process of travelling that Tim Ingold reflects is something that we undergo as much as do (Ingold, 2022b). In the early part of the discussion, the following quotation was cited: "learning starts from what we already know, and proceeds toward where we want to be" (Hattie and Yates, 2014 p.xii). At least initially, many of the participants in both studies, in their imposed learning situations, hoped that it would be so simple. They expected to begin their learning, stop once it was completed and then leave. The reality was, though, that the learning involved in both rehabilitation generally and physiotherapy specifically is often neither quick nor easy. Instead, it is a complex and evolving process that is influenced by the past as well as by the learner's understanding of their future. Patients learn that they can make progress but, equally, that they can stall and stop, producing emotional highs and lows. Part of the challenge is that, as described by Roth (2011) in respect to learning generally, learning as a patient is travelling a path that is going somewhere that the learner does not yet know. A key reflection was that, as novice learners, in trying to furrow their path patients needed to cast off into the unknown to reach a point that often had very little, or even no, visibility for them. What I had not appreciated was how much they were therefore often learning into the unknown and how hard it is to learn blind.

In his book, *The Life of Lines* (2015), Ingold discusses how this path of learning and education can be likened to travelling either through a maze with high walls, points of decision, and dead ends, or a labyrinth that meanders on an unknown course, with decisions still to be made, but only one direction of travel and no particular end. To succeed in a maze, one ideally needs to know the way through it in advance. This is not so with a labyrinth, where one is able to wander, as Ingold says, in a way that is attentional rather than intentional in order to get towards the next goal. The participants in both studies experienced emotional highs and lows as they made their way along their respective paths – sometimes labyrinthine and sometimes maze-like – trying to attend to the right things, make the right decisions, and not lose their way. They believed, expected, wanted, and looked for help to firstly see the path, then to be invited on to it, and finally to be invited to stay and successfully navigate along it to the end. When given this, they were literally and metaphorically able to start to step forward towards recovering.

13.2.2 Further learning/reflection about the content and purpose

What I had not understood so much from the meta-ethnography but which came through strongly in the ethnography was the importance for patient learning of both the learning content and the purpose of the learning overall making sense to the learner. The impact of this on the person’s emotional wellbeing was extremely clear and very strong, highlighting the importance of the bidirectional relationship reflected at the top of Illeris’ learning triangle between cognitive and emotional learning (Illeris, 2002). This sense making particularly related to the participants’ beliefs of what the planned curriculum should include and their perception of how far the received curriculum aligned or not with their desired curriculum. Despite not knowing the ins and outs of the processes involved, the participants across both studies knew whether what they were experiencing felt right or not. When it did, then they were at emotional ease; when it did not, then they were not. Staff designing and delivering a planned curriculum, need to know what their patients expect the content and purpose of what they are receiving to be so that the two can be aligned. By doing this, it should be possible to successfully invite the learner into an environment that makes sense to them such that learning is optimised to occur.

My own learning is that it is key that clinicians understand what their patients are understanding at the start of their learning. They need to know what knowns and unknowns, and therefore conceptions and misconceptions, the patients hold as they build their learning, and their thoughts about their desired curriculum both when they enter their learning and as this evolves. This is important as it will determine first what the patients believe, what they expect and therefore what they want; and secondly, what they look for and see more widely, and what they find invitational or not about what they receive. Without this understanding of one's patients, what clinicians develop and then deliver of their planned curriculum may go partially or completely unseen, and the patients will act, or fail to act, accordingly. The role of the healthcare professional is therefore, as inviter and teacher, to work from the person's starting point and gift them the knowledge, skills and belief in the truth of what to attend to and how to perceive the invitations offered. By doing this, they can reduce misconceptions and help the patients gain new conceptions in order to navigate the right path and not lose their way. For this, the patient as learner needs time to pause, attend, think and act – submitting to what they experience within their recovery in the hope of finding mastery along the pathway that they travel.

13.2.3 Further learning/reflection about the people, processes, and places of delivery (the therapist as teacher and the guidance received)

Learning results from interactions between people, processes, and place. Just as others navigating new paths look for experts who can help them read the signs and explain what to attend to so that they stay on track and find their way, so too did the participants from both studies. They wanted the staff as teachers to both teach and guide them. As novices, they welcomed a behaviourist approach, where the environment was adapted for them to learn through exposure, reducing the cognitive effort needed to work out what to do. For those with ongoing learning needs, however, this incidental method of learning was not enough to develop sufficient skills and learning strategies to translate learning to home. Learning, even of motor skills, is a cognitive task and this needs to be accounted for with a cognitivist approach.

As a final reminder, it is important to reflect once more on how learning as an adult is different from learning as a child or, as has been extrapolated in work related to enriched environments, learning as a mouse or rat. Whereas for animals and young children, new environments and learning situations are full of excitement and wonder to be explored, this is often not the case for adults, who are much more cautious and sceptical. Learning environments for adults need be filled with things that make sense, that are believed, trusted, and wanted, and that are delivered in a systematic and predicable way by people offering the right level of kindness, interest, expertise, and support. What we design and how we deliver both need to be visible and intentionally invitational to the learner.

13.2.4 Summary

At the start of this work the questions were posed whether patients realised that they were receiving education, whether they knew that they were supposed to learn from the experience, and whether healthcare professionals were sufficiently cognisant of the contextual factors that influenced successful transmission. The findings from both studies showed that, in part, the patients did, but that their ability to see the full learning picture was limited. They saw what they were looking for and so not necessarily everything that was offered. Equally, while good teaching practice was demonstrated by staff, this was mostly under-theorised and unintentional, and so was at risk of being lost. For both patients and staff, the landscape of learning and teaching is complex and there remains much scope for further understanding.

Unlike education where theory abounds, rehabilitation is under-theorised, with the focus much more on the doing itself than on the *why* of the doing (McPherson et al., 2015). It may be that rehabilitation is too multifaceted for there to be one overarching theory (McPherson et al., 2015). Whether or not the findings from this research would therefore apply to all areas of rehabilitation or just some, it is proposed that learning in its broadest context, and the education that brings this about, should be the phenomenon of interest, and therefore the underpinning concern, for the theory of rehabilitation related to stroke.

In their second order meta-analysis of patient education, Simonsmeier et al (2022) suggest that greater links between theory and practice are needed and that theory-driven interventions might be well placed to guide best practice. This PhD has started to link theories from education, teaching and learning to the process of rehabilitation and recovery post stroke. What undertaking this work has revealed is how much commonality there is between these two areas but also how more there is to explore in this regard.

From the findings of this research, it is proposed that patient learning should not be seen as either something that can be achieved through specific episodes of information giving nor as something that is so embedded into one's practice that it is not visible at all. Instead, the moment a person receives their diagnosis should be seen as the start of a multi-faceted evolving process of learning, and rehabilitation as the associated process of education needed to support this. Perceiving things in this way provides a different approach for thinking about recovery and rehabilitation with the aim of enhancing outcomes for patients.

13.3 Revised visualisation of the three dimensions of learning when linked to the patient as learner within healthcare

Because of the large number of parallels between the meta-ethnography and the ethnography, the model presented at the end of Chapter 4 (p.79), has been modified and extended to encompass the richer understanding gained from the ethnography (Figure 24). I have proposed a learning theory and schema for rehabilitation based on the findings of the two studies. In this new iteration the person is more prominent at the centre of the learning. Reflected in the revised model is the importance of what the person comes to the learning with and how this shapes both what they believe, expect, want and therefore look for in their current situation as well as their vision of where they are going in the future. Relatedly, it now emphasises the complex position that patients find themselves in of being caught between their past that is known and in many ways is yet to end and a future that is unknown and invisible but that has already begun.

Retained from the earlier model are the three dimensions of learning content, learning incentive, and learning interaction. These have been simplified, though, to focus on just one rather than two time periods, and then modified slightly to make clearer what, as novice learners, the patients expected, wanted, and looked for. Around this triangle, the inner circle indicating the something (the what) of learning has been maintained but then an outer circle has been added to highlight the purpose of the learning. All of this has now been placed in an outer box, surrounding the person, to indicate that the person's learning is situated in a context of place, with the people of that place – the teachers – enacting the right policies, practice, and procedures, i.e., the teaching.

Representing the entirety of patient learning and education on just one diagram means that much is left out, but it is hoped that such a model might be helpful for clinicians to see clearly the different facets involved, and reflect on how their practice might take these different aspects into account.

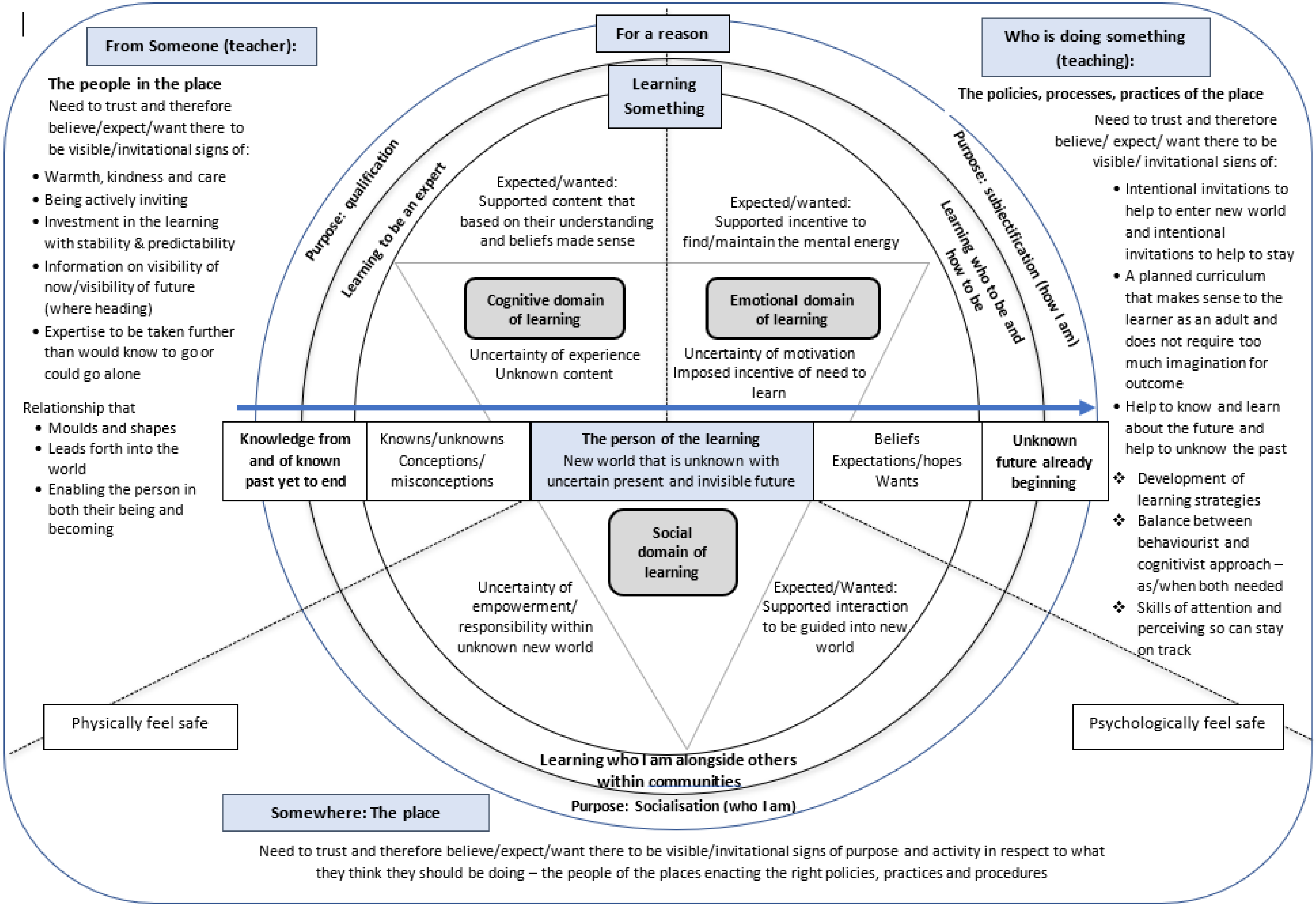


Figure 24 Revised visual representation illustrating the different aspects of therapy-based/patient learning

13.4 Clinical considerations

This next section uses the six elements to summarise key considerations for clinicians working both in stroke rehabilitation and, because they have been informed by the meta-ethnography, also more widely. Although the research has started to offer a novel theoretical understanding of patient learning, this is still in its infancy and so these thoughts are intended as considerations of interest that would nevertheless require further exploration and testing.

13.4.1 The patients

Patients and their families are very often newcomers to the learning situation that they find themselves in, even if this is just by dint of a progression of disease or transfer to somewhere new. They are often uncertain and frightened, and may well be tired. The learning that they are facing is likely to involve, at least to some degree, the risk of stepping out into the unknown and heading to a future that may not be visible to them. As adults who never sought the pathology that imposed the need to learn, it may also be learning that, deep down, they never wanted, and do not want, to do. The findings from this research highlight that patients come with a past and an understanding – their knowns and unknowns – and that they develop their conceptions and misconceptions about what they are experiencing on this basis. These appear to then shape what they expect, want, and look for in respect of 1) what they think they should be learning, 2) why they think they should be doing the learning, 3) what qualities they think the teachers should have, 4) what they think these individuals should offer and be doing in respect to their teaching, and 5) what they think of the place where this is occurring. These aspects may be hard for the patient to articulate, but the findings suggest that how a person acts, or fails to act, is shaped by the sense that they make of the situation they are in and what belief and trust they have in it. This could be helpful for clinicians to consider in the context of their patients.

13.4.2 Learning something for a reason

The emerging theory suggests that for those designing and delivering a planned curriculum of rehabilitation, practice may be developed by understanding what sense making is occurring and what the person involved expects, wants and is looking for in their recovery and from their interaction with healthcare. This would translate to comparing the person's desired curriculum to both the planned and, ultimately, delivered curriculum to establish possible alignments and misalignments between them. What is being aimed at by both sides, and why, needs to be visible as it appears that through the matching of the received to the planned and delivered curriculum, the patients will either trust or not trust what is delivered. If the planned, delivered and desired curriculum are not understood and do not match, it may be that both sides will have disappointments which, for the patients anyway, will likely lead to strong emotional lows and subsequent distrust and discontinuance of involvement. The findings highlight that being aware of a patient's sense making of what they experience is important as this has a strong influence on their emotional wellbeing.

Having a clearly articulated curriculum, with alignment between what is delivered and what is desired, could help patients emotionally in a way that does not need specialist input from other members of the multidisciplinary team. Seeing the world, both current and future, as the patient sees it – through their eyes and understanding as the learner – could offer valuable insights. This appears to be especially important if, as was seen across both studies, the patients' understanding is muddled and contains misconceptions. Particularly in the early stages, when knowledge and visibility of the future are so limited, rather than framing discussions around patients' goals, which, if anything like the participants in study 2, had little resonance for them, they could instead be framed around exploring understanding and expectations and trying to help the patient make visible and articulate what they are expecting to learn, who they see themselves as being, and how they see themselves being this person in the future. It is not then necessary to stay on their page, but knowing what this page is should make it more possible to tailor rehabilitation to enable the patient to move to a new page. Indeed, this is one of the gifts of education: to take the person who is learning to a place where they could not get to alone.

13.4.3 From someone (teacher) who is doing something (teaching)

For clinicians, understanding as much as possible the patients' sense making and desired curriculum should provide a deeper appreciation of what they will be looking for and what they are likely to be seeing of what is offered from the planned/ delivered curriculum. Patients see what they are looking for and it is important to know what that is. From this, it should be possible to establish what the patients feel they should be seeing but are missing, and what is being offered but they do not see (see Figure 25 below for possible questions). Once this is understood, what is visible or invisible can then be linked to what the patients find invitational or dis-invitational. Establishing both of these aspects, visibility and 'invitationality', should give an indication of what the patients find enriching about their environment. This might be quite different from what the staff feel is enriching. If these factors are not understood and do not make sense, activities are likely not to be invitational or visible, and may therefore not be enriching to those receiving them. Exploring what the patient feels to be invitational or dis-invitational will help to establish if these were designed or planned intentionally, and they are aware of them, or were unintentional. Unintentional invitations can hopefully be made intentional so that they are not lost to chance, and acts that are unintentionally dis-invitational can hopefully be stopped.

Possible questions to ask:

- What does my patient know/not know about their current/future situation?
- What of this would I conceive of as their conceptions and misconceptions?
- Based on the above, what desired curriculum might they be looking for?
- From what is being delivered
  - What are they seeing – what is visible to them?
    Of this do they feel these to be:
    - Invitational?
    - Dis-invitational?
  - What might they be looking for, and feel is missing?
  - What are they not seeing – what is invisible to them?

Figure 25 Potential questions for a clinician to ask in respect to visible/invisible and invitational/dis-invitational to the patient

One of the aspects that the patients found most invitational was seeing the curriculum enacted in a predictable way. This gave them hope for a future that they wanted so much and took away the burden of uncertainty and the effort of having to try to get to their desired end point alone. As is common for adult learners, if the alignment is there, or almost there, between what they are doing and what they expect to be doing, then they will give the learning a try. They do, though, remain cautious and sceptical and, if not immediately won over such that they truly believe, are likely to raise learning defences and stop.

One further consideration about structuring the delivery of the planned curriculum that has evolved from the findings is the place of an overt cognitivist approach, with a focus on teaching a range of learning strategies, for patients with ongoing deficits and therefore longer-term practice/learning needs. Persistence with experiential learning following a behaviourist approach of exposure to an enriched environment of opportunity may well not be enough for patients to learn sufficient skills to enable them to carry on and progress their recovery at home. This particularly relates to the upper limb, where patients, when alone at home, were often at a complete loss to know what to do. Assuming that patients will just pick up what to do from what they experience within a treatment session may be insufficient, and they may instead need much more structured, overt and invited teaching. To help them learn the additional skills of being able to progress their exercises at home, the finding suggest that patients need to learn more explicitly what key aspects they should to be attending to and what they should be perceiving so that they can both stay on and progress along the right path.

13.4.4 Somewhere

Importantly, especially as uncertain novice learners, patients may need to be actively invited and welcomed into the learning, and then actively invited and welcomed to stay there. This learning needs to be in a space, real or virtual, that feels right by making sense, so that the person feels physically and psychologically safe. Practice may be enhanced by clinicians being mindful of how frightening learning can be, with the prospect of stepping out into the unknown. Although there can be a lot to gain, there can also be a lot to lose and fear of the latter can block achievement of the former.

What patients see as enriched might be quite different from what staff see as enriched, and what patients are looking for and think that they need for their recovery may be at odds with what those designing the environment think. Basing enrichment for adult learners on a model derived from what either children or animals find stimulating might well be particularly misguided, given that learning as an adult is quite different from learning at other stages in life.

13.4.5 Summary

Once out of the hyper-acute stage, rehabilitation and recovery might be further understood and optimised if additional consideration is given to the complexities inherent in the identities of nurses, therapists and patients. This research has offered insights into the potential for rehabilitation if the identities of nurses and therapists as teachers, and patients as learners are better theorised and understood. Adopting new identities would not be at the expense of losing established ones, since those roles are needed, but rather add the new role label alongside. Thinking more broadly about how people learn and drawing upon the evidence and theory of best practice for teaching could allow both those who work in, and those who are in receipt of, rehabilitation to understand more about how recovery is experienced and why it achieves, or fails to achieve, its goal. It should be emphasised that there are few, if any, successful instances of learning in any other walks of life that are based on the practices that are currently offered in recovery from ill health.

13.5 Implications for future research

To progress the findings from this work and to continue to develop both theory and practice in respect to patients as leaners at a point of life disjuncture imposed by ill health, the following studies are suggested – firstly more related to the person and then to the place and processes involved.

13.5.1 Future research topics related to people learning something for a reason:

1. **A longitudinal study to explore stability or change over time in respect to what stroke survivors see/do not see and find invitational/dis-invitational in respect to current rehabilitation practice.**

Having recognised that a person’s sense making, what becomes visible to them, and what they find invitational, are all linked to what they understand, believe, expect, and want, it would be of value to continue the data gathering over time to see how these aspects develop as the person moves from being a novice learner to becoming more established in the world of their health condition. This would give an indication of the stability of these aspects, if they change for some, or all people, and if this happens in any consistent way and with any consistency of timing.

2. **A qualitative study to explore typologies of patient groups in respect to ongoing learning needs at discharge.**

Developing typologies of patient groups in respect to ongoing rehabilitation needs was not an objective of this research. The findings, however, seemed to suggest that there were three possible ideal types: 1) people who recovered fully enough to allow life to continue with little need for further learning; 2) people who did not recover enough, so that life for them would be different, but who were not looking for high levels of ongoing input; and 3) those people who did not recover fully and were seeking intervention to make more recovery. These are just preliminary findings that would benefit from deeper exploration to firstly see if these ideal types hold true as meaningful clusters of patients or need refining, and, from there, to understand more about the different learning needs and the approaches to teaching that could be adopted for each.

3. **A mixed methods study exploring attributes of self-directed learning in stroke survivors in the early to late sub-acute stage post stroke**

In part building on the study above, with regard to longer-term learning in the content/qualification domain, it would be of particular interest to look further into the published work on self-directed learning and to explore if/how the different tools that are available to assess this construct in people generally could be applied to patient learning. Once I recognised the wealth of literature that there is in this field, I made the decision not to revisit the preliminary model offered at the end of Chapter 2 (p.56), as I now consider that more needs to be understood in order to give this further theoretical foundation. However, I still think that there could be value in the development of a tool to enable assessment of the patient as a self-directed learner to guide practice in the prescription of home-based exercise.

4. A qualitative study to explore the sense making of a diverse range of both stroke survivors and people with other neurological conditions of pathology, rehabilitation and recovery.

Because of who was present on the rehabilitation unit and fitted the inclusion criteria at the times of data collection, all the participants had had a stroke rather than other forms of ABI. From the analysis, there was little that seemed so specific to stroke that an exploration of learning and being learners in other people with sudden onset neurological impairment could not use these findings as a foundation. It would, though, be of interest to explore this area with these other patient groups to see what commonality there was in the findings. Indeed, this could extend also to people with other healthcare conditions unrelated to neurology. The participants were also from a narrow socioeconomic and cultural/ethnic background and expanding this would also be an important avenue for further research.

Additionally, this work only included the views of family members where they were present and part of the conversations held with the patient participants. Those who were included were all supportive spouses and were all wives. As living with long-term neurological conditions, such as stroke, is so often a family undertaking, understanding more about family member learning and being learners could provide further valuable insights into their sense making of recovery and rehabilitation and, from this, their perceptions of their role and their learning needs.

13.5.2 Future research topics related to someone (the HCP as teacher), doing something (teaching), somewhere

5. A qualitative exploration of staff perceptions of patients as adult learners, learning from need at a point of life disjuncture imposed by ill health

An important area for further research is to explore in more detail the findings generated from the staff conversations. Additional analysis from these could be undertaken to explore their understanding of patient learning more specifically. This could then be developed to look at this both in a wider group of staff working in a rehabilitation setting and staff working in other parts of the patient pathway. From this, it would be possible to provide a more comprehensive comparison of the understandings and sense making of staff and patients to see where and why they do and do not align.

6. A coproduction approach involving stroke survivors and staff to develop understanding about what constitutes an enriched environment for people at all stages of the stroke pathway

Building on the studies above exploring stroke survivors as learners and what they find visible and invitational, the next stage would be to align their beliefs, expectations and wants to how this might look in practice in the design of environments that they see as enriched for recovery from the acute setting through to the person being at home. This would be enhanced by a continued exploration of the complex situation of stroke survivors being at the same time patients, adults (with the continued application of adult learning literature) and novice learners (with some of the broader work on educational theory which has largely been derived from children and young people learning).

Summary

By continuing to draw upon the rich body of work in teaching and learning theory – both that which relates to adults specifically and also broader education practice – there is further opportunity to look at different sources to help provide greater explanation of the what, why, how and where of patient learning. This piece of research has certainly not done full justice to the enormous breadth of literature in the field of education theory and practice. The studies suggested above are just some of a number of specific areas that it would be of interest to understand further from the perspective of both patients/the person and the staff who work with them.

13.6 Dissemination

To date, one paper has been published from this work. This was in a broad rehabilitation journal and therefore had readership outside physiotherapy specifically. Future publications will also be targeted at multi-professional groups as the findings could be of interest to clinicians across the multidisciplinary team. In addition to journal publications, the plan is to disseminate the findings at relevant conferences. In the first instance, these will be those targeted at stroke or neurorehabilitation more generally, such as the UK Stroke Forum, ACPIN conference and European or World Stroke conferences, but will extend to other rehabilitation and generic physiotherapy conferences such as the Society for Rehabilitation Research and Physiotherapy UK.

In addition to professional audiences, the aim will also be to share the findings with the stroke community. From this, the hope would be to identify stroke survivors and their family members who might be interested in joining with future co-production ventures.

Chapter 14 Conclusion

This research has offered a novel lens through which to understand the experiences of patients as learners in a healthcare setting, and through this advanced the theory of learning in neurorehabilitation. The findings showed how recovery post stroke is a complex process of new learning that is imposed by the sudden change to a person's health status, and how learning theory can be applied to the stroke rehabilitation context to help make sense of how and why stroke survivors feel and act as they do.

The participants in both studies were not passive recipients of their treatment but instead tried, often on the basis of very limited knowledge and understanding, to make sense of what they were experiencing. This sense making was concerned with the alignment between what they were receiving with what, based on their knowns and unknowns and conception and misconceptions, they expected and wanted to be receiving. Where these aligned, they felt that things were right and so were at emotional ease. Where they did not, there were often high levels of sadness and distress. It is very important for clinicians to understand, therefore, what the people they are working with understand, believe, expect, and want from rehabilitation, as this will determine what they look for, what they trust, whether they feel safe and at ease, and how they act.

Further to this, this research has also provided new insight into what it means to be an adult learner in a healthcare setting, learning from need because of ill health rather than from choice, and at a time of life when long-term formal learning was neither anticipated nor wanted. As newcomers to their situation, patients are often learning almost blind towards a future that is unknown, whilst holding on to a past that for them is yet to end. They are therefore having to submit to the learning, and to step out into an unknown with no surety of the end result. This uncertain and frightening position often leads to barriers to learning being raised. To help limit the impact of these negative factors, people who are faced with new learning situations imposed by ill health need to be actively invited into their learning with a clear curriculum that aligns the planned learning with their desired learning and that they can thus believe and trust is right for them. This concept of a rehabilitation curriculum is new and requires further exploration and development to determine its value within practice.

Although many rich findings were generated from this work, it was just a small exploration of one site with one group of people. While there is much scope for further research to develop many of the points explored here, it can now be from the foundation provided by this work.

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Appendix 2 Meta-ethnography data extraction sheet

Source Authors (details of researchers/ previous work etc), year, article title, journal, volume, pages, country/study location	**Theoretical approach, Aims, Research question, Design** inc: setting, Intervention (if any)	**Participants** Inc: Recruitment Eligibility Demographics sample size	**Methods of Data collection and analysis** e.g. focus group, interviews, by whom, where, when, how Method of analysis	**Main findings/ themes**	**Themes of interest related to engagement/ adherence in relation to teaching/learning Associated quotes**	**Further Associated quotes**

CASP Qualitative	**Yes**	**Unclear**	**No**
Was there a clear statement of the aims of the research			
Is qualitative methods appropriate			
Was the research design appropriate to address the aims of the research			
Was the recruitment strategy appropriate to the aims of the research			
Was the data collected in a way that addressed the research issue			
Has the relationship between researcher and participants been adequately considered			
Have ethical issues been taken into consideration			
Was the data analysis sufficiently rigorous			
Is there a clear statement of findings			
Is the research of clinical value			

Additional assessment of quality based on Toye et al (2013b)

INTERPRETIVE RIGOUR
Is there a clear rationale? Is there a clear aim?
Does the study describe who the researcher is? If so, is the relationship between researcher and participant likely to affect the data collected? (balance of power?)
Has the researcher challenged their own interpretation? (e.g. constant comparison, theoretical sampling, co-coding, member checking.)
Does the researcher’s interpretation come from the original data? (i.e. does the narrative used clearly illustrate the researcher’s interpretation?
Are any voices missing? (e.g. does the researcher describe any contradictory cases)
CONCEPTUAL CLARITY
Can you translate the researcher’s concept into a simple statement?
Are you recoding the original data because it does not make sense, or because you would interpret it differently?

Appendix 3 Expanded version of Table 14 showing themes/subthemes with supportive constructs, illustrative quotes and sources

Themes/ subthemes	Supportive constructs	Illustrative quotes	Sources	
The Person as a learner: starting – having to engage and learn				
Need, Expectations/ hope, Ownership/ readiness	**Need**: persistent symptoms; worried; frightened me; no control; painful; stressed out, mentally and physically; killing me; scared for the future	‘I said “I’ve got toothache in my leg…my back and my leg…and I just can’t go on”. I was worried that it was something more sinister it lasted so long!’ [Liddle 2007] ‘I was really stressed out, mentally and physically, and I had a really bad flare-up, and I was like, I need to go to school but this is killing me and I think it took about a week for it to resolve, so I’m kind of scared for the future, especially next year on how it’s going to affect me and how I can prevent that from happening. So I think that’s kind of what’s motivating me to do these exercises, as regular as I am now, because I really don’t have time for that…’ [Stilwell 2017] ‘I need to work harder at it. And, because, I’ve already been pretty sick, I don’t want to get sick again’ [Constantinescu 2017]	Constantinescu (2017) Eng (2014) Liddle (2007) Lindfors (2017) Palazzo (2016) Stilwell (2017)	
	Expectations/Hope: get rid of the pain; help symptoms; don’t know what hoping for; don’t know what to expect; previous experience; building hope; expectations different now; validation; knowing more; return to baseline; expecting a miracle	‘I really had great expectations, I was sure this was gonna be it, but it's not, so I have to move forward’ [Maiers 2016] ‘To be honest I wasn’t quite sure what to expect from the physio appointment other than this vague idea that I would be given exercises only because it’s what I expect a physio to do…’ [Stenner 2016] ‘I thought, well, if you don’t use muscles, they, sort of, stop working, don’t they? I’ve seen it with people with broken legs. If they don’t use them the muscles wither. And so I thought if that’s just going to happen to my throat, I don’t want that happening’ [Govender 2017] ‘…I hope to just reach my former level, for the injured leg ... As long as it can become as it once was’ [Rathleff 2017]	Cheshire (2020) Constantinescu (2017) Eng (2014) Govender (2017) Liddle (2007) Maiers (2016) Rathleff (2017) Resnick (2005) Stenner (2016)	
	Ownership/readiness: Determined; pushing a little bit extra each time; tenacity to get better; motivation; personal attributes/coping/ responsibility; own destinies; response/ attitude from others; waiting for others; own practice; active input; quick	‘I was just determined to do them, and I was determined to walk. I was determined to do everything for myself that I could. I just knew that it was the best way to get well’ [Resnick 2005] ‘I used to do triathlon. And I knew about sort of pushing myself a little bit extra each time I trained to accomplish a little bit more… It sort of made perfect sense to me that there would be similar approach with the therapy’ [Cheshire 2020] ‘It’s your own tenacity to get better’ [Govender]; ‘out of control over their own recovery’ [Eng 2014] ‘You need motivation’; ‘If you’re not really motivated to really want to change, you’re not going to. It’s hard work.’ [van Leer 2012] ‘The medication takes just one minute, while the exercises take 30 minute. Although medications may be bad for my health, they are easier to take’ [Escola-Reina 2010]	Cheshire (2020) Eng (2014) Escolar-Reina (2010) Govender (2017) Hamilton (2018) Liddle (2007) Palazzo (2016)	Rathleff (2017) Resnick (2005) Slade (2009) Stenner (2016) van Leer (2012)

	fix; ambivalence; trust in others			
Starting from scratch – unsure, scared, overwhelmed	**No idea:** can't help myself; don't know how to help myself; not knowing what doing; starting from scratch; Inadequate understanding of why exercises; lack of clinical knowledge; suspicious; sceptical	'It's all well and good you going to a physio and them saying you have to do this…you need to help yourself, and you come out and burst into tears and think I can't help myself I don't know how to help myself…'[Stenner 2016] 'They say, I'll do anything to get out of here, but I just don't know what to do' [Eng 2014] 'I think just for the physio not to take for granted that the person knows exactly what they're telling them without showing them how to do' [Liddle 2007] 'So it's hard to get…like if I was going to answer that question … if there is some sort of way that you weren't just left on your own to try and work out what's available and what's appropriate…cause I mean you're left to…' [Liddle 2007] 'I don't know how long the full set is. If you are doing three reps it's… it's hours a day, particularly when you've got the emphysema exercises bolted in. And that's quite hard to achieve' [Govender 2017]	Cheshire (2020) Eng (2014) Escolar-Reina (2010) Govender (2017) Hamilton (2018) Liddle (2007) Palazzo (2016) Rathleff (2017)	Resnick (2005) Slade (2009) Stenner (2016) van Leer (2012)
	Sure/Unsure: no certainty; avoid aggravation; make it worse; worrying; don't know; no certainty on that; do it, but don't know why; sort of slightly kind of worrying; doing them right; lacked confidence; unsure on accuracy; prefer to stop; prior success with ex made think that could do it again;	'If I do [the exercises], will I actually avoid aggravation? Maybe so,I don't know. I have no certainty on that' [Palazzo 2016] 'It's completely impossible to envisage what your throat and mouth and tongue might feel like if you are a healthy person. So doing things like holding your tongue and trying to swallow…you do it, but you don't know why, and it feels sort of slightly kind of worrying' [Govender 2017] 'I wanted to do exercise for at least two weeks at the centre, but she only gave me instructions on the first day, and she did not tell me if I was doing it correctly or not. In my house I was alone and I had pain, and I did not know if I was making a mistake […] or if I was doing them too hard' [Escola-Reina 2010] 'At first I was a bit skeptical … whether a couple of exercises would really help my jaw' [Lindfors 2017] 'As long as you've got someone with you, that's fine, but if, you know, if you're on your own, it's a little bit harder…Some of my family learnt them as well. If I wasn't working with it one day, at least somebody was there to help, because I used to get a bit muddled!' [Horne 2015]	Cheshire (2020) Escolar-Reina (2010) Govender (2017) Hamilton (2018) Horne (2015) Liddle (2007) Lindfors (2017) Palazzo (2016) Rathleff (2017)	Resnick (2005) Slade (2009) van Leer (2012)
	Fear/scared: alone; scared; unpleasant sensations; scared of getting hurt; dare not to train; not scared before but am now; things would go again as it did before; can do thing better if supported and guided	'I think reassurance is a huge part of it for any patient, they want to know that there's nothing serious' [Stenner 2016] 'First of all, I have to make sure I was doing it right, and sometimes I wasn't sure if I was … He […] did it with me … the next time I'd come in he'd add another one in … he showed me these same exercises four or five times, which was good … I knew I was doing them right then, I felt pretty confident' [Stilwell 2017] 'I think that every time that we are supported or guided, like in physical therapy, like the osteopath … We can do things better. Because when you're alone you're scared! You're scared of getting hurt; you don't know what needs to be done. In the end, that's what made me quit doing the moves' [Palazzo 2016]	Escolar-Reina (2010) Palazzo (2016) Resnick (2005) Slade (2009) Stenner (2016) Stilwell (2017)	

Starting from scratch – unsure, scared, overwhelmed	**No idea:** can't help myself; don't know how to help myself; not knowing what doing; starting from scratch; Inadequate understanding of why exercises; lack of clinical knowledge; suspicious; sceptical	'It's all well and good you going to a physio and them saying you have to do this…you need to help yourself, and you come out and burst into tears and think I can't help myself I don't know how to help myself…'[Stenner 2016] 'They say, I'll do anything to get out of here, but I just don't know what to do' [Eng 2014] 'I think just for the physio not to take for granted that the person knows exactly what they're telling them without showing them how to do' [Liddle 2007] 'So it's hard to get…like if I was going to answer that question (how would you improve the management of LBP), if there is some sort of way that you weren't just left on your own to try and work out what's available and what's appropriate…cause I mean you're left to…' [Liddle 2007]	Cheshire (2020) Eng (2014) Escolar-Reina (2010) Govender (2017) Hamilton (2018) Liddle (2007) Palazzo (2016)	Rathleff (2017) Resnick (2005) Stenner (2016) van Leer (2012)
	Sure/Unsure: avoid aggravation; no certainty; make it worse; worrying; don't know; no certainty on that; do it, but don't know why; sort of slightly kind of worrying; doing them right; lacked confidence; unsure on accuracy; prefer to stop; prior success with ex made think that could do it again;	'If I do [the exercises], will I actually avoid aggravation? Maybe so,I don't know. I have no certainty on that' [Palazzo 2016] 'It's completely impossible to envisage what your throat and mouth and tongue might feel like if you are a healthy person. So doing things like holding your tongue and trying to swallow…you do it, but you don't know why, and it feels sort of slightly kind of worrying' [Govender 2017] '(I felt) a bit nervous (during the first session), because… I didn't have much use of my limbs … So I was wondering when I'm going to fall over. It looks like the near impossible, 'Am I confident enough to do it yet?' [Hamilton 2018] 'I didn't know how to do anything and I wasn't really interested in (the technology), so I was saying 'I don't want to do this, I'll move on' [Hamilton 2018]	Cheshire (2020) Escolar-Reina (2010) Govender (2017) Hamilton (2018) Horne (2015) Liddle (2007) Lindfors (2017) Palazzo (2016)	Rathleff (2017) Resnick (2005) Slade (2009) van Leer (2012)
	Fear/scared: alone and scared; scared of getting hurt; unpleasant sensations; dare not to train; never been scared before but am now; things would go again as it did before; can do thing better if supported and guided	'I think reassurance is a huge part of it for any patient, they want to know that there's nothing serious' [Stenner 2016] 'First of all, I have to make sure I was doing it right, and sometimes I wasn't sure if I was or not … He (chiropractor) did it with me … the next time I'd come in he'd add another one in … he showed me these same exercises four or five times, which was good … I knew I was doing them right then, I felt pretty confident' [Stilwell 2017] 'I think that every time that we are supported or guided, like in physical therapy, like the osteopath. . .We can do things better. Because when you're alone you're scared! You're scared of getting hurt; you don't know what needs to be done. In the end, that's what made me quit doing the moves' [Palazzo 2016] 'I was very athletic. [Having experience] makes you less fearful, willing to take the risk of doing' [Slade 2009]	Escolar-Reina (2010) Palazzo (2016) Resnick (2005) Slade (2009) Stilwell (2017) Stenner (2016)	
Starting from scratch – unsure,	**Information** – need to understand; desire for information; lack of knowledge; motivated	'Loads and loads of stuff was happening that was unfamiliar and a bit scary, and so, you know, I, sort of, felt a bit bombarded with stuff' [Govender 2017]	Cheshire (2020) Constantinescu (2017)	

scared, overwhelmed	when received explanation; given information but don't know why; overwhelmed; bombarded with stuff	'I think I felt the same as when I was prescribed painkillers because I felt that there was a fairly vague explanation of what might be wrong with my back I wasn't sure whether what was being suggested was targeted enough' [Stenner 2016] 'I was given some leaflets on swallowing exercises and told that I would probably get a dry mouth and that would cause problems with swallowing' [Govender 2017] 'I need you to come with me today because I don't feel it or hear it unless I'm thinking about it' [van Leer] 'When I went to the clinic and asked the professional what I had, he explained it clearly, so I truly participated in the treatment' [Escola-Reina 2010]	Escolar-Reina (2010) Govender (2017) Lindfors (2017) Slade (2009) Stenner (2016) Stilwell (2017) van Leer (2012)	
The Person as a Learner: Continuing – having to adhere and practice				
On-going needs, expectation, ownership and readiness	**Needs/expectations:** Stopping when better/ perceived as better; didn't think needed to do it anymore; wish it was just like…quick fix; capacity in lives to keep going; don't see any more progress, not doing this anymore; rapid progress providing motivation	'I wish it was just like…quick fix' [van Leer 2012] 'I feel much better, my hip is doing better, and I didn't think I needed to do it anymore' [Resnick] 'I don't see any more progress, I'm not doing this anymore' [Constantinescu 2017] '…because when the pain goes…you think you are out of the woods you know that's it…you just carry on just doing what you were doing…previously' [Liddle 2007] 'I think my expectations are different now certainly from when I first took back pain because my expectation was a ''quick fix'' and that (it) would be okay just, you know, ''fix me'' do something to me and I'll go out and I'll never have it (the pain) again. I don't expect to be pain free after eh treatment em I expect it to take time so it's a different attitude to it, I don't expect the 'quick fix' [Liddle 2007] 'Yes, if the pain has sort of eased and you're more or less back to normal, with just a niggle here and there, you feel well that's it over and done with 'til the next time, type of thing' [Liddle 2007]	Constantinescu (2017) Liddle (2007) Lindfors (2017) Resnick (2005) van Leer (2012)	
	Have to keep going: become negligent, low back pain returns; easier if perceiving benefits but hard if not; not doing me any good; good to know what to do if pain returns; do all of the exercises because they are going to help	'I used to do the exercises at home because then I could better move my arm. I did them for a long time, until I realized that my arm was not aching and my hand was no longer numb. Since then, I have not done the exercises' [Escola-Reina 2010] 'I wasn't really doing the stretching stuff anymore, because it wasn't doing me any good' [Palazzo 2016] 'I started the stretching at home and then I introduced just a couple of minutes further walking. I'd just found, it was just enough to tip me over the edge really. … Towards the end I sort of said I can't do this and you know it was impacting on me and obviously my family in turn quite massively. So, I think I gave it a fair go but I was happy to stop' [Cheshire 2020] 'It was a bit random; I would just do it when I remembered, some of the time' [Govender 2017] 'If you don't do your homework there's no sense to come and see you (for therapy)' [van Leer 2012]	Cheshire (2020) Constantinescu (2017) Escolar-Reina (2010) Govender (2017) Hamilton (2018) Horne (2015)	Liddle (2007) Lindfors (2017) Palazzo (2016) Resnick (2005) van Leer (2012)
On-going needs, expectation, ownership and readiness	**Ownership/readiness:** have to do it; commit 100%; gotten to point when can't quit; have to continue it…on my own; stubborn;	'one should not think well I'm all done doing these voice exercises. I have to continue it on my own' [van Leer 2012] 'My goal was to be able to keep one foot in front of the other. The trainer told me that if I stop exercising I would be back to where I started in 2 weeks. I thought, I have gotten to this point I can't quit…' [Resnick 2005]	Cheshire (2020) Constnatinescu (2017) Escolar-Reina (2010)	Palazzo (2016) Resnick (2005)

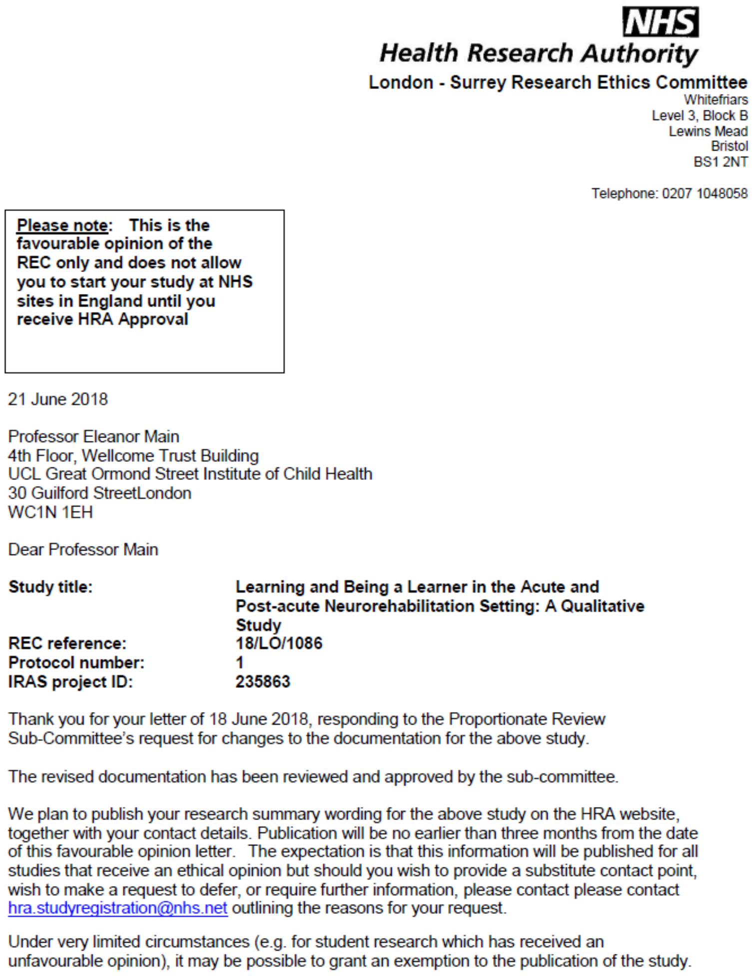
	more aware more motivation	‘The discipline, it must be done, accept it. So I set a challenge every day and that’s the reward. I love it’ [Slade 2009] ‘I try to exercise every morning, because I just think it makes so much of a difference’ [Liddle 2007] ‘It required discipline and I'm not a real disciplined person; I had to work at keeping that as part of my routine’ [Maiers 2016]	Govender (2017) Horne (2015) Liddle (2007) Lindfors (2017) Maiers (2016)	Slade (2009) van Leer (2012)
Practising – unsure and hard	**Hard/effortful:** hard to continue; hard to motivate; hard work; forgetting to do exercises, no system of keeping track; degree of attention; awareness and compliance needed; lack of support; effort involved	‘If you’re not really motivated to really want to change, you’re not going to. It’s hard work’ [van Leer] ‘It was because of the exercises and awareness. You do have to be aware. Seriously, you’re like in my mind’ [van Leer 2012] ‘I’d get home and you’d hand it to me, like do this, this and this, and I’d go, ‘Well that’s so simple’ Good God. And I’d get home and go… ‘What, what (...) oh man, I don’t remember, I don’t know what this means, and I’m not gonna phone because this is grade 3 instructions’ know what I mean?’ [Constantinescu 2017] ‘I have a lot of problems with my memory. So, even remembering to do these things, it is the hardest part’ [Cheshire 2020] ‘because you’re being taken care of in such a good way and after that, you’re back into the wild on your own’ [Palazzo 2016] You tended to get left alone to your own devices, and I think sometimes it would have just been … a little prompt keeping people going…and remind to do the exercises…It’s hard to self-motivate, you know, to keep going [Horne 2015]	Cheshire (2020) Constantinescu (2017) Escolar-Reina (2010) Govender (2017) Hamilton (2018) Horne (2015) Liddle (2007) Lindfors (2017) Palazzo (2016) Rathleff (2017)	Slade (2009) van Leer (2012)
	Embarrassing **Bored:** didn’t ask what thought and wanted **Sad/lonely/miserable/ despondent:** initial improvement, plateau, exercises tougher to complete	‘Silly’, ‘weird’, ‘unnatural’; ‘teasing’; ‘That sounds so affected’ and ‘Oh, is that how you’re going to talk now?’ [van Leer 2012] ‘So there is an embarrassment factor that you have to get over. But I just go down into in my room in the basement and sortta, I guess isolate myself a lot to do certain exercises’ [Constantinescu 2017] ‘I have my rehabilitation sheets that I really struggle to follow every day, because it’s so boring’ [Palazzo] ‘After a bit you get bored…you were repeating, repeating…you constantly are up and down and, say well liftingfingers and that, for half an hour that is so boring’ [Horne 2017] ‘It’s like being fed up. I can’t spend all my life doing this all the time…When am I getting better?’ [Palazzo 2016]	Constantinescu (2017) Govender (2017) Horne (2015) Lindfors (2017) Palazzo (2016) van Leer (2012)	
The Guidance Received				
	Recipe: boundaries; limits; specificity; ambiguous; being told what exercises to do and how to do them helpful; what to do, how to do, when to do	‘Ambiguous” limits and guidelines’ [Eng 2014] ‘Every time I tried to do it myself, just from what other people had said to me I just always overdid it and ended up having to stop so…I thought right the only way I’m going to do this is by sticking exactly to this plan of like increasing it slowly’ [Cheshire 2020]	Cheshire (2020) Constantinescu (2017) Eng (2014) Horne (2015) Maiers (2016)	

		'The types of exercises that were given and then explaining how to do them, when to do them…that process I think has helped…making the commitment that, yep, that's a daily thing that's going to be done' [Maiers 2016]	Resnick (2005) van Leer (2012)	
	Routine: routine and/or having a trigger to do the exercises; routine and structure key to facilitate recovery outside of therapy; information on how to structure day; clear, step by step; explicit education; strategies; exercise at desk, when hoovering	'Either when I get up in the morning or when I'm going to bed, that's when it's easiest...you remember because it's a kind of routine when you're getting ready for bed or before you get up' [Lindfors 2017] 'a continuation of this really structured program" inside of therapy to outside of therapy' [Eng 2014] 'I would say my problem is to find out when to do it actually. Because in the morning, I have a hard time getting started…Getting up is difficult enough, and then at the end of the day, after work, I am too tired' [Palazzo 2016] 'I just think I need to get myself on a schedule and do the exercises in the morning before I do anything else. Otherwise there is always something else that comes up and happens…' [Palazzo 2016] 'Having the booklet with the exercise helped. I would open that up and do them; I plan to continue to keep a calendar and write it down when I exercise. If I don't write it down I know I can let something slide for a couple of days' [Resnick 2005] 'At first, I'd get up in the morning and do them, kind of when I did my meds and stuff…' [Constantinescu 2017]	Cheshire (2020) Constantinescu (2017) Eng (2014) Escolar-Reina (2010) Govender (2017) Lindfors (2017) Maiers (2016) Palazzo (2016) Rathleff (2017) Resnick (2005)	Slade (2009) Stenner (2016) van Leer (2012)
	Personalisation, individualisation: person more important than the exercises; exercise matched to level of ability – both high enough and low enough; individualized objectives	'Looking at different background with exercise and finding out where somebody comes from, so you can actually base the programme on what people are used to' [Slade 2009] 'They'd think about what would help me instead patients one, two, three, four or five' [van Leer 2012] 'Everybody's an individual and you cannot make one size fit all, and most of us have probably found we have been put in 'one size fits all' [Slade 2009] 'It did feel like it was four exercises and that's what they gave to everybody…' [Stenner 2016] '… it felt very conveyor belt. I think it was very generic, it was 'ok so you have got back pain, yeh your movements are not great, you are tall and thin and people like that suffer…I'm going to give you some exercises' [Stenner 2016]	Cheshire (2020) Constantinescu (2017) Liddle (2007) Maiers (2016) Palazzo (2016) Resnick (2005) Slade (2009) Stenner (2016)	van Leer (2012)
	Complexity/attractiveness of programme: simple v complex; functional, relevant; schedule v fits with lifestyle	'We almost have 10 exercises. It's too much. There should be a limit: 3 or 4 max' [Palazzo 2016] 'There was a book with more elaborate things which I did not do as well…I did them when I could get through them but they were really just too complicated' [Resnick 2005] 'What would be nice is to have exercises you can do while sitting at the office, or doing something else, or vacuum cleaning…' [Palazzo 2016] Maybe if you change the program after so many weeks, it might crank (create) more interest [Hamilton] 'He only gave me a couple… And they're part of my repertoire, and they do work. Just simple stuff' [Hamilton 2018]	Cheshire (2020) Constantinescu (2017) Eng (2014) Escolar-Reina (2010) Govender (2017) Hamilton (2018) Horne (2015) Lindfors (2017)	Palazzo (2016) Rathleff (2017) Resnick (2005) Slade (2009) Stilwell (2017)

	Teaching: pace/timing; demonstration; feedback; supervision; observation; renewal; exercise more difficult when care providers failed to observe; more difficult if lack of feedback, inadequate instructions leading to poor adherence as insecure and lacked confidence in whether properly doing exercises at home or not	'If they demonstrate it on your body you tend to remember. It does help your image in your mind later on' [Slade 2009] 'Doing the ex with her helped me believe that I could do them when alone' [Resnick 2005] 'With the personal trainer I learnt what I had to do in a non-hazardous, for me, way. It basically turned my life around. I don't think I ever really knew what it was I had to do before. He was an educator…' [Slade 2009] 'Feedback is useful' [van Leer 2012] 'I don't know. Maybe pictures with diagrams or something to show what part of your tongue you should be tensing up, like more emphasis on when you are swallowing, because you weren't sure really…' [Govender 2017] 'I guess, in my case, he could explain what would happen and where everything would position and how that would help you long term to get better…Instead of just printing off some exercises and just doing them sort of thing. Just explain what's important…' [Stilwell 2017] 'I asked her (therapist) because she was telling me (verbally) and I said Could you write it out for me?' [Hamilton 2018] Heaps of explaining, telling you why you're doing this particular exercise. I think just having things explained to you is very important. Tell me why, tell me why. Explain it to me' [Slade 2009]	Cheshire (2020) Constantinescu (2017) Eng (2014) Escolar-Reina (2010) Govender (2017) Hamilton (2018) Liddle (2007) Lindfors (2017) Maiers (2016) Palazzo (2016) Rathleff (2017) Resnick (2005) Slade (2009)	Stilwell (2017) van Leer (2012)
The Therapist as Teacher				
	Adjuncts: likes/dislikes; supportive; motivation; interest; reminder; apprehension; easier to follow; self-correction; cueing	'Written checklists with tasks they could tick off' [Eng 2014] 'I had a form from the team and I used to mark down how many - on a Monday, four times, I'd mark it off four times, Tuesday four times, all the way up to Thursday. And I didn't do them on Friday. It was a Friday morning. I had it marked out on the chart' [Govender 2017] 'I said, 'Oh well I might as well just use those (exercise on paper)'. It's easier. I just look at it (rather than) mucking around with that (iPad). Touching this and that, and sliding that' [Hamilton 2018] 'A video, that would be good really … it's a simulation straight from the rehab department' [Palazzo 2016] 'Oh I guess it's more interesting watching a screen rather than reading a boring sheet of paper' [Emmerson 2018]	Constantinescu (2017) Emmerson (2018) Eng (2014) Escolar-Reina (2010) Govender (2017)	Hamilton (2018) Palazzo (2016) Resnick (2005)
	Support/feedback/ monitoring access to staff for guidance, instruction and safety; role of clinical staff as key to equip with knowledge /understanding of what could do indep outside of	'But he had a plan, he said 'this is where I expect us to be' and she (previous practitioner) never really had that plan…' [Stilwell 2017] 'I see it differently, It's not about what we want as we can have misconceptions, I think we need to be told what we need and what we are going to get and be realistic' [Stenner 2016] 'She (therapist) adjusted it (the settings of the technology) as I got better…So I had to do a little bit more work but…not enough that I'd fall over…That's been good' [Hamilton 2018] '(...) you slide into bad habits pretty fast. If you're not constantly monitored' [Constantinescu 2017] 'When I went in the morning and he asked me, 'have you done the exercises,' or 'have you felt some improvement,' I got motivated to do the exercises' [Escola-Reina 2010]	Constantinescu (2017) Escolar-Reina (2010) Govender (2017) Hamilton (2018) Horne (2015)	Slade (2009) Stenner (2016) Stilwell (2017) van Leer (2012)

	therapy; confidence; improvement; motivation		Liddle (2007) Palazzo (2016) Resnick (2005)	
	Characteristics of person Kind; caring; nice; interested; valued; believed; trusted; non-judgmental; helpful and empowering; effective educator, motivator and communicator; praise; enthusiastic; gentle; understanding; role of the care provider's style	'Yes I was really pleased with the first meeting, with the way they dealt with me and how much they knew it felt professional and well thought-out it feels that you're in good hands and that they understand your problems' [Lindfors 2017] 'I think the trainers were very caring people, and we were very compatible…They were good at recognizing what I could and couldn't do' [Resnick 2005] 'He was motivating; he didn't make me feel guilty for being in the situation that I was in. He was encouraging, and every little step was an achievement' [Slade 2009] 'Trust in where you go. Personability, how they react to you, and be non-judgmental; not you're an idiot for doing that or how did you get to this situation' [Slade 2009] 'She sat there and talked to me…Such a gentle way she's got. I just sort of felt 'Yeah, sounds alright to me'…There was just something about the way I was told. I had confidence' [Hamilton 2018]	Cheshire (2020) Escolar-Reina (2010) Hamilton (2018) Lindfors (2017) Maiers (2016) Resnick (2005) Slade (2009) van Leer (2012)	
	Relationship: therapist on one's side; helping to get through it, in it together; my spirit you are taking care of; physiotherapist close to me; asking me what I think not telling me what to do; listening; not judging; trust; helping me get through this	'You're helping to get through it…if you didn't do that I wouldn't…try…I wouldn't try as much' [van Leer] 'It's a partnership, it really has to be a partnership…' [Stilwell 2017] 'Asking me what I think, not saying this is what you should do' [Slade 2009] 'I'm only starting to learn to be more assertive and I've now realised that you go to this person and say: 'I want that from you' [Slade 2009] 'It's all well and good you going to a physio and them saying you have got to do this, if you don't do this it's not going to get any better you need to help yourself, and you come out and burst into tears and think I can't help myself I don't know how to help myself. You can try and do the exercises but you haven't got the motivation there' [Stenner 2016] 'I wasn't given any contact details, and the minute I walked out and the doors closed behind me I felt I was in a prison when I walked out and I couldn't get back in. I had to go and see the doctor which I had bad experiences with trying to get physio in the first place' [Stenner 2016] 'You're helping to get it there though…if you didn't do that I wouldn't try… I wouldn't try as much'' [van Leer 2012] 'The physiotherapist, she was just amazing, she was so encouraging and understanding. I mean I just, yeah she was phenomenal. There was a part of me that was, I know this is working but you really need to clone this particular woman to make it work. …The thing also, once it got started, because it was like every fortnight and someone was taking interest in what I'd been recording because I felt so isolated, it was almost like I wanted to do a good job for my teacher!' [Cheshire 2020]	Cheshire (2020) Escolar-Reina (2010) Govender (2017) Hamilton (2018) Liddle (2007) Lindfors (2017) Maiers (2016) Resnick (2005) Slade (2009) Stenner (2016) Stilwell (2017) van Leer (2012)	

Appendix 4 Letters providing ethical approval for original application and amendment



NHS
Health Research Authority
London - Surrey Research Ethics Committee
Whitefriars
Level 3, Block B
Lewins Mead
Bristol
BS1 2NT

Telephone: 0207 1048058

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

21 June 2018

Professor Eleanor Main
4th Floor, Wellcome Trust Building
UCL Great Ormond Street Institute of Child Health
30 Guilford StreetLondon
WC1N 1EH

Dear Professor Main

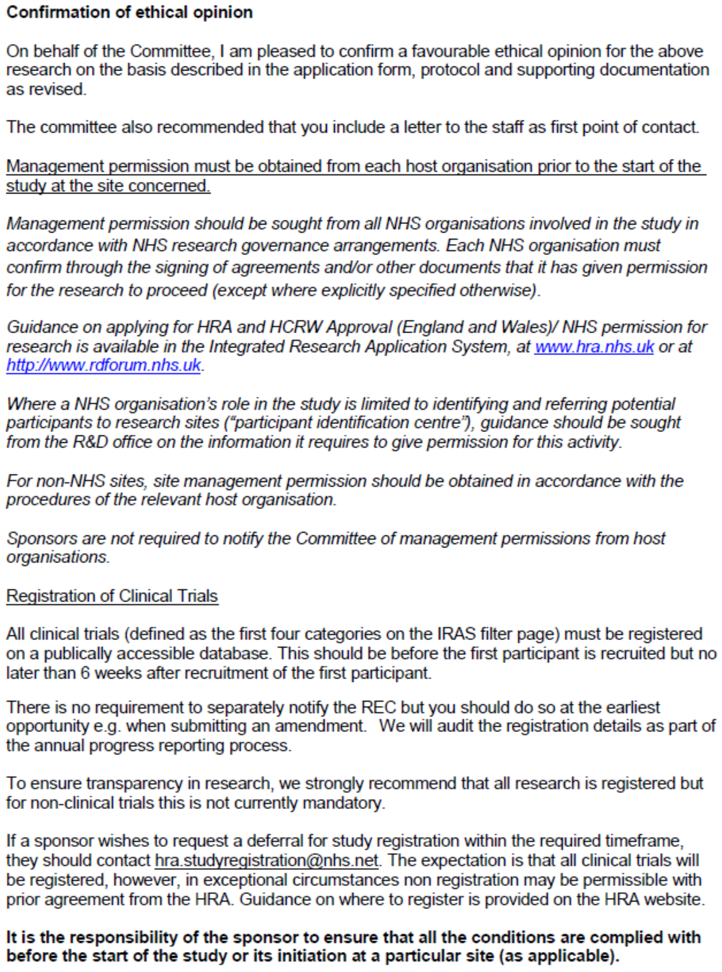
Study title:	**Learning and Being a Learner in the Acute and Post-acute Neurorehabilitation Setting: A Qualitative Study**
REC reference:	**18/LO/1086**
Protocol number:	**1**
IRAS project ID:	**235863**

Thank you for your letter of 18 June 2018, responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the sub-committee.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.



Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

The committee also recommended that you include a letter to the staff as first point of contact.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System, at www.hra.nhs.uk or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations.

Registration of Clinical Trials

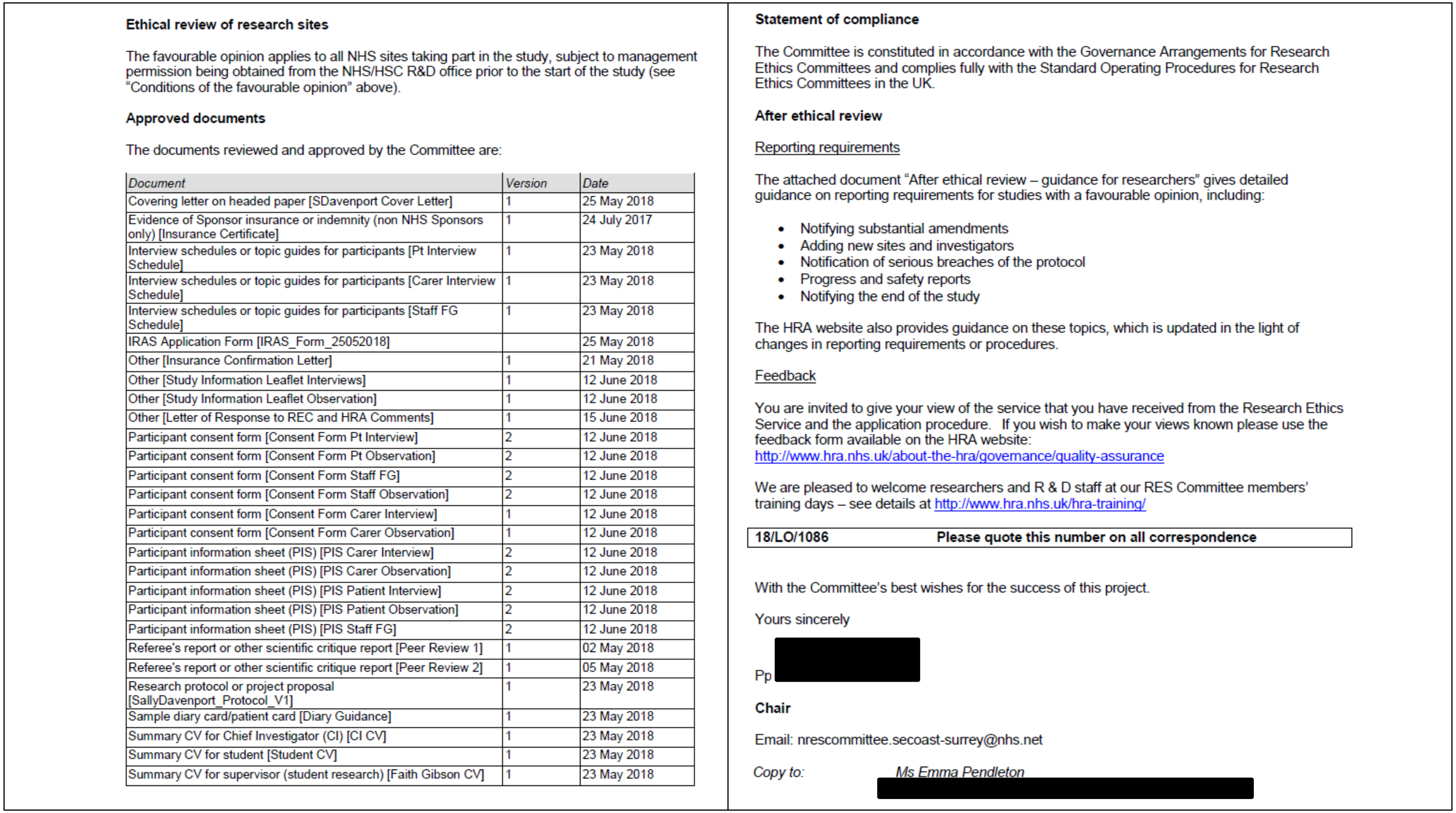
All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).



Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" above).

Approved documents

The documents reviewed and approved by the Committee are:

Document	*Version*	*Date*
Covering letter on headed paper [SDavenport Cover Letter]	1	25 May 2018
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance Certificate]	1	24 July 2017
Interview schedules or topic guides for participants [Pt Interview Schedule]	1	23 May 2018
Interview schedules or topic guides for participants [Carer Interview Schedule]	1	23 May 2018
Interview schedules or topic guides for participants [Staff FG Schedule]	1	23 May 2018
IRAS Application Form [IRAS_Form_25052018]		25 May 2018
Other [Insurance Confirmation Letter]	1	21 May 2018
Other [Study Information Leaflet Interviews]	1	12 June 2018
Other [Study Information Leaflet Observation]	1	12 June 2018
Other [Letter of Response to REC and HRA Comments]	1	15 June 2018
Participant consent form [Consent Form Pt Interview]	2	12 June 2018
Participant consent form [Consent Form Pt Observation]	2	12 June 2018
Participant consent form [Consent Form Staff FG]	2	12 June 2018
Participant consent form [Consent Form Staff Observation]	2	12 June 2018
Participant consent form [Consent Form Carer Interview]	1	12 June 2018
Participant consent form [Consent Form Carer Observation]	1	12 June 2018
Participant information sheet (PIS) [PIS Carer Interview]	2	12 June 2018
Participant information sheet (PIS) [PIS Carer Observation]	2	12 June 2018
Participant information sheet (PIS) [PIS Patient Interview]	2	12 June 2018
Participant information sheet (PIS) [PIS Patient Observation]	2	12 June 2018
Participant information sheet (PIS) [PIS Staff FG]	2	12 June 2018
Referee's report or other scientific critique report [Peer Review 1]	1	02 May 2018
Referee's report or other scientific critique report [Peer Review 2]	1	05 May 2018
Research protocol or project proposal [SallyDavenport_Protocol_V1]	1	23 May 2018
Sample diary card/patient card [Diary Guidance]	1	23 May 2018
Summary CV for Chief Investigator (CI) [CI CV]	1	23 May 2018
Summary CV for student [Student CV]	1	23 May 2018
Summary CV for supervisor (student research) [Faith Gibson CV]	1	23 May 2018

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance

We are pleased to welcome researchers and R & D staff at our RES Committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

18/LO/1086 **Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project.

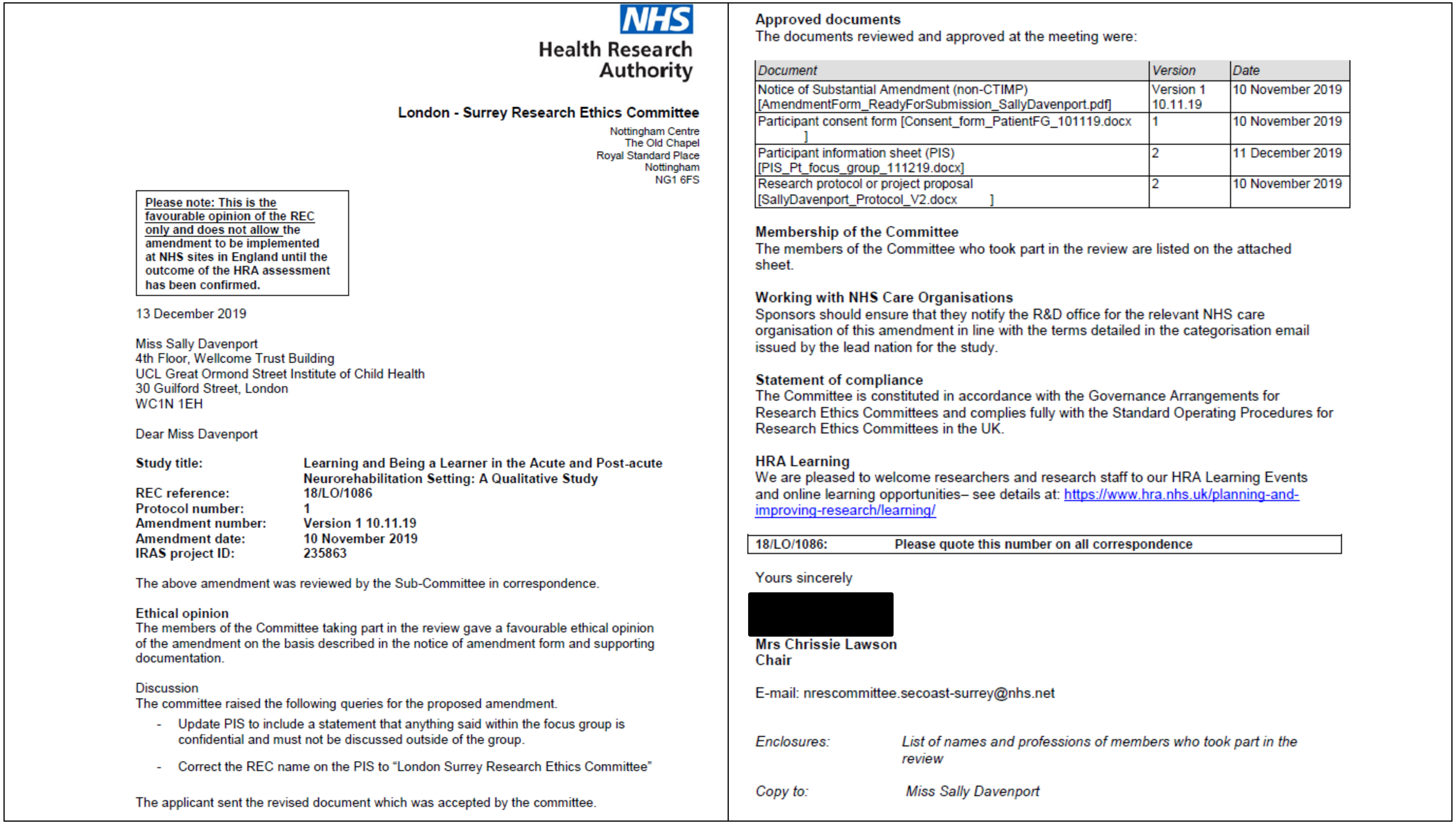
Yours sincerely

Pp [redacted]

Chair

Email: nrescommittee.secoast-surrey@nhs.net

Copy to: Ms Emma Pendleton
[redacted]



NHS
Health Research
Authority

London - Surrey Research Ethics Committee
Nottingham Centre
The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

Please note: This is the favourable opinion of the REC only and does not allow the amendment to be implemented at NHS sites in England until the outcome of the HRA assessment has been confirmed.

13 December 2019

Miss Sally Davenport
4th Floor, Wellcome Trust Building
UCL Great Ormond Street Institute of Child Health
30 Guilford Street, London
WC1N 1EH

Dear Miss Davenport

Study title:	**Learning and Being a Learner in the Acute and Post-acute Neurorehabilitation Setting: A Qualitative Study**
REC reference:	**18/LO/1086**
Protocol number:	**1**
Amendment number:	**Version 1 10.11.19**
Amendment date:	**10 November 2019**
IRAS project ID:	**235863**

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Discussion

The committee raised the following queries for the proposed amendment.

- Update PIS to include a statement that anything said within the focus group is confidential and must not be discussed outside of the group.
- Correct the REC name on the PIS to "London Surrey Research Ethics Committee"

The applicant sent the revised document which was accepted by the committee.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Notice of Substantial Amendment (non-CTIMP) [AmendmentForm_ReadyForSubmission_SallyDavenport.pdf]	Version 1 10.11.19	10 November 2019
Participant consent form [Consent_form_PatientFG_101119.docx]	1	10 November 2019
Participant information sheet (PIS) [PIS_Pt_focus_group_111219.docx]	2	11 December 2019
Research protocol or project proposal [SallyDavenport_Protocol_V2.docx]	2	10 November 2019

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

Working with NHS Care Organisations

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: https://www.hra.nhs.uk/planning-and-improving-research/learning/

18/LO/1086: Please quote this number on all correspondence

Yours sincerely

[redacted]

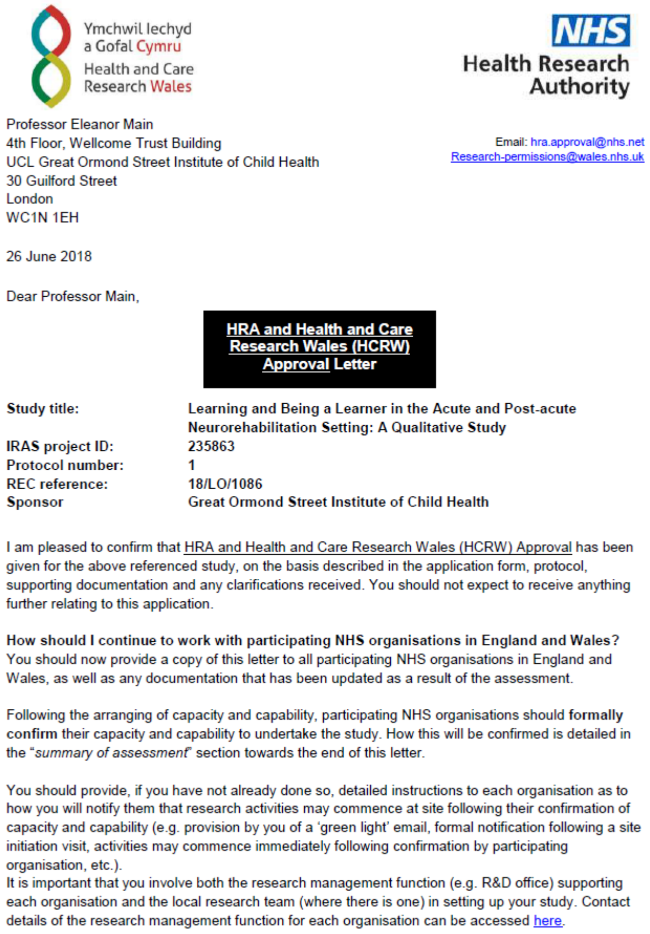
Mrs Chrissie Lawson
Chair

E-mail: nrescommittee.secoast-surrey@nhs.net

Enclosures: *List of names and professions of members who took part in the review*

Copy to: *Miss Sally Davenport*

Appendix 5 Letter providing HRA Approval



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

Email: hra.approval@nhs.net
Research-permissions@wales.nhs.uk

Professor Eleanor Main
4th Floor, Wellcome Trust Building
UCL Great Ormond Street Institute of Child Health
30 Guilford Street
London
WC1N 1EH

26 June 2018

Dear Professor Main,

HRA and Health and Care Research Wales (HCRW) Approval Letter

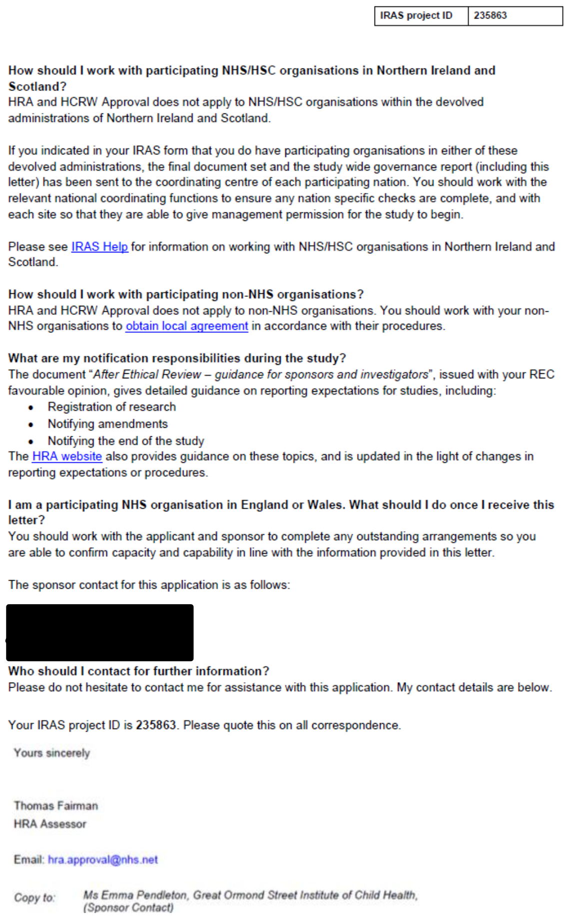
Study title:	**Learning and Being a Learner in the Acute and Post-acute Neurorehabilitation Setting: A Qualitative Study**
IRAS project ID:	**235863**
Protocol number:	**1**
REC reference:	**18/LO/1086**
Sponsor	**Great Ormond Street Institute of Child Health**

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.).
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.



IRAS project ID	235863

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:

[redacted]

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 235863. Please quote this on all correspondence.

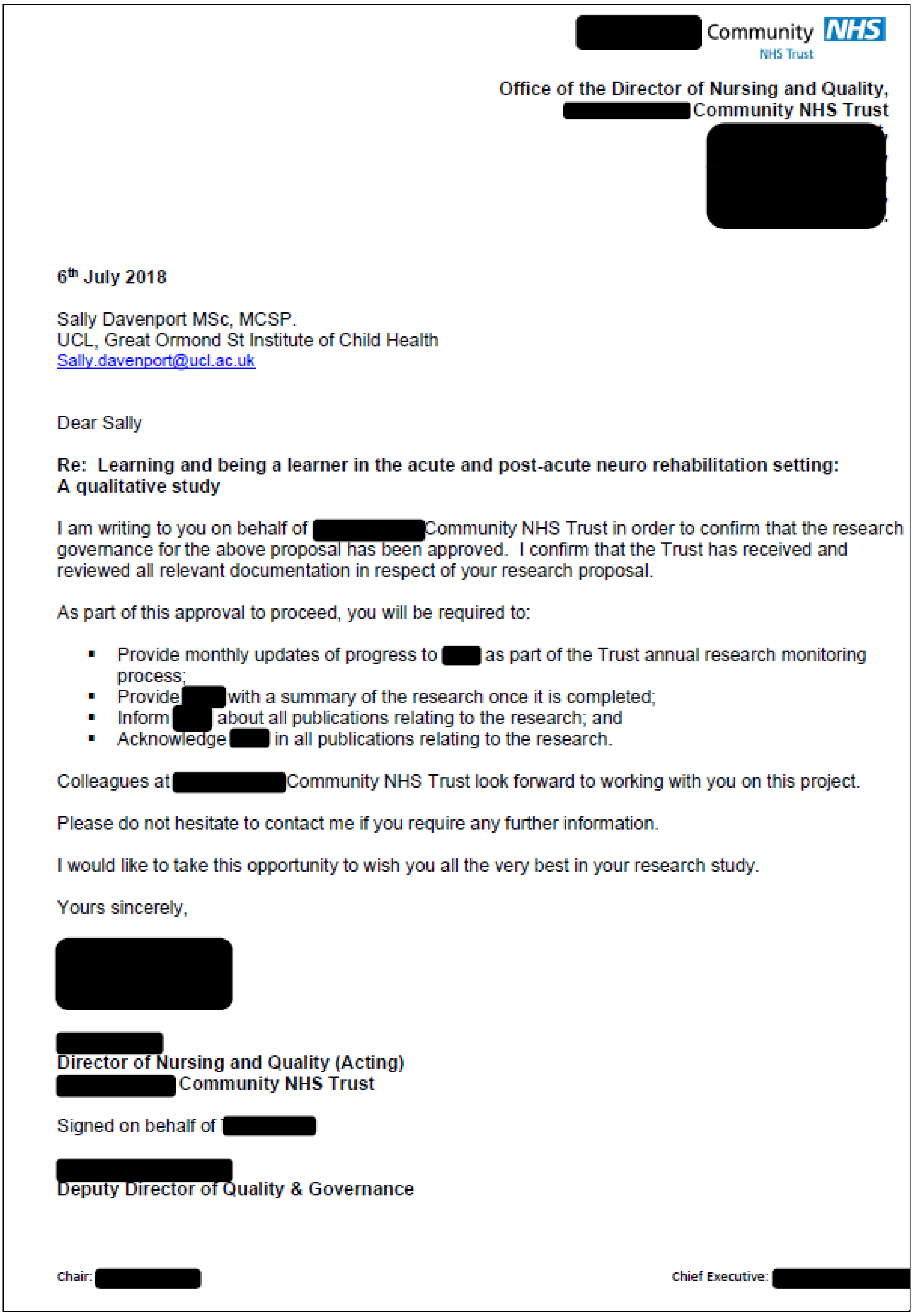
Yours sincerely

Thomas Fairman
HRA Assessor

Email: hra.approval@nhs.net

Copy to: *Ms Emma Pendleton, Great Ormond Street Institute of Child Health, (Sponsor Contact)*

Appendix 6 Letter providing Trust R&D Approval



[redacted] Community NHS
NHS Trust

Office of the Director of Nursing and Quality,
[redacted] Community NHS Trust
[redacted]

6th July 2018

Sally Davenport MSc, MCSP.
UCL, Great Ormond St Institute of Child Health
Sally.davenport@ucl.ac.uk

Dear Sally

Re: Learning and being a learner in the acute and post-acute neuro rehabilitation setting: A qualitative study

I am writing to you on behalf of [redacted] Community NHS Trust in order to confirm that the research governance for the above proposal has been approved. I confirm that the Trust has received and reviewed all relevant documentation in respect of your research proposal.

As part of this approval to proceed, you will be required to:

- Provide monthly updates of progress to [redacted] as part of the Trust annual research monitoring process;
- Provide [redacted] with a summary of the research once it is completed;
- Inform [redacted] about all publications relating to the research; and
- Acknowledge [redacted] in all publications relating to the research.

Colleagues at [redacted] Community NHS Trust look forward to working with you on this project.

Please do not hesitate to contact me if you require any further information.

I would like to take this opportunity to wish you all the very best in your research study.

Yours sincerely,

[redacted]

[redacted]
Director of Nursing and Quality (Acting)
[redacted] Community NHS Trust

Signed on behalf of [redacted]

[redacted]
Deputy Director of Quality & Governance

Chair: [redacted] **Chief Executive:** [redacted]

Appendix 7 Participant Information Sheet for patient observation

Trust Logo

Participant Information Sheet – Patient Observation

Study Title:

Learning and Being a Learner in the Acute and Post-acute Neurorehabilitation Setting: A Qualitative Study

Invitation to participate in the above study:
I would like to invite you to take part in a research study. Before you decide, it is important that you understand why the research is being done and what it will involve for you. Please take your time to read the following information carefully and discuss it with others if you wish. Thank you for reading this.

I will be happy to go through the information sheet with you and answer any questions you have.

What is the purpose of this study?
My name is Sally Davenport and I am a PhD student. As part of my PhD I am undertaking a research study about **how patients and carers learn** in the **rehabilitation unit** and when they go **home**. Very little is known about how people learn following damage to their brain and whether this is the same as the way people learn in other situations. The results from this study will hopefully improve the way therapists help people with their rehabilitation.

To help me understand this topic better, the study involves:

- Spending time with patients, carers and staff and watching what they do during their time on the rehabilitation unit.
- Asking questions of patients, carers and staff about what they do during the day.

I am looking for patients who would be happy if I **spent some time with them** watching what they do during the day. If you took part, this might involve me **watching** some of your **therapy sessions** and being with you when you spend your **time on the ward**. It would never involve watching aspects of personal care such a using the toilet or having a bath / shower. As part of the time that I spend with you, I may also **ask some questions** to find out more about what you think and feel about your rehabilitation.

Why have I been asked to take part?
I am asking all patients at [Rehabilitation unit name] who are having rehabilitation because of recent damage to their brain if they would be happy to take part. To understand more about rehabilitation it helps to watch it take place and to learn more about your experience of this. Your **experiences** and **opinions** will help healthcare staff to understand how to support **patients** best who are having rehabilitation.

What will participation involve?
With your permission, I will **sit** quietly and **watch** some of your **rehabilitation sessions** and some of the time that you spend on the **ward**. When I am watching I might **ask** you some **questions** to help me understand more about what you are doing and feeling at the time. If you are happy for me to **look at your medical and therapy notes**, I might do this so that I can understand more about what you are doing when you are at [Rehabilitation unit name]. Afterwards I will make some notes about what I have seen and anything that we have talked about, or I have read. If at any stage you **don't want me to watch**, you can tell me to **stop** and I will **go away**.

I will not normally spend more than about 30 minutes to 1 hour with you at any one time. I can spend less time than this if you wish. During your time at [Rehabilitation unit name], I may spend some time with you over a number of days. At any stage you can tell me to stop and I will leave you.

If you are **interested in taking part**, please **let your therapist know**. I will come and see you, to answer your questions. If you still want to take part, I will ask you to sign a consent form.

Do I have to take part?
No. It is up to **you to decide** whether or not to take part. It won't make any difference to your treatment that you are receiving at the moment or any treatment that you have in the future in any way.

If you do take part, you will be given this information sheet to keep and asked to sign a consent form to show that you are happy to be involved. You are still free to withdraw at any time and without giving a reason.

What if I want to withdraw?
You may withdraw from the study at any time. If you withdraw after I have spent some time with you it will not be possible to remove all of the information that you have contributed to the study and therefore some of your information may still be used. You do not have to give a reason for withdrawing, and your **care will not be affected**, now or in the future.

Will you keep my information confidential?
Yes. All collected data will be **confidential**. A code name will be used instead of your real name to make sure everything you say and that I have seen is **anonymous.** The only time when I will need to talk to someone about what I have seen is if I see anything about your welfare or safety or the welfare or safety of others that is concerning. The policies from the Trust say that I must report this.

So that I can work on the information that I gather from you as part of the research, it will need to be transferred from [Rehabilitation unit name] to my computer system at UCL. The information may be as notes made in my notebooks which I will type up. These will never contain your name and therefore no-one will be able to recognise you from this. It may also be as audio-recordings from the interviews or video-recordings from the filmed treatment session. To keep this information safe, as soon as these recordings have been made, I will upload them at [Rehabilitation unit name] to the UCL computer system (transfer them remotely using a secure system). I will then delete the original recordings from the recording device so that no-one else can listen to or see these. The consent form that you sign will also be uploaded securely as an electronic copy to the UCL computer system with the original paper copy being kept in a locked drawer in a locked office at [Rehabilitation unit name].

The documents from the study will be all be stored securely. It will not be possible to identify you from the information that is collected.

Are there any possible benefits?
There is **no direct benefit** to you from taking part in this study but we hope that learning about patients and carer experiences can help us to continue to improve the support and care that we offer.

Are there any possible disadvantages or risks?
We do **not anticipate** any **disadvantages** or **risks** from taking part. If at any stage you feel **tired or uncomfortable** about me spending time with you, I will **stop** and **go away**.

What happens when the study ends?
I will give you a **summary** of the findings if you wish. I will **present the results** at conferences. I will **write up** the results for publication. **We will understand more** about what patients and carers learn in their first six months after brain injury and how they feel about this.

Who has reviewed this study?
This research has been reviewed by the Surrey, NRES Committee SECoast (Health Research Authority); Ethics No: 18/LO/1086

University College London Great Ormond Street Institute of Child Health (UCL GOSICH) is the sponsor for this study based in the United Kingdom. We will be using information from you 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.

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. Sally Davenport, on behalf of UCL GOSICH, will use your name and contact details to contact you during 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 UCL GOSICH may look at the research records to check the accuracy of the research study. The only people at UCL GOSICH who will have access to information that identifies you will be people who need to contact you to carry out the research or audit the data collection process. You can find out more about how we use your information by contacting Sally Davenport.

What is the purpose and legal basis of the personal data collected?
As a university we use personally-identifiable information to conduct research to improve health, care and services. As a publicly-funded organisation, we have to ensure that it is in the public interest when we use personal-identifiable information from people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use your data in the ways needed to conduct and analyse the research study.

Health and care research should serve the public interest, which means that we have to demonstrate that our research serves the interests of society as a whole. We do this by following the UK Policy Framework for Health and Social Care Research.

Who will receive and handle your personal data?
UCL GOSICH may use your name 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 UCL GOSICH may look your medical and research records to check the accuracy of the research study. [Trust name] will pass these details to UCL GOSICH along with the information collected from you and your medical records. The only people at UCL GOSICH who will have access to information that identifies you will be people who need to contact you to 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 or contact details.

UCL will not keep identifiable information about you from this study after it has finished.

Who do you talk to if you wish to complain about handling of your personal data?
If you wish to raise a complaint on how we have handled your personal data, you can contact our Data Protection Officer who will investigate the matter. If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO). Our Data Protection Officer is Lee Shailer and you can contact them at data-protection@ucl.ac.uk

What if there is a problem?
Questions and Concerns: If you have a concern about any aspect of this study, you should ask to speak to me as the researcher and I will do my best to answer your questions. Please contact: Sally Davenport (Principal researcher):
Email: sally.davenport@ucl.ac.uk

Complaints: If you have a complaint, you should talk me, and I will do my best to answer your questions. If you remain unhappy, you may be able to make a formal complaint through the NHS complaints procedure. Details can be obtained through the Patient Advice and Liaison Service (PALS) who can be contacted on [number] or [email address].
Harm: We do not anticipate that you will come to any harm. The sponsors (University College London) will at all times maintain adequate insurance in relation to the study. The

Trust also has a duty of care to patients via NHS indemnity cover, in respect of any claims arising as a result of clinical negligence by its employees, brought by or on behalf of a study patient.

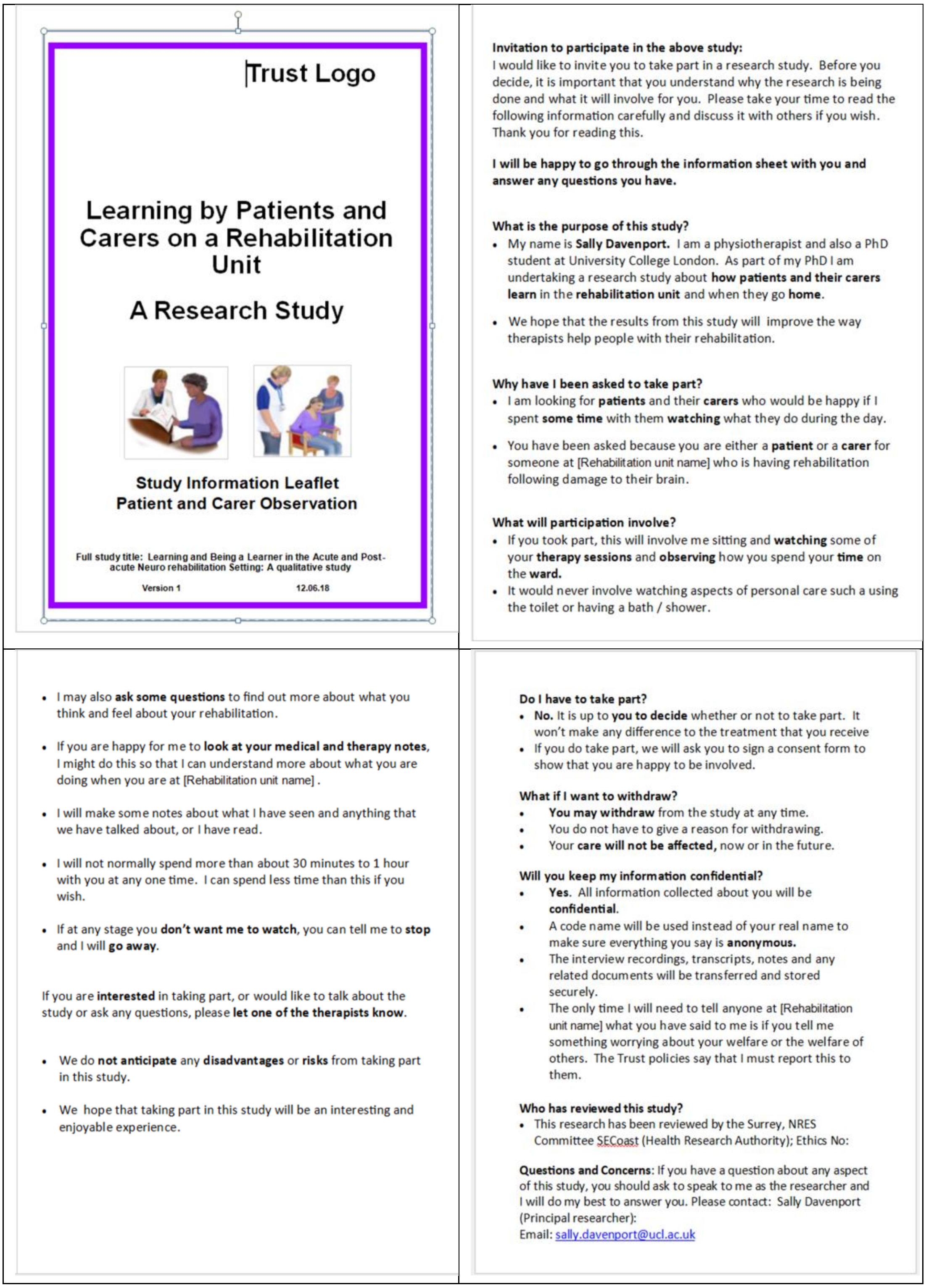
Who do I contact for more information?

Sally Davenport (Researcher)
Contact Address: 4th Floor Office, Wellcome Trust Building
UCL Great Ormond Street Institute of Child Health
30 Guilford Street, London, WC1N 1EH
Email: sally.davenport@ucl.ac.uk

Eleanor Main (Chief Investigator)
Contact Address: 4th Floor Office, Wellcome Trust Building
UCL Great Ormond Street Institute of Child Health
30 Guilford Street, London, WC1N 1EH
Email: e.main@ucl.ac.uk

Thank you very much once again for reading this information and giving consideration to taking part in this study.

Appendix 8 Simplified leaflet for patient and carer/family members to accompany the patient and carer participant information sheets



Trust Logo

Learning by Patients and Carers on a Rehabilitation Unit

A Research Study

Study Information Leaflet
Patient and Carer Observation

Full study title: Learning and Being a Learner in the Acute and Post-acute Neuro rehabilitation Setting: A qualitative study

Version 1 12.06.18

Invitation to participate in the above study:
I would like to invite you to take part in a research study. Before you decide, it is important that you understand why the research is being done and what it will involve for you. Please take your time to read the following information carefully and discuss it with others if you wish. Thank you for reading this.

I will be happy to go through the information sheet with you and answer any questions you have.

What is the purpose of this study?

- My name is **Sally Davenport.** I am a physiotherapist and also a PhD student at University College London. As part of my PhD I am undertaking a research study about **how patients and their carers learn** in the **rehabilitation unit** and when they go **home**.
- We hope that the results from this study will improve the way therapists help people with their rehabilitation.

Why have I been asked to take part?

- I am looking for **patients** and their **carers** who would be happy if I spent **some time** with them **watching** what they do during the day.
- You have been asked because you are either a **patient** or a **carer** for someone at [Rehabilitation unit name] who is having rehabilitation following damage to their brain.

What will participation involve?

- If you took part, this will involve me sitting and **watching** some of your **therapy sessions** and **observing** how you spend your **time** on the **ward.**
- It would never involve watching aspects of personal care such a using the toilet or having a bath / shower.
- I may also **ask some questions** to find out more about what you think and feel about your rehabilitation.
- If you are happy for me to **look at your medical and therapy notes**, I might do this so that I can understand more about what you are doing when you are at [Rehabilitation unit name] .
- I will make some notes about what I have seen and anything that we have talked about, or I have read.
- I will not normally spend more than about 30 minutes to 1 hour with you at any one time. I can spend less time than this if you wish.
- If at any stage you **don't want me to watch**, you can tell me to **stop** and I will **go away**.

If you are **interested** in taking part, or would like to talk about the study or ask any questions, please **let one of the therapists know**.

- We do **not anticipate** any **disadvantages** or **risks** from taking part in this study.
- We hope that taking part in this study will be an interesting and enjoyable experience.

Do I have to take part?

- **No.** It is up to **you to decide** whether or not to take part. It won't make any difference to the treatment that you receive
- If you do take part, we will ask you to sign a consent form to show that you are happy to be involved.

What if I want to withdraw?

- **You may withdraw** from the study at any time.
- You do not have to give a reason for withdrawing.
- Your **care will not be affected,** now or in the future.

Will you keep my information confidential?

- **Yes**. All information collected about you will be **confidential**.
- A code name will be used instead of your real name to make sure everything you say is **anonymous.**
- The interview recordings, transcripts, notes and any related documents will be transferred and stored securely.
- The only time I will need to tell anyone at [Rehabilitation unit name] what you have said to me is if you tell me something worrying about your welfare or the welfare of others. The Trust policies say that I must report this to them.

Who has reviewed this study?

- This research has been reviewed by the Surrey, NRES Committee SECoast (Health Research Authority); Ethics No:

Questions and Concerns: If you have a question about any aspect of this study, you should ask to speak to me as the researcher and I will do my best to answer you. Please contact: Sally Davenport (Principal researcher):
Email: sally.davenport@ucl.ac.uk

Appendix 9 Participant information sheet for staff observation

Trust Logo

Participant Information Sheet – Staff Observation and Focus Groups

Study Title:

Learning and Being a Learner in the Acute and Post-acute Neurorehabilitation Setting: A Qualitative Study

Invitation to participate in the above study:
I would like to invite you to take part in a research study. Before you decide, it is important that you understand why the research is being done and what it will involve for you. Please take your time to read the following information carefully and discuss it with others if you wish. Thank you for reading this.

I will be happy to go through the information sheet with you and answer any questions you have.

What is the purpose of this project?
My name is Sally Davenport and I am a PhD student. As part of my PhD I am undertaking a research study about **how patients and carers learn** in the **rehabilitation unit** and when they go **home**. Very little is known about how patients and their carers learn and whether this is the same as the way people learn in other situations. In particular, I am interested in what patients and carers feel that they learn, how they learn, where the learning takes place and what factors influence this.

The study aims are to better understand:

- What patients and their carers perceive that they learn and how they make sense of this learning in the short to medium term post stroke/ABI
- How and where this learning occur
- What factors shape the level and direction of the learning effort
- What it is like to learn and be a learner in the short to medium term post stroke/ABI.

I hope that by understanding more about patient and carer learning, it will help guide the rehabilitation that we offer so that we can continue to give best care to the patients that we work with.

To help develop this understanding, I will be based at [Rehabilitation unit name] for some of the time between July-September 2018 and then again between May-September 2019. During these times, I hope to spend some time with patients, carers and staff, watching people as they go about their daily activities on the rehabilitation unit, such as giving/receiving different types of therapy and working or being a patient on the ward. Alongside this observation, I would then like to ask some questions so I can learn more about what people are thinking and feeling about the learning that they are doing whilst they are having their rehabilitation.

Why have I been invited?
All staff who work at [Rehabilitation unit name] and some therapy staff who work for other parts of [Trust name] Neurological Services and are particularly involved in patient and carer learning, are being invited to take part.

What will participation involve?
Participation will involve taking part in either one or both of the following:

1. **Observation:** If you work at [Rehabilitation unit name], with your permission, I will spend some time with you off and on over the course of some of your days as you go about your everyday activity on the unit. The aim of this time will really be to focus on watching the patients/ carers that you are working with and looking at what they are doing but it is difficult to watch them without also watching you too. What I am interested in is their learning and not so much what you are doing. The types of things that I am interested in watching are therapy sessions, time spent on ward with the patient by themselves and time spent with then with others. I will never observe instances of personal care, such as bathing and toileting.

   Whilst I am with you, I might ask some questions to understand more about what you are doing and thinking or feeling at the time. Afterwards I will make some notes about what I have seen and anything that we have talked about. If you decide to take part but at any stage don't want me to be with you, you can tell me to stop and I will go away.

   Importantly, as stated above, the aim of this phase is to particularly observe patients and their carers as they spend their time on the unit. By watching them, I hope to observe and better understand what they are learning, how and where this occurs and what shapes it. I will aim to be as unobtrusive as possible and not to get in the way of your everyday work.

   As part of the research, I am undertaking some patient interviews. To help with these, I hope to video a therapy session for each of the patient's involved so that it can form the foundation of discussion in the interviews. As it is likely that the therapists involved will be captured within this recording, I will only video record if both the patient and the therapist give their permission for this to take place.

2. **Focus groups/interviews:** For both the staff at [Rehabilitation unit name] and others who work for [Trust name] Neurological Services, you will have the opportunity to take part in a focus group (group discussion) to talk more about your experience and opinions about patient and carer learning. Because it will be difficult to get everyone together at one time, it is likely that I will hold a number of focus groups, some with the nursing staff at times that suit them and some with the therapy staff. If you are not able to make any of the times of the focus groups or you would rather speak alone, we can do a one-to-one interview.

   The length of the focus groups will depend on how much people want to talk, but we anticipate that they might be between 45min-2 hour each. The exact length of time will be determined by the group and how much they have to say. We will arrange for these to be at times to suit as many people as possible. The focus groups will be audio-recorded and once they are over, I will transcribe them.

If you are interested in participating in either or both of these things, please let me know – either by email (sally.davenport@ucl.ac.uk) or by speaking with me on the unit. We can then go through any questions that you might have and if you are still interested in taking part, I will ask you to sign a consent form.

Do I have to take part?
No. It is up to you to decide whether or not to take part. Your decision won't make any difference to your employment now or in the future. If you do take part, you will be given this information sheet to keep and asked to sign a consent form to show that you are happy to be involved. You are still free to withdraw at any time and without giving a reason.

What if I want to withdraw?
You may withdraw from the study at any time. You do not have to give a reason for withdrawing, and your employment will not be affected, now or in the future. If you withdraw after I have spent some time with you it will not be possible to remove all of the information that you have contributed to the study and therefore some of your information may still be used.

Will you keep my information confidential?
Yes. All information collected about you will be confidential. A code name will be used instead of your real name to make sure everything you say is anonymous**.** The focus group recordings, transcripts, notes and any related documents will be stored securely. The only times when I will need to tell anyone what you have said are if you tell me something worrying about your welfare or the welfare of others, or if you report instances of malpractice, unprofessional behaviour or make unprofessional comments. The Trust policies say that I must report these.

So that I can work on the information that I gather from you as part of the research, it will need to be transferred from [Rehabilitation unit name] to my computer system at UCL. The information may be as notes made in my notebooks which I will type up. These will never contain your name and therefore no-one will be able to recognise you from this. It may also be as audio-recordings from the interviews or video-recordings from the filmed treatment session. To keep this information safe, as soon as these recordings have been made, I will upload them at [Rehabilitation unit name] to the UCL computer system (transfer them remotely using a secure system). I will then delete the original recordings from the recording device so that no-one else can listen to or see these. The consent forms that you sign will also be uploaded securely as electronic copies to the UCL computer system with the original paper copies being kept in a locked drawer in a locked office at [Rehabilitation unit name].

I might use direct quotations from the focus groups, but I will not use your name so you will never be able to be recognised.

Are there any possible benefits?
There is no direct benefit to you from taking part in this study but we hope that learning more about patients and carer experiences can help us improve the rehabilitation that we offer.

Are there any possible disadvantages or risks?
We do not anticipate any disadvantages or risks from taking part. We understand, however, that knowing that someone is spending time with you as you go about your daily work might make you anxious. **This study will not be judging you and what you do**. It is the patients/

carers and their learning that I am interested in. Should you have any concerns about the observation that is taking place, you can report this to [unit manager name]

Everything that is said during the focus groups will be treated as confidential, and all those who take part will be reminded that what is discussed should not be shared with others outside of the session. If there is anything that is discussed which causes you discomfort, you can refuse to answer any questions or opt out of that bit of the discussion.

What happens when the study ends?
I will present the results at conferences and will write up the results for publication. This will all be anonymous and it will not be possible to identify you in any way. By the end, the aim is to understand more about what patients and carers learn in their first six months after brain injury and how they make sense of this.

Who has reviewed this study?
This research has been reviewed by the Surrey, NRES Committee SECoast (Health Research Authority); Ethics No: 18/LO/1086

University College London Great Ormond Street Institute of Child Health (UCL GOSICH) is the sponsor for this study based in the United Kingdom. We will be using information from you 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.

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. Sally Davenport, on behalf of UCL GOSICH, will use your name and contact details to contact you during 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 UCL GOSICH may look at the research records to check the accuracy of the research study. The only people at UCL GOSICH who will have access to information that identifies you will be people who need to contact you to carry out the research or audit the data collection process. You can find out more about how we use your information by contacting Sally Davenport.

What is the purpose and legal basis of the personal data collected?
As a university we use personally identifiable information to conduct research to improve health, care and services. As a publicly-funded organisation, we have to ensure that it is in the public interest when we use personally-identifiable information from people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use your data in the ways needed to conduct and analyse the research study.

Health and care research should serve the public interest, which means that we have to demonstrate that our research serves the interests of society as a whole. We do this by following the UK Policy Framework for Health and Social Care Research.

Who will receive and handle your personal data?
UCL GOSICH may use your name 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 UCL GOSICH may look at the research records to check the accuracy of the research study. [Trust name] will pass these details to UCL GOSICH along with the information collected from you. The only people at UCL GOSICH who will have access to information that identifies you will be people who need to contact you to 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 or contact details.

UCL will not keep identifiable information about you from this study after it has finished.

Who do you talk to if you wish to complain about handling of your personal data?
If you wish to raise a complaint on how we have handled your personal data, you can contact our Data Protection Officer who will investigate the matter. If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO). Our Data Protection Officer is Lee Shailer and you can contact them at data-protection@ucl.ac.uk

What if there is a problem?
Questions and Concerns: If you have a concern about any aspect of this study, you should ask to speak to me as the researcher and I will do my best to answer your questions. Please contact: Sally Davenport (Principal researcher): Email: sally.davenport@ucl.ac.uk

Complaints: If you have a complaint, you should talk me, and I will do my best to answer your questions. If you remain unhappy, you may be able to make a formal complaint through the NHS complaints procedure. Details can be obtained through the Patient Advice and Liaison Service (PALS) who can be contacted on [number] or [email address].

Harm: We do not anticipate that you will come to any harm. The sponsors (UCL GOSICH) will at all times maintain adequate insurance in relation to the study. The Trust also has a duty of care to patients via NHS indemnity cover, in respect of any claims arising as a result of clinical negligence by its employees, brought by or on behalf of a study patient.

Who do I contact for more information?

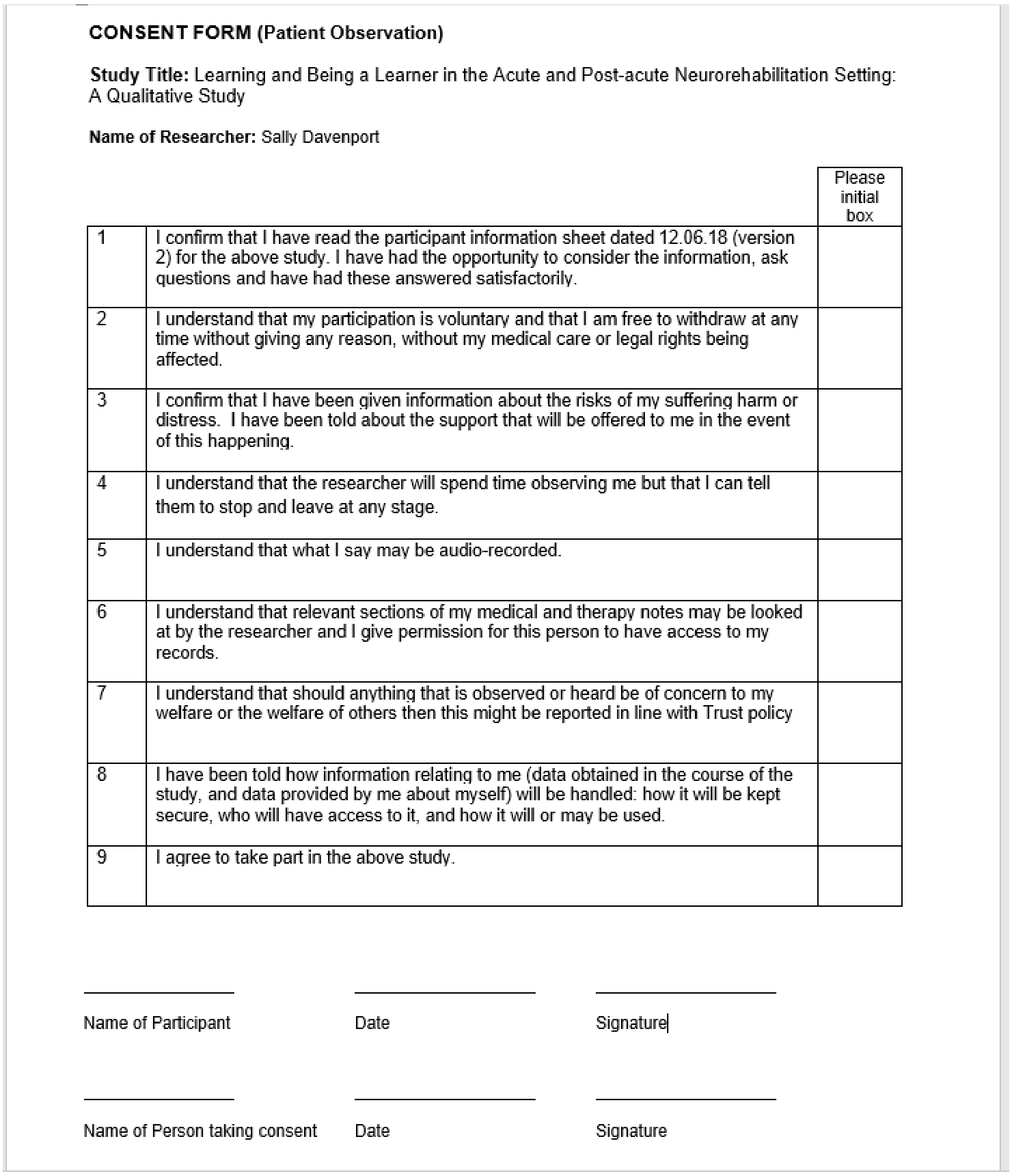
Sally Davenport (Researcher)
Contact Address: 4th Floor Office,
Wellcome Trust Building
UCL Great Ormond Street Institute of Child Health
30 Guilford Street, London, WC1N 1EH
Email: sally.davenport@ucl.ac.uk

Eleanor Main (Chief Investigator)
Contact Address: 4th Floor Office,
Wellcome Trust Building
UCL Great Ormond Street Institute of Child Health
30 Guilford Street, London, WC1N 1EH
Email: e.main@ucl.ac.uk

Thank you very much once again for reading this information and giving consideration to taking part in this study.

Appendix 10 Consent form for Patient Observation

Trust Logo



CONSENT FORM (Patient Observation)

Study Title: Learning and Being a Learner in the Acute and Post-acute Neurorehabilitation Setting: A Qualitative Study

Name of Researcher: Sally Davenport

		Please initial box
1	I confirm that I have read the participant information sheet dated 12.06.18 (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
2	I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.	
3	I confirm that I have been given information about the risks of my suffering harm or distress. I have been told about the support that will be offered to me in the event of this happening.	
4	I understand that the researcher will spend time observing me but that I can tell them to stop and leave at any stage.	
5	I understand that what I say may be audio-recorded.	
6	I understand that relevant sections of my medical and therapy notes may be looked at by the researcher and I give permission for this person to have access to my records.	
7	I understand that should anything that is observed or heard be of concern to my welfare or the welfare of others then this might be reported in line with Trust policy	
8	I have been told how information relating to me (data obtained in the course of the study, and data provided by me about myself) will be handled: how it will be kept secure, who will have access to it, and how it will or may be used.	
9	I agree to take part in the above study.	

Name of Participant Date Signature

Name of Person taking consent Date Signature

Appendix 11 Participant Information sheet for patient formal conversations/ interviews

Trust Logo

Participant Information Sheet – Patient Interviews

Study Title:

Learning and Being a Learner in the Acute and Post-acute Neurorehabilitation Setting: A Qualitative Study

Invitation to participate in the above study:

I would like to invite you to take part in a research study. Before you decide, it is important that you understand why the research is being done and what it will involve for you. Please take your time to read the following information carefully and discuss it with others if you wish. Thank you for reading this.

I will be happy to go through the information sheet with you and answer any questions you have.

What is the purpose of this study?

My name is Sally Davenport and I am a PhD student. As part of my PhD I am undertaking a research study about **how patients and carers learn** in the **rehabilitation unit** and when they go **home**. Very little is known about how people learn following damage to the brain and whether this is the same as the way people learn in other situations. The results from this study will hopefully improve the way therapists help people with their rehabilitation.

To help me understand this topic better, this study involves:

- Interviewing patients, and if they wish, a family member or close friend (carer) about their experiences of rehabilitation and then again about their first few months after leaving rehabilitation.

Why have I been asked to take part?

I am looking for patients at [Rehabilitation unit name] who would be happy to take part in some **interviews**. You have been asked because you are at [Rehabilitation unit name] for rehabilitation after damage to your brain.

To understand more about the first few months after damage to the brain, it helps to ask the people involved to tell us what they experience and feel. Your **experiences** and **opinions** will help healthcare staff to understand how best to support **patients** having rehabilitation.

What will participation involve?

Participating in this study will involve taking part in up to **4 interviews**. These can either just be **you or with your carer** (family member/friend). We hope to do 2 interviews when you are still at [Rehabilitation unit name]. 1 interview will then take place shortly after you have left [Rehabilitation unit name] and the last interview will be 3-4 months after you have gone home.

The length of the interviews will depend on how much you want to talk, but is unlikely to be more than 1 hour and we can **stop** at any time. If you get **too tired** we can **stop and continue after a rest**. We will arrange for the interviews to be at a time that suits you.

We will choose a quiet place so that others cannot hear what you say. For the 2 interviews at [Rehabilitation unit name], this will probably be in a quiet treatment room and the other 2 interviews, if you agree, would be at your home.

I will ask questions during the interviews and I will record your answers on a voice recorder. The questions will be about the things that you have been doing in rehabilitation and then at home and what you feel about this. Once we have finished, I will type up the discussion that we have had.

To guide the first interview, I would like to **video record** one of your **normal therapy sessions**. We can then watch this together and you can talk to me about what you did. If you don’t want to be videoed, you can still take part in the interviews. For the other interviews, I will then ask if you (and your carer) would be happy to keep a short record, or **diary**. This can be paper or audio recorded and will be a place for you to note down what you have done. This doesn’t need to be completed every day. What you record in it and when you do it will be your choice. Again, if you do not want to keep this short diary, you can still take part in the study.

If you are **interested** in participating, please **let your therapist know**. I will come and see you, to answer your questions. If you still want to take part, I will ask you to sign a consent form.

Overall, if you choose to take part in this study, you will be involved for about 4 hours in total spread over about 5-7 months.

Do I have to take part?

No. It is up to **you to decide** whether or not to take part. It won’t make any difference to your treatment that you are receiving at the moment or any treatment that you have in the future in any way. If you do take part, you will be given this information sheet to keep and asked to sign a consent form to show that you are happy to be involved. You are still free to withdraw at any time and without giving a reason.

If you agree to take part but become unwell at any stage we may decide that it is best for you not to continue. We will discuss this with you. If this happens after I have spent some time with you it will not be possible to remove all of the information that you have contributed to the study and therefore some of your information may still be used.

What if I want to withdraw?

You may withdraw from the study at any time. You do not have to give a reason for withdrawing, and **your care will not be affected**, now or in the future. If you withdraw after some of the interviews have taken place, it will not be possible to remove all of the information that you have contributed to the study and therefore some of your information may still be used.

Will you keep my information confidential?

Yes. All information collected about you will be **confidential**. A code name will be used instead of your real name to make sure everything you say is **anonymous.** The interview recordings, transcripts, notes and any related documents will be stored securely. The only time when I will need to tell anyone at [Rehabilitation unit name] what you have said to me is if you tell me something worrying about your welfare. The Trust policies say that I must report this to them.

So that I can work on the information that I gather from you as part of the research, it will need to be transferred from [Rehabilitation unit name] to my computer system at UCL. The information may be as notes made in my notebooks which I will type up. These will never contain your name and therefore no-one will be able to recognise you from this. It may also be as audio-recordings from the interviews or video-recordings from the filmed treatment session. To keep this information safe, as soon as these recordings have been made, I will upload them at [Rehabilitation unit name] to the UCL computer system (transfer them remotely using a secure system). I will then delete the original recordings from the recording device so that no-one else can listen to or see these. The consent form that you sign will also be uploaded securely as an electronic copy to the UCL computer system with the original paper copy being kept in a locked drawer in a locked office at [Rehabilitation unit name].

I might use your words from the interviews as direct quotations, but I will not use your name so you will never be able to be recognised.

Are there any possible benefits?

There is **no direct benefit** to you from taking part in this study, but we hope that by understanding more about patients and carer experiences, we can continue to improve the rehabilitation that we offer.

Are there any possible disadvantages or risks?

We do **not anticipate** any **disadvantages** or **risks** from taking part. During the interviews, you may find that talking about your experiences is **upsetting or tiring**. If this happens, you can choose not to answer any questions which you feel uncomfortable with or you can stop the interview at any time.

What happens when the study ends?

I will give you a **summary** of the findings if you wish. I will **present the results** at conferences and I will **write up** the results for publication. This will all be **anonymous** and it will not be possible to identify you in any way. **We will understand more** about what patients and carers learn in their first six months after damage to their brain and how they feel about this.

Who has reviewed this study?
This research has been reviewed by the Surrey, NRES Committee SECoast (Health Research Authority); Ethics No: 18/LO/1086

University College London Great Ormond Street Institute of Child Health (UCL GOSICH) is the sponsor for this study based in the United Kingdom. We will be using information from you 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.

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. Sally Davenport, on behalf of UCL GOSICH, will use your name and contact details to contact you during 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 UCL GOSICH may look at the research records to check the accuracy of the research study. The only people at UCL who will have access to information that identifies you will be people who need to contact you to carry out the research or audit the data collection process. You can find out more about how we use your information by contacting Sally Davenport.

What is the purpose and legal basis of the personal data collected?
As a university we use personally identifiable information to conduct research to improve health, care and services. As a publicly-funded organisation, we have to ensure that it is in the public interest when we use personally-identifiable information from people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use your data in the ways needed to conduct and analyse the research study.

Health and care research should serve the public interest, which means that we have to demonstrate that our research serves the interests of society as a whole. We do this by following the UK Policy Framework for Health and Social Care Research.

Who will receive and handle your personal data?
UCL GOSICH may use your name 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 UCL GOSICH may look your medical and research records to check the accuracy of the research study. [Trust name] will pass these details to UCL GOSICH along with the information collected from you and your medical records. The only people at UCL GOSICH who will have access to information that identifies you will be people who need to contact you to 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 or contact details.

UCL will not keep identifiable information about you from this study after it has finished.

Who do you talk to if you wish to complain about handling of your personal data?
If you wish to raise a complaint on how we have handled your personal data, you can contact our Data Protection Officer who will investigate the matter. If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO).

Our Data Protection Officer is Lee Shailer and you can contact them at data-protection@ucl.ac.uk

What if there is a problem?
Questions and Concerns: If you have a concern about any aspect of this study, you should ask to speak to me as the researcher and I will do my best to answer your questions. Please contact: Sally Davenport (Principal researcher):
Email: sally.davenport@ucl.ac.uk

Complaints: If you have a complaint, you should talk me, and I will do my best to answer your questions. If you remain unhappy, you may be able to make a formal complaint through the NHS complaints procedure. Details can be obtained through the Patient Advice and Liaison Service (PALS) who can be contacted on [number] or [email address].

Harm: We do not anticipate that you will come to any harm. The sponsors (University College London) will at all times maintain adequate insurance in relation to the study. The Trust also has a duty of care to patients via NHS indemnity cover, in respect of any claims arising as a result of clinical negligence by its employees, brought by or on behalf of a study patient.

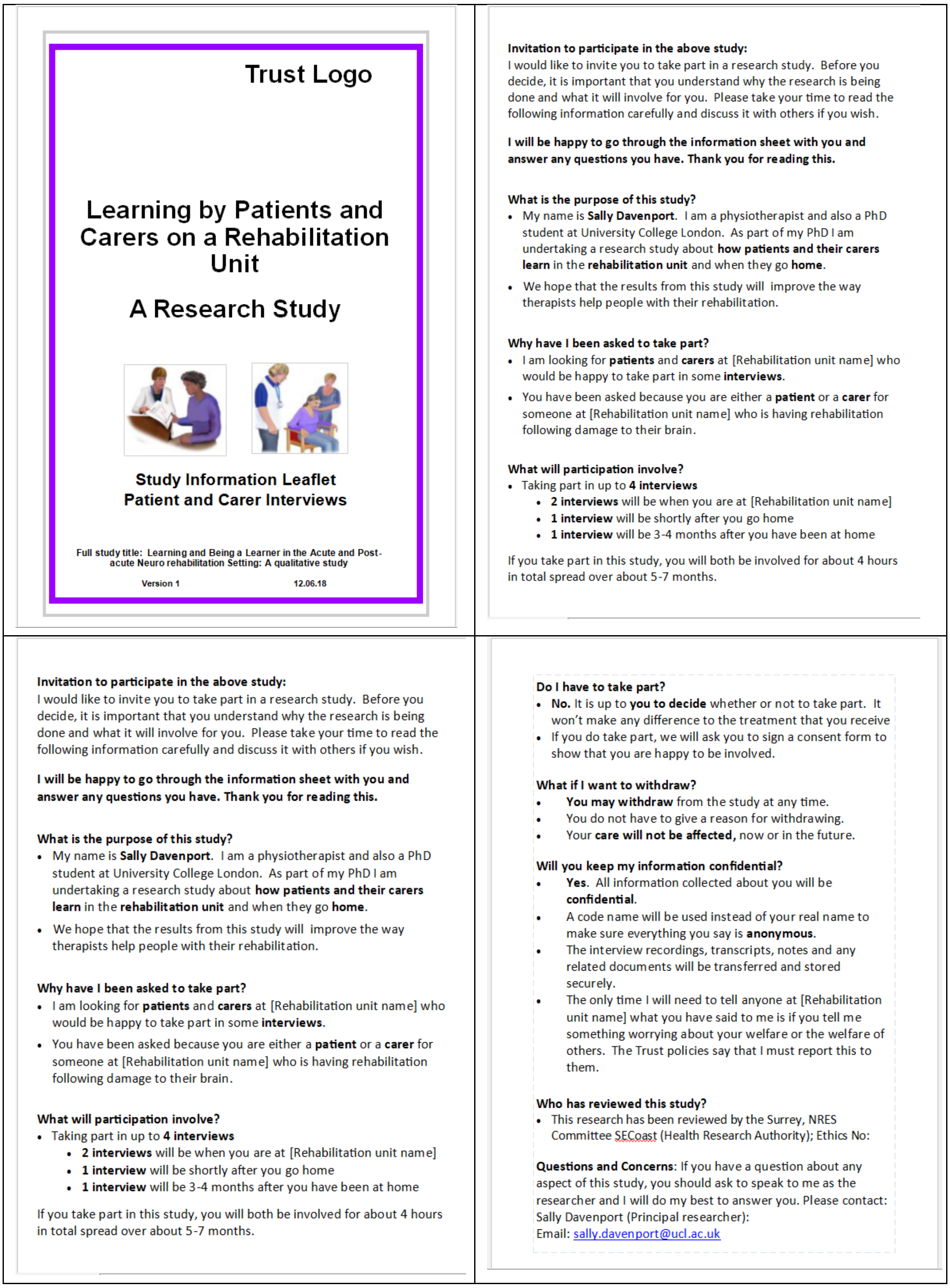
Who do I contact for more information?

Sally Davenport (Researcher)
Contact Address: 4th Floor Office, Wellcome Trust Building
UCL Great Ormond Street Institute of Child Health
30 Guilford Street, London, WC1N 1EH
Email: sally.davenport@ucl.ac.uk

Eleanor Main (Chief Investigator)
Contact Address: 4th Floor Office, Wellcome Trust Building
UCL Great Ormond Street Institute of Child Health
30 Guilford Street, London, WC1N 1EH
Email: e.main@ucl.ac.uk

Thank you very much once again for reading this information and giving consideration to taking part in this study.

Appendix 12 Simplified leaflet for patient and carer/family members to accompany the patient and carer participant information sheets



Trust Logo

Learning by Patients and Carers on a Rehabilitation Unit

A Research Study

Study Information Leaflet
Patient and Carer Interviews

Full study title: Learning and Being a Learner in the Acute and Post-acute Neuro rehabilitation Setting: A qualitative study

Version 1 12.06.18

Invitation to participate in the above study:
I would like to invite you to take part in a research study. Before you decide, it is important that you understand why the research is being done and what it will involve for you. Please take your time to read the following information carefully and discuss it with others if you wish.

I will be happy to go through the information sheet with you and answer any questions you have. Thank you for reading this.

What is the purpose of this study?

- My name is **Sally Davenport**. I am a physiotherapist and also a PhD student at University College London. As part of my PhD I am undertaking a research study about **how patients and their carers learn** in the **rehabilitation unit** and when they go **home**.
- We hope that the results from this study will improve the way therapists help people with their rehabilitation.

Why have I been asked to take part?

- I am looking for **patients** and **carers** at [Rehabilitation unit name] who would be happy to take part in some **interviews**.
- You have been asked because you are either a **patient** or a **carer** for someone at [Rehabilitation unit name] who is having rehabilitation following damage to their brain.

What will participation involve?

- Taking part in up to **4 interviews**
  - **2 interviews** will be when you are at [Rehabilitation unit name]
  - **1 interview** will be shortly after you go home
  - **1 interview** will be 3-4 months after you have been at home

If you take part in this study, you will both be involved for about 4 hours in total spread over about 5-7 months.

Invitation to participate in the above study:
I would like to invite you to take part in a research study. Before you decide, it is important that you understand why the research is being done and what it will involve for you. Please take your time to read the following information carefully and discuss it with others if you wish.

I will be happy to go through the information sheet with you and answer any questions you have. Thank you for reading this.

What is the purpose of this study?

- My name is **Sally Davenport**. I am a physiotherapist and also a PhD student at University College London. As part of my PhD I am undertaking a research study about **how patients and their carers learn** in the **rehabilitation unit** and when they go **home**.
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If you take part in this study, you will both be involved for about 4 hours in total spread over about 5-7 months.

Do I have to take part?

- **No.** It is up to **you to decide** whether or not to take part. It won't make any difference to the treatment that you receive
- If you do take part, we will ask you to sign a consent form to show that you are happy to be involved.

What if I want to withdraw?

- **You may withdraw** from the study at any time.
- You do not have to give a reason for withdrawing.
- Your **care will not be affected,** now or in the future.

Will you keep my information confidential?

- **Yes**. All information collected about you will be **confidential**.
- A code name will be used instead of your real name to make sure everything you say is **anonymous**.
- The interview recordings, transcripts, notes and any related documents will be transferred and stored securely.
- The only time I will need to tell anyone at [Rehabilitation unit name] what you have said to me is if you tell me something worrying about your welfare or the welfare of others. The Trust policies say that I must report this to them.

Who has reviewed this study?

- This research has been reviewed by the Surrey, NRES Committee SECoast (Health Research Authority); Ethics No:

Questions and Concerns: If you have a question about any aspect of this study, you should ask to speak to me as the researcher and I will do my best to answer you. Please contact:
Sally Davenport (Principal researcher):
Email: sally.davenport@ucl.ac.uk

Appendix 13 Examples of photographs used as triggers for the initial participant conversations













Appendix 14 Example of an extract from fieldnotes made from one day during Phase 3 of data collection

This exert has been selected as an example of extracts of fieldnotes from one day of observation. Alongside these, quotations have been given from some of the staff conversations to show their thoughts/understanding alongside my initial notes/thoughts.

Thursday 11th July 2019	Associated quotations from Staff conversations	Reflection
Late morning discussion with Richard wife's – was sitting in the gym writing up a few reflections and she came in via the doorway into the gym as hadn't been able to get into the doorway downstairs – daily visit to see her husband; wanted to briefly pass over to me the one main comment about rehab unit that she felt was most important for me to be aware of – this was about the information given to patients and their relatives at the beginning of their stay about what went on, on the unit; talked about expert syndrome and how everyone who works here knows what is going on but that this isn't the case for relatives or patients who instead are largely in the dark. When she arrived at the unit was very anxious and unsure, told that had 6wks as length of stay and very anxious that this wasn't going to be enough; didn't feel at all in control esp as Richard was so poorly and was so up and down for much of his stay. Feels that they probably were given information about rehab and recovery but didn't take it in – wasn't the right type of format of info, or right info, in right way, at right time. With expert syndrome mix of assumption that everyone knows and understands including pt and family and/or why would they need to know so not informed – didn't really know so perhaps didn't know what to take in. Not sure how would want the info about how the unit worked and what it should be – probably something in writing from them to read/refer to.	**And do you provide patients and their relatives with any information about the unit, how it works, I just wonder if there is any pre-made information that is given to patients and their relatives?** **HCA5** When they come here? **HCA6** I think they get a pack don't they **HCA5** They get a pack but they're not told **HCA6** No, they will ask questions **HCA5** They will ask questions and some because they come in the ambulance closed up, they don't even know where they are [laughter], they are so confused, some of them they say, they didn't even tell me I was coming here, they thought they were moving from one ward to another and to get them to know they are in this place, it is because, they come from a hospital and they haven't been out from the hospital and now they are put in another **HCA6** they think they are in the same place sometimes, I think **HCA5** Driven here, they don't know where they are **PT2** I mean, in terms of understanding, patients understanding, it is quite variable in terms of, yeah, I'm not sure what education they get at [acute trust] in terms of what's going on and physiologically what is happening, um, but yeah, I just always try to get in there quite early about what's happening and what driving and how to assist with it but you know it's up to the brain now as to how much ultimately it can find those new connections and you can help by x, y and z but ultimately your recovery is going to be limited by how much is going on in terms of those plastic changes, it's quite hard sometimes to talk to the patients about those kind of, to find an opportunity to talk about that, I find	*Info giving more of a point of note for some pts and relatives than others – balance more towards relatives with pts like Stewart, Steve and Jim who wanted to know more in the minority; wives able/having to think ahead more whereas for most of stay in rehab pts living in the present; ? place that wanted to be/with limited energy levels, only place that could be/place that needed to be/no reason not to be with no awareness of need to be anywhere but the moment.* *Little questioning of input that was offered on the rehab unit – enjoyed, trusted, felt safe, felt right, mostly could see progress.* *From most pts, little questioning of how things were working – happy with what was being delivered.* *Did shift for some over time but not really for all, and for some it felt that shift to be more questioning and to thinking ahead shaped by family.* *Some conversations with staff about current/presenting position; little about the future. Not sure if ever saw any discussions about future life over and above immediate concerns for discharge; perhaps they were occurring with others/in places where*

Now that coming towards discharge feeling more in control; DC planned for next Friday and equipment starting to be delivered and going into their home for this DC to occur; now more confident with how everything works Wife previously married to someone who died at quite an early age after a long period of ill health – knew how tiring it was to be a patient in hospital and also being a relative/visitor; at this stage developed awareness of what she calls expert syndrome – doctors and others having knowledge which either reluctant to share of don't see any need to share not seeing/ understanding that the pt and/or their relatives might be interested; talked a lot about the importance of communication, thought that it should be a large part of training and surprised to hear that it wasn't; resentful that pts not helped and supported more through better communication and information giving so anxieties are allayed somewhat Mentioned term expert syndrome a number of times – clearly a really important point and something that had been really impactful for her *Conversation just brief and in the gym, didn't want any longer or to go elsewhere that might have been more private; keen then to go down to the ward to see her husband; equally it was clear that she wanted to say what she did as felt that it was important to share this as if this had been her experience, it probably was also for others; Said that wasn't a criticism and everything had been excellent but had been thinking and this was the aspect of information that wanted to pass over*	**OT4** Yeah, we try and do a bit in the goal planning meeting…if you have other family there listening to that as well that might be able to grasp those concepts as well and then reinforce **PT2** And some patients are really driven to find stuff out and they've been looking at stuff, reading stuff and others aren't at all interested in wanting to know or discover, so it's really interesting seeing the difference between the different patients and some are obviously really driven to find out and search, you know, all this sort of stuff and coming out with can we try this, I've read this, and others aren't proactive I don't think and are happy to go with the flow and not necessarily fully understand what is going on [pause] I think, I think, yeah, patient education **OT1** [quietly] I think, I think it's something that we could probably be better at **PT2** But not necessarily better because not everyone wants it do they, but just to finding the opportunity, or just finding a space where they can kind of go if they want to but not everyone's going to want to access that, or, um, want to know what the outcomes going to be in a way that others are really wanting to know the end point **OT2** Yeah, we talk about home quite early on, I wonder if, sometimes in the goal planning meetings, even in one this week, the family were kind of saying, this has been really great because it's the first time we've had the chance and have really had the space to talk with healthcare professionals about, you know their relative's stroke, and they haven't really had a chance to do that yet	*not observing, but not sure where this would have been.*
Early morning on ward seeing Tony before his DC home Tony again tearful on a couple of occasions during his recorded chat, esp when reflecting on how tough life was for some of the other people there on the unit and how they had been DC home to such complex situations; realised that it was as it was but still tearful – clearly moved and upset by this, having got to know a couple of the individuals, he didn't know	**RA1** you know we actively encourage them to leave the unit if they can, you know be able to go out for lunch, or coffee or whatever, um, and I guess some patients like their own space don't they **RA3** yes **RA1** they like their individual bedrooms, some of them don't, but actually a lot of the younger patients I think prefer to be in their own room, in their own space, to have a bit more quiet time rather than being in a sort of ward based environment; I mean it has its advantages	*A lot of discussion about single rooms and their pros/cons* *Shared rooms universally not liked by the staff but in discussion, could see that for some pts they could be lonely; all remained not in favour of pts sharing feeling that this was more hassle than they were worth.*

how they would cope and felt their home situations weren't conducive to any further recovery taking place; said that it was probably best not to think about it and just think about oneself instead; clearly bothered though by the lives of others and how tough and unjust he felt life was. Feels ready to go home, cannot see any reason still to be in rehab, can be depressing being around some of the other people who were there, people who were so poorly/needy and not really progressing in any way; would have liked it if more people like him had been around, aware that had been lucky with some of the others and enjoyed sitting with them at lunchtime and chatting then, would just have liked this to have been a bit more and then there would perhaps have been a reason to be out of his room a bit more; enjoys the banter as makes a difference, enjoyed banter with the others but they had either also gone home or were going so feels right time to be going too. Without others, felt strongly that no real reason to be out of his room; why would he want to be around others if not like him; definitely didn't want to join in with any activities; happy with the peace and quiet of his room.	and disadvantages um but I think the majority of the patients quite like the fact that they can have their own space if they want to **The patients talk quite a lot about having their rooms, what are your thoughts about single rooms and the shared room** **HCA1** The shared rooms don't work **HCA2** They're not working, privacy wise they're not working, the curtains are all, they don't meet, you have to peg them together **HCA1** In fact I thought that Room X was decommissioned as a room, that was my understanding, then you have two patients in the same room, waking each other, the other night J was waking J up, and J was waking J up and J was walking over to other J, it was awful **HCA2** And the other night, one of the Js was up packing because he didn't want to be there with him, we have had conflicts like that, so, we have mentioned it before but it's something that's got to be, you know, we've got to have rooms **HCA1** It's a rubbish idea **HCA2** As we say, it's not working **HCA1** A lot of moneys been put into them when we had the extension, they spent a few millions pounds didn't they, you would have thought they would have done the rooms, make them two singles	*Patients a bit more equivocal; all, on balance, happy with their own rooms but this may well have been shaped by the nature of the patient participants who were all at a cognitive level where able to take on indep exercise practice.* *Liked the privacy and the place to escape to; most aware though that if their situation was different and they didn't have visitors, then a room alone could be lonely; most voiced awareness of possible benefits of sharing.* *None linked any of these discussions to indep exercise practice and see their room as a place to enhance recovery; linked to privacy/escape, time with relatives and sleeping.*
In dining room over lunchtime, watching from doorway; normal banter now observed on a number of occasions; lunchtime and dinner time very ritualised in how and where people sit, what they drink, how food served and in what order etc – *in a way probably no different from meals at home being ritualised* Lots of people serving today with the HCAs, housekeeper, caterer, student nurses and a volunteer Separation of space with staff on one side over by the serving area and then pts at tables; come together at the moments of giving and clearing food but otherwise not really at all; very friendly with a high degree of care for different needs: where one wants to sit (men and women separately), what they wanted to drink	**And from a therapeutic point of view, do you have many with adapted cutlery and things?** HCA1 Occasionally HCA2 We have got adapted cutlery but at the moment HCA1 It's occasional isn't it that we have a spoon or something **I was just wondering, let's say someone was trying to do UL rehab, how much that gets, how much meal times are, does that get promoted or is it more** **HCA1** Yeah, we encourage them to use it as much as possible **HCA2** Yeah, but it can be embarrassing **And they have two meals in here don't they, suppers in here as well, and sitting in the same places?** **HCA1** Yeah they do like to sit in the same places, it's funny **HCA2** Yeah they do like it	*Ritual of mealtimes – set pattern that was always followed and a set routine; lots of care with what people were eating and that the mealtimes were enjoyable; intentional invitations to eat; wishes known to staff who were broadly able to attend to these.* *Very much an institutionalised space though – jolly and socially therapeutic even if not really physically therapeutic – everything set up to enable single handed indep eating rather than pts facing and overcoming any real challenges as might have to*

(although enquiry made by housekeeper, she knew what people liked and therefore asked them in the context of it they would like it again), whether one wanted gravy or any extra sauces on food (one pts liked his food with a separate chili sauce made especially for him and kept in a Tupperware pot) Definite concerns about immediate care needs being met whilst eating as well as nutritional needs being met; Dietician in and out trying to work out meal plan for pt with diary allergy who was losing weight – read through ingredients on different biscuits and then organised bread with sunflower spread, very keen that the team knew how to support this and trying to impress upon them the need to follow this through Overall, room felt busy with lots of activity going on, pts partly involved with this but partly not	**HCA1** They get used to it, that's my chair **HCA2** They get upset if someone sits there **I was just doing the UL grp upstairs [HCA 3 joins] and there are five of them and it's the same, they go to the same spot and they've only been in for five weeks** **HCA1** I think six weeks is long enough for it to become home as well and that's their spot, and that's their favourite arm chair **HCA2** Six weeks must be a long time for them, mustn't it, it must feel like six months **HCA1** I was talking to [female pt with MS] and she was saying that she feels she wasn't ready to go home but it also feels like she has been here long enough to, she knows everyone, she knows my footsteps **HCA2** a lot of them say that don't they, that they don't want to go home because they are so used to it, so they get a bit anxious **HCA1** and she was saying that she knows my steps, and she knows everyone by their walk up the corridor	*do when eating at home (e.g. non slip mats, plastic cups, food cut up, food brought to them etc; no real signs of physical functioning practice which could be enabled in the functional setting).* *For those who did go to the dining rooms, divide between staff and pts; also between the men and the women who largely sat separately; for those who had the choice of when to come/go, length of time spent in dining room really depended on the presence of like mined others – some periods where quite a lot of camaraderie and others times none*
In the afternoon, writing motes in gym and joined again by Richard's wife as she came up to watch his physio session that afternoon; chatted across the table in the middle of the room, not recorded Richard medically a bit more stable, still very tired but some moments of day when a bit less so; had been woken from sleep for physio session at 2.30pm that day, so all a bit washed out for much of Rx session Seen by a couple of the physios who were less familiar with his normal schedule; progressed standing practice from side of plinth, standing with 2-3 people, short stands and then returned to sitting again, pt always keen on the sitting down bit; wife commented that when he arrived was unable to sit indep but was doing this fine now; fatigued quite quickly so after 4-5 stands, did rest of session on the bed trying to recruit some LL activity through L side – some return even if not terribly selective Wife commenting that she would like the ward staff to use the Re-turn more as often use the hoist; as using it in the gym, would like this carried over more	**Do you get much time to go up to the therapy gym?** **HCA2** No, no, **HCA4** no never **HCA3** I've never been **HCA2** we've never been asked actually, I mean a couple of times I've been to a few goal planning meetings and things **HCA1** it was a while ago wasn't it we were encouraged to go up with them, do you remember **HCA2** no **HCA1** yeah, about a year ago **HCA2** Oh really **HCA1** we were supposed to be going individually, spending a day with the OTs, did you never do it? **HCA2** No I didn't do it, did you? **HCA1** well when I was going to do it, I got sick or something **HCA2** no I didn't do it **HCA1** did you not **HCA2** I've only been to goal planning meetings **Would it interest you to go up?** **HCA4** Yeah, I think so, again, I think it's better to see what the team **HCA3** what's happening	*The divide between upstairs and downstairs talked about a lot by staff but not at all by the pts – this wasn't something that I particularly anticipated as my impression was of a very cohesive unit; although broadly true, this was more perhaps from the more senior staff who worked really hard to build a shared identity than from some of the others; through discussion, quite a lot of them and us (as reflected in these extract of quotes); what happened in therapy gym had really no visibility to the ward staff at all (to the extent that didn't know the names of the therapists); ward activities had greater visibility to the therapists but what they didn't see was this lack of visibility; some resentment/bafflement that the ward staff didn't carry over*

to the ward; feels that it's more normal to stand up than be hoisted and with more opportunity, Richard would improve with this	**HCA4** are trying to achieve, I mean quite often we look at people and think oh no rehab potential, no, and it would be interesting to see actually what they can do upstairs **HCA1** and then we can do it downstairs **HCA2** because sometimes the patients do more for them upstairs than they do for us, don't they **HCA1** and then we can bring the ideas back down on the ward and continue it **HCA2** Then you know what they're capable of with the, if they're trying to say that they can't do it **HCA5** Because sometimes the patients, when they come down here, they think we are carers, we're supposed to help with everything, if we were, like to see what they are doing, we can tell them, no, I saw you are walking, you can walk, you can do this and that because I saw you doing this, and I was there when you did that, you know, because when they come down, you know, because you are the carers and they are the physios, it's different **HCA7** I think they come from places like [acute trust] don't they, they see the same uniforms and think they are in the same sort of place **HCA5** Even simple things they can do but they do more when upstairs, but when they come down	*rehab more on the ward but because they didn't realise that the ward staff had almost no idea what went on in rehab, how impossible it would be for them to carry anything over; both sides really waiting for the other side to make the first move but, from listening to the different voices, joining up the two spaces would need to involve a much more invitational and active process than just being present more in each other's spaces; similar to how pts don't automatically pick up what indep practice to do and need a much more invitational approach, so too from the staff*
Chatting with wife about DC home, planned for this to be a week on Friday and feels that she and Richard will be ready for this; not fully sure why feels this but thinks that Richard will enjoy being back at home again in familiar environment even if not in familiar routine; had been very concerned about the first DC date but now feels with the extra couple of weeks, that things are ready Have organised live in care for the immediate period on getting home – doesn't feel that this is really necessary but done to please his daughters As yet has not had any training about moving and handling/caring; a bit anxious about this; feels has been able to watch so far and expects/hopes training	**How do you think relatives fare here, what do you feel their role is, their?** **N3** Well we try to get them involved as much as we can, like **N2** Some of them **N3** I had MP11 before he left, his wife was passionate to know how to do things, I was more than happy to show her, and get involved **N1** That's why they, that's why we've got these visiting times **N3** yeah, open visiting times **N1** Yeah, open visiting times, so they can come in and help them feed or even wash them if they wanted to **And have you ever worked with a relative to help them do, let's say a washing or,** **N1** Yeah, yeah **N3** yeah	*Despite these sentiments, from observations on both the ward and the gym, very little involvement of family; felt such a shame as open visiting hrs meant that many family members were on site a lot and could have been much more actively involved; on both the ward and in the gym, family there really as passive observers with little active teaching regarding either help with exercises or help with personal care; if the family pushed, then would be shown and involved, but the initiative for this really needed to come from them.*

to happen in this week in readiness for going home – not really sure though if should ask or if it will happen Thinks that community team will come after that but not fully sure when this might be or what really it will involve	**N1** yeah, if they're keen to learn themselves then you, and also stuff as well, it's nice to **An extra pair of hands** **N2** definitely, them getting themselves used to it	
Asked if all regions had somewhere like this rehab unit, discussed a bit about what stroke rehab places can be like; feels that the unit has really been nothing but excellent and that it has made a big difference to them; been incredible		*Common thread; more than being supported, guided and nurtured; Richard's physical level remains relatively low so the unit clearly offered them something more than just physical recovery*
One final point of note was that in earlier part of the week there had been another flood from one of the pipes in the ceiling – whole ward needed to be evacuated again to nearby hospital until safe to be returned; pipe fixed and dayroom just waiting deep clean – hopefully to be done today and then everything to be moved back in from where it had been in the dining room The latter had been used temporarily as a day room, but no real personalisation of this space, although windows and a glass door, feels a darker, less pleasant room to be in Really showed the impact of the space on the feel of somewhere and how can just really work or not work.	**PT** potentially the fact that they have their own space a little bit, it's not, I don't feel that it feels like a hospital, it's not a hospital setting, it's more of a kind of, um, more of a relaxed atmosphere, it's less frenetic, it's a bit quieter **Nurse** Yeah, I think people like it because it's quiet, I think the day room is probably quite a big pull because you're not just sitting by your bed all the time, you have got another space to go into, and I think the garden, people are always a bit like, the garden; I think this is quite a unique place because of the space, the quality of the space that we have **HCA2** Yeah and they see mostly, they see a lot of little things, even allowing them to wear their own clothing, that defines a hospital setting and a rehab setting, and the visiting, relatives as well, they can bring their children here, they can bring their dogs, those little, little things, they do help, it might not mean a lot to any of us but to them, it does mean a lot **HCA3** And going home for the weekend or a night, something like that, that doesn't happen in hospital, does it **HCA1** And when we know, even though were very busy, we spend with them, talking to them, trying to know them much better, but in hospital I don't think you get that, there is like always like rushing about, here it is more calmer, yeah, it can be busy but we still have a bit of time to have a little chat with them, yeah	*Space and what it offered; builds in part on the point above about the unit offering so much in many ways that are less tangible and complex to unpick; what staff felt though were the positives about the space and the ways of working not always the case at all from the pts and their thoughts – for example, staff really positive about the dayroom but these sentiments not shared so much by the pts – more dependent on the people in the place than the place per se; seemingly so enriched to look at but not used in such a way that this was felt by all the pts – can a space ever be invitational for recovery in its own right? Spaces very much seen and used as they would normally be as not seen as spaces for recovery.*

Appendix 15 Example of initial workings from a patient participant transcript – extracts from focused contextualised conversation with Jim

First stage of analysis working with each transcript looking at collections of lines of conversation and reflecting on what was said, possible meanings, reasons for thinking feeling, sense making – from Jim and me of Jim

Extracts from transcript	**Initial thoughts/interpretation**
And you had two weeks at acute hospital? Yes, on both wards, they moved me overnight down to X ward which was quite disconcerting because I woke up in the middle of the night, didn't know where I was because the light pattern was different on the ceiling, and you know the blood pressure band was very tight, and my hand was going dead and my fingers were tingling and I thought, oh God, I want this loosening and asked them to take it off and they said that they couldn't and it had to be on all night and I thought I struggling, I'm strapped down, why am I strapped down, um, I think that has a slight negative effect on me really; but that's not a complaint at all, so you, you don't need to take that **No, no … and that was disconcerting because of not knowing where you were?** Yes, not knowing where I was and feeling that I was being restrained 'cause I couldn't move my legs and I couldn't turn over in bed with the rails up as well **So your time on the wards there [stroke wards at acute hospital], can you tell me what you were doing during the day?** [with ironic laughter] lying in bed, listening to what was going on, chatting to the other patients, you know because there were six of us in the small room, there might have been eight, no there were six of us so just passing the time of day with them; there was a television room next door that we could have gone to, but I wasn't particularly interested in watching television [laughter] **So largely in bed during that time – did you have a chair by your bed?** Yes, yes **And did you sit out in the chair?** No, no, I didn't, again not to complain **No, and did you want to sit out in the chair?** I guess so yes, **Can you tell me more about that, could you have got yourself into the chair if you had wanted?** Yes, I think with determination, I could, but with the rails up at the side, you couldn't reach over and release them; but I never asked to, I just lay there, zonko [laughter] **And were you were very tired during that time?** I did sleep a lot, yes, because the consultant had said on one of his visits that sleeping is one of the best cures, and I thought well, you're the boss, you're the expert, I'll take your word for it, Doc	Frightened / lost 'Trapped' in bed with bed rails up / BP cuff on / legs not working / not able to do as would normally do Knowing something wasn't right but not sure what Long days in bed – little/no therapy; little/no sitting out To do more, would have had to be self-initiated rather than be facilitated or encouraged – go outside the pattern of care Waiting Company of others/peers Recollection of being advised to sleep by consultant – followed advice as authority ? linking sleep as helping with recovery Largely dis-invitations – nothing here that was very invitational

And did you start to see any therapists on those wards? No, no, not 'til I came here, I arrived here late on a Friday night at about half past seven and um, they wheeled me in, asked me how I was, and I said that I'm freezing cold, what did I want, a cup of tea and a nice warm bed please, and that was it and I woke up at twenty past ten the next morning **Having had a cup of tea and a good night's sleep!** Yes, yes, I guess so **So, you came here by ambulance did you?** Yes, yes, I did **And can you tell me a bit about that arrival** It was very welcoming [pause]; wheeled me in through the dining room, you know the dining room downstairs, and as I was in, I recognised the gentleman that was opposite me in [acute] ward and his niece and they were all waving, and I thought that was nice and of course putting me in a warm bed with a cup of tea	Not able to remember any formal therapy input in the acute setting Warm welcome literally and metaphorically – drawn into the unit and held there/as if hugged by it Welcomed by staff as well as by pts from the acute setting – felt straight away like the right place to be Wanted to be warm and wanted then to sleep – resulted in deep long sleep Wanted to be somewhere different from acute setting Visible invitational arrival
One of the other people has mentioned about being made a cup of tea when they arrived, was that important? Yes, it was a warming drink, I'll tell you why, again this is not a complaint, when we left [acute trust], we were taken in a wheelchair down to the departure area which was out in the open and I only had a pair of hospital pyjamas on and it was pouring with rain and freezing with cold, and I had to wait to get in the ambulance and it was cold in the ambulance, so when I got here I was shivering, I couldn't stop shivering, so a warm cup of tea was very welcome **So, a warm cup of tea and a bed** Yes, a warm bed, a warm comfortable bed, yes, that's it; they go out of their way to make you comfortable here **And what kind of thing do they do that make your comfortable?** Well, with this bad arm, I call it my bad arm, they made sure I had a pillow to rest it on at night, and again, if you said that you were cold, they would bring you another blanket, that sort of thing, and you know how they bring the back of the bed up; one night, I didn't get my pillows right, so I woke up with a very stiff back, so then I said can I have a pillow in the small of my back just to pad it up, um and, you know, every night I say can you put a pillow in my back and they say is that where you want it, and that's fine, that's the sort of thing **So, it's quite individual to you?** Yes, yes it was, it was, but I'm sure it's like that across the board	Importance of actions on arrival These remained as something important – to be made seen as a valued person; helped to be made comfortable Immediacy and visibility of these actions being on arrival People going out of their way for them as pts Done with care and commitment to get things right – not just basic attention given but extra attention given (phrase no one knows how much you know until they know how much you care) Comfortable of body, comfortable of mind, know people care and will look after one / safe Seen as an individual whose wellbeing is important – valued Some actions in healthcare just are/have to be (like the transport) but eased by then being welcomed, made warm, made comfortable Invitational nature of the actions of people in the place of the rehab unit Importance of being in a safe place/ space – conferred by place itself, the actions of the staffand things that happened
And were you R corridor or Y, for your room? R2, I was **And is that a single room or a shared room?** Shared, and I was sharing with the gentleman who was opposite me in [acute], so we would chat to each other which was good, actually	Initially shared room with someone known from the acute setting – nice that had company and was able to chat – no ill feeling towards shared room Episode of waking during first night, unlike experience in acute setting

So, who welcomed you when you got here, the patient and his niece which was nice, did anyone else welcome you on to the ward? I don’t know, I think R (HCA), I’m not sure, now this is very vague, very vague indeed, [tearful] I have a vague memory of waking up in the night, half awake, and someone was looking over me looking at me, do you know what I mean **During that first night when you were here?** Yes, during that first night, it was comforting, it’s only very vague, you know when you are half awake and half asleep, you just get an impression that someone’s there, it wasn’t frightening at all, it was comforting, I’m sorry but it was so different to [acute] ward **Right, are you able to talk about in what way?** Well, I felt that there was someone there to look after me, especially after my experience of the change of wards at [acute hospital] **And that felt different here?** Oh Yes, very different, very good; the staff here are incredible, they’re really good	where had been frightened and disorientated by a move between wards in the middle of the night – not expecting and woke feeling very lost, because this time felt that someone was looking down on him/after him, it was a reassuring sensation and felt safe and could trust Knew immediately that rehab units was different from the acute setting – looked after/safe/secure and not frightened/lost/disorientated To be looked after – to be in the hands of people who care; also in the hands of the right people who were exacting the right things/being helped
Are you able to tell me more about what is it about the staff here, if you had to pick out…? They’re very caring, they look after you, you’ve only got to ask them for something and they will do it as soon as they can; bearing in mind they are looking after several other people, you don’t expect them to be instantaneous, say in the middle of the night, you know, you want a bottle which they’ve got to go and get, they have other people to look after so it doesn’t come back within ten seconds, you know what I mean, but I realise that, you just accept it, you plan ahead [laughter] **So, caring, is there anything else about them?** Sympathetic, oh yes, definitely **And is that you? To your family?** Yes, of course, yes, they learn your name very quickly, my official name is [full name] but everyone calls me [preferred name] **And was that different on [acute] ward?** No, not, there was one nurse on [acute] ward, [male name], um, I didn’t know because I don’t know the levels of nurses, he might have been a senior or something like that, he was the same, he called me G [shortened] as well **And do you think that the other nurses on [acute ward] knew your name?** Oh I’m not sure they did, there were so many, I don’t know them all; like here, we have name boards on our doors, they didn’t have that there, for one thing there was no door because we were in a big communal ward, it was just different organisation; there they were to get you well medically, here they’re to get you well physically, a slight difference as far as I am concerned	Caring, attentive, do their best for one Know one’s name which was a sign of knowing one altogether – seen as the person that one is – more so in rehab than in the acute Smaller place so possible to be known and also to know others Names by rooms – have rooms, have own space and can own that space because one’s name is by it – have a door Nurses can’t do things straight away but will do their best to do what they can – day or night Have to have some give or take with other pts Role of the acute setting to get one well medically and of rehab to get one well physically Two different place/two different aims
Absolutely, so you arrived here on a Friday, when did you start your rehab, your therapy sessions, can you remember? Probably the Saturday or maybe the Sunday, I can’t remember, very quickly, yes **And what did that feel like?**	*[My phrasing of linking rehab to therapy as if the two are completely synonymous]* Feedback straight away that could do/would be able to do

I can walk [surprise and laughter], yes [pause] **So, when you were at acute hospital, were you walking there?** Yes, hobbling a bit, I can't remember, I walked down to the shower room and back again, without a stick, without holding on to anything, except for my towel and I had my washbag in my hand but that was all, I don't know, you know [male nurse] said I was walking, but I don't know, it doesn't sink in like that **So, you are walking now with the stick?** Without it [laughter] at times **Without it, so will you take it home with you?** Yes, I've been told to take it home, so PT5s done a lot of work with me and we were finishing in here one day and she said, do you want to come for a walk with me, and I thought why not, so we walked out the door, down to the carpark to the entrance, out of the entrance along to road, up to the next turn up that one and back in the top, amazing, didn't expect it	Goal to be able to walk, unknown though on arrival, straight away got feedback that could achieve this unknown Recovery being a surprise, didn't know what might happen Even though reports that was walking in the acute setting – interesting that couldn't/didn't translate this into being able to walk Needed to be shown what could do – that could walk Invisibility and uncertainty of recovery
And when you go home, do you have a programme of exercises that are lined up? Yes, yes, I have, I had a go with that with PT3 at the weekend, who passed them over from PT5 and I did them with her this morning, there um, sort of walking exercises, walking on my heels, um, walking on my toes, walking heel to toe like that, forwards and backwards, and um, standing, this is with a hand resting on one of the rails, but can be the work surface in the kitchen, standing on one leg and lifting the other one up, touching my knee; lots of combinations, that sort of things, all balance stuff **And do you have a specific exercises for your arms or are they all for your legs?** All for my legs **And when you go home, do you have thoughts about what you might do for your arm to...?** [long pause] Well I have a big workshop at home, back out into that, it's got a lot of machine tools in it, a big lathe, a big milling machine, I'm sure you know what they're like, um [pause], because the voluntary work that I do at the museum, we don't have all the parts so I make them, most of the work is single handed really, it's either putting stuff in the vice and clamping it up, so that can be done and pressing the 'go' button; on the lathe, it's the manipulation of the two cross wires, so it would be this and that would be doing that, so that's where the multitasking comes in; but that's going to be a week or so off	Has balance/gait exercises to be doing at home – has practised them with support of therapists so knows what to do No equivalent for the arm – no structured plan for this Aim – to use it again so that can get back to doing all the jobs that would have done before Thinks that will be able to do this whether one functioning arm or two – because this will only be for the short term/a week or so and will then be able to use it again No concern expressed about not having an UL prog as sees involving it in the tasks that did before
So when you were at [acute trust] and they said you are going to rehab, did you have a picture in your mind about what that might mean? No, not at all **Did you have any?** Preconceived ideas, no, none what's so ever, well to a degree yes because one of my neighbours had been in here a few months ago, he did say that you had to go and make yourselves tea and coffee and if you have visitors, you have to go and make them tea and coffee, so I thought OK	Expectations: No idea what was coming to at all, no notion of what rehab might mean, no expectations Knew there were places called rehab but didn't know which one was going to and what it would involve No preconceived ideas – except from a neighbour who had said that if one had visitors, had to make them tea and coffee

that’s alright, so they were the only preconceived ideas that I had **And did you know what it looked like or what you would do in the day?** No, not at all, the only time I had ever been down here was when one of my neighbours was in the next one down **X up the hill?** Yes, yes, and I didn’t even know this place existed; I told my sister about it who lives in P, and when she came up she said, oh, I googled that place and checked it out on the web and it’s OK **She gave it the seal of approval** Yes, yes she did, my big sister, if she says it’s OK, it’s OK	No idea what the place looked like or what would do during the day - didn’t really even know that the place existed let alone what when on inside Invisibility of rehabilitation – place and process Approval from family member
If you had to sum up what you thought [rehab unit] has meant to you and your recovery and your rehabilitation since your stroke Well I can’t praise it enough actually, in some ways you could sort of relate it to a health spa because it’s got a gym, the only thing it hasn’t got is a swimming pool, but you don’t expect that, um and you’ve got a physiotherapist here, so they are very helpful, they push you but they don’t, they’ll stop when they think you have had enough, for the sake of, I’m tired, you can sit down and have a rest, which is good because I like being pushed, and PT3 is very, very good at that, and apart from standing like this, you know, with his hands very closely but not actually touching you, you know you’re going to be safe, and he watches your body movements so he knows when you’re doing something wrong, or could do it better, and he watches your facial expressions so he knows when it’s going to hurt, ‘cause he says tell me when it’s going to hurt, and I say when it hurts, I shall scream **So, to sum up [rehabilitation unit] itself is?** Brilliant, I can’t think of any other way of describing it, or put it this way, it’s put me where I am now, which is great	Very complimentary of the place – and from there, the people in it who, he felt had done/were doing the right things; has got him to where he has got to; end outcome is the proof References to being like a health spa; not like a hospital – doesn’t look like a hospital; hasn’t got a feel of a hospital; much more welcoming – both initially and then continuing Personal, know name, encourage/ push one to improve demonstrating care about end outcome – want the individual to get better Couldn’t expect more on the NHS Reference also straight away to the gym and to the physio – physios will push and challenge which is good/ likes – not too much so knows when needs to rest, but enough and at the right times Physios watch and know – know what can push and not to push
Excellent, excellent; and you say different from [acute trust] where you came from? Oh yes, entirely different, I can’t say it’s like a holiday camp or anything, but it’s that type of difference; I was counting the days [pause] because I was a bit depressed in [acute trust], because I didn’t want to be in hospital and I didn’t like the food, because they thought I had swallowing problems, so they had me on, um, not mushed up, um **Pureed?** Yes, that’s the word I wanted, pureed, which was not very good, so **So when you were there, did you have thoughts about what you would like to be doing, what you were hoping for?** Yes, definitely, get back to normal, that’s what I’m going to do [said with force]	Very different from the acute setting; whole feel completely different Much more relaxed and enjoyable; more like being on holiday and doing something pleasant Invitational rather than dis-invitational Had been low in mood when at the acute setting and counting the days to get out Didn’t like the pureed food, lack of visibly of any therapy Determined to achieve final outcome

Appendix 16 Translation of patient conversation into grid reflecting what was visible/invisible and from this, what was invitational/dis-invitational

Second stage analysis, translating initial thoughts from the transcript of Jim's conversation and categorising these into aspects that seemed visible or invisible and invitational or dis-invitational

Visible to Jim	Invisible to Jim
Acute setting: • Knew that stroke had occurred – knew himself that this is what it was when first occurred but then confirmed when taken to the stroke ward • Visibility of things not being right/not being normal – puree diet because told swallow impaired • That other people had also had strokes – shared spaces so able to chat • Medical role of the acute setting Rehabilitation unit: • Physical role of rehab – different places with different aims • Welcome to rehab – warm physically and emotionally – immediate message that in a place where would be cared for – welcoming message continuing • Being checked to see that was all right – visibility of care/reassurance that it was a place that could feel safe and could trust • Company of others with the shared room – able to be seen by someone else in the room and therefore not forgotten about, ignored, walked past – visible entity • Despite sharing room, being in a room with a door where could sit quietly and think, provided space for quiet when chose to adopt it • The care from the staff – their kindness, their encouragement, going the extra mile, not just basic attention but extra attention, doing even the grimest of jobs without complaint • Nurses have visibility as carers – some have visibility as encouragers of recovery but only a few • Determination to get better seen by staff and valued by staff • Being known, valued and seen as the person that one has always been – known by the right name – seen as an individual whose wellbeing is important and valued; unit small enough to be able to know the staff in return • As part of being known as a person is being able to share one's own sense of humour and for this to be responded to – individual/person • Overall, a comfortable place to be – comfortable of body and comfortable of mind	• Physical recovery in the acute setting – any sign of rehabilitation or anything to influence this recovery • Had activity in LL and able to walk even from the acute stage – however, somehow invisibility of this • Even though reported that able to walk, that this was 'normal' walking and being normal was invisible – didn't really know that was able to walk/was walking even when told that was; needed input of therapists to guide and show that was walking; to help make it visible – needed to be told and shown – needed to build confidence and be reassured • What recovery/outcome might look like/be like – what it does look like/what it is – what it is even when it is occurring • Complete invisibility of where coming to what coming to, what it looked like, what would be involved – not bothered as long as was different from what he had left; invisibility of preconceived ideas • The structure of UL indep exercises – when, how, how often, in what way…not really practised in the hospital so no visibility of doing them at home – ongoing recovery therefore to occur through everyday use – thinks will take about a week [which in longer-term turns out not to be the case] • As part of this, what is invisible is knowledge of recovery and what might drive/facilitate this [although in this interview, not asked overtly, nothing in what was said at any stage gave any indication of understanding of processes/mechanisms of recovery]

• Progress made in the acute setting/immediate feedback about what could do – esp with walking – walking goal – that walking might be possible/is possible • The lack of mvt in the UL, the accompanying pain • LL related indep exercises – shown what to do, practised in therapy, confident to do at home • Rehab unit as a place – both the physical environs and what occurred within it • Not being a hospital and not looking /acting like a hospital – more like a spa • Physios knowing how much to push, able to work out where the limitations are and address them with no words or fuss – just know and then do • Ward generally has visibility for freedom to plan day and develop personal routine – as long as felt to be safe then able to do – ward itself has its own routines and ways of being that the ward would like one to stick with but within this, able to develop one's own routines • Mealtime visible for the opportunity to compare notes with peers about their physio and their recovery – able to benchmark some idea of progress • Seen recovery from previous ill health as something that happens with time and determination – sees now that this time things a bit different – still sees future though as being recovered and able to do activities as did before • Bedroom seen as a place to keep tidy but overall someone else's responsibility • Dining room has visibility as somewhere to chat and compare notes of physio and progress being made with fellow, like minded pts; sense making • Showering seen only as a place to get clean, not place for recovery – other than helping to establish some sort of routine • Dayroom seen as a place where able to be in charge of some of own activities and routine • Gardens seen as place of some normality like home – esp if like gardening; seen as a place of quiet and privacy • Dining room seen as possible place of failure if tries to use both hands – better to stick to one and succeed rather than fail • Gym seen as place overflowing with equipment - a very visible, expensive sign of recovery • No lack of visibility of the physios, OTs in contrast hardly mentioned • Visibility of own fragility and fear of falling; visibility of how easy it is to fall but doesn't want that happening again as may not be so lucky • Visibility of time spent making sure that safe before doing things alone – opportunity to practise – supported to go outside of comfort zone; good clear feedback [all related to LL] • Need to be shown what to do, to see what to do as wouldn't have done/ worked it out alone • Visibility of people saying positive and encouraging things – helpful	• Past experience or any knowledge of anything similar before, invisible • Invisible on ward is any notion of everyday ADLs influencing recovery physically – relates to W&D, showering, eating – seen as important for establishing routine and then for the end outcome of being clean and fed • Bedroom only in small part a place to exercise – following ex given in part by OTs but also by items bought in by family from home to promote UL use • No real visibility of bedroom, or really anywhere on the ward being part of physical recovery • On the ward, use of L UL invisible • In the gym, no visibility about what to practice and how – knows that can come to the gym away from scheduled sessions but doesn't as wouldn't know what to do and not confident to do ex alone without therapist being present • Invisibility of knowing what day of the week it was – lacking normal structure and routine so muddled over days

• Visibility of the skill involved by some staff/by physios • Timetable useful to some degree for orientation – useful to be able to plan one's day, be efficient, sort oneself out, have some control, develop a bit of a routine; ownership and control • Visibility of relaxed, friendly, jolly place, having banter, being happy – contrast to the acute • Key learning – pleased to have got there; lucky for opportunity; could not have progressed so well at home as wouldn't have had access to the equipment			
Invitational		**Dis-invitational**	
Intentional	**Unintentional**	**Unintentional**	**Intentional**
• Help from neighbours when stroke occurred/ ambulance called • Warm cup of tea, warm bed • Nice building/nice surroundings – more like a spa than hospital • Care and attention from staff – concerns about his welfare and progress • Set up of the gym; therapy session and walking practice	• Chatting with other pts and their family/visitors when in the acute setting – able to build some relationships from acute which carried over into rehab • Welcome/wave/greeting from fellow pt and his niece on arrival at rehab – familiarity • Being checked up on in the night on first night – reassurance that someone cared – was safe and could place trust in the place • Shared room providing company of another – could chat and could help each other out – nice to have company so that not lonely/ someone knows that you are there and not forgotten about – nice also to be able to help other person and in turn to be helped • Having one's name outside one's room – defines one's own space, own personal space (even though shared), ones home from home for the few weeks that there – point of refuge – has a door • The impact of rehab starting straight away – both because different from acute where didn't remember having any therapy and because able to start seeing progress	• Mvt between wards overnight when in acute – hadn't been told this would occur; terrified on waking not knowing where he was/what was happening; felt trapped because of blood pressure cuff, strapped down/tied down; desperate to move and be released; told that not able to; feeling of being restrained and trapped in the bed with bedrails up; frightening/ vulnerable and long standing impact – would have been different if had just been told that would be moving or even that at some stage would/ might be moving • Within the acute setting, being in bed all day with the bed rails up; not receiving any therapy until getting to rehab; not being assisted to be up and out of bed –perhaps could have done more but because it wasn't encouraged and being in bed was encouraged, went along with this – led though to being in a low mood and 'depressed'- didn't then have any clue of where going to and what rehab was but didn't mind as long as it was different from the acute setting • Transfers in cold ambulance having sat waiting in cold ambulance bay exposed to the elements	

Appendix 17 Combined grid reflecting some of the visible/invisible and invitational/dis-invitational aspects identified/discussed across the group of participants

Third stage of analysis combining what was visible/invisible and invitational/dis-invitational across the group – this list is not exhaustive but reflects many of the common aspects

Knowledge of stroke, recovery, and rehabilitation	
Visible	
Some broad information giving about condition - leaflets given about stroke but didn't really want them – don't want to look back – the stroke has happened, don't want to revisit – wished it hadn't but it has and therefore just need to move on – you are where you are so don't dwell on it – can't go back	Anne; Martin; Roger; Stewart
Links the stress of the job to the stroke occurrence – family history of stroke – stroke resulted from heart condition	Liz; Martin
With the stroke, body out of kilter – instructions not getting through – things just not working – used to be so active/hard not to be – need to gradually get the body to do normal things again – like a child learning to walk – will fail and fall down but will then get there – need to put the systems in place for practise like one would do with a child until skill mastery gained – need to put in place a system when can practise balance and walking so that muscles that have wasted or temporarily gone to sleep for a while can be brought back to life – it takes time, probably need to use it, but it takes time	Anne; Martin; Paul; Roger; Stewart
That stroke must have been large because of concerns of staff – when unable to move left side, knew that was serious and was panicky as a result – anxious and fearful about what return of function would get – growing awareness of nature of physical limitations and what couldn't do	Martin; Paul
The underlying premise of repetition – new routes, electrical, new pathways to muscles – doing more of the same exercises, only way that brain will find new pathways – brain has been somewhat damaged but will work around this to learn other ways of doing things – "if you don't use it, you'll lose it"	Anne; Jim; Martin; Paul; Stewart; Tim
Invisible Knowledge of what stroke/recovery/rehabilitation were – many don't knows – half trying to make sense of things that don't make sense – all quite uncertain, vague and patchy – esp in the earlier stages of rehab mainly just accepting and not really questioning or wanting to know – changed a bit for some later on when opportunities for asking were reduced or absent	
Knowledge of what stroke was – many don't knows/mixed/muddled understanding – e.g. brain controlling opposite side of body but doesn't know why – had a clot, might have had a bleed, doesn't really know/no one has explained – stroke came from hardened bits from clots from heart attacks – clots will always go to the left brain whether right or left handed – heard of cholesterol but didn't really know what it was – body fails; muscles tendon fail – something that happens to older people not someone young	All
What causes a stroke nobody seems to actually know – particularly in the night, so just one of those things – how can one have high blood pressure when you're asleep – it must have, could it cause, I don't know – guess it would be good to know – scary not knowing – what to do so doesn't happen again – can't think of much that can change in lifestyle	Adam; Anne; Gordon; Liz; Martin; Paul; Rachel
Can't really understand why had a stroke when led quite a healthy lifestyle between the level of exercise done and food eaten – associates stroke with stress as this was the key thing that knew was probably wrong – knows in theory that cholesterol was high and statin level low but feels that lifestyle should have negated these – searching for something in lifestyle that could be changeable, not sure what this could be but desperate because couldn't cope with another stroke and being back in acute setting	Gordon; Jim; Liz, Martin
Thinks that was told that had had a stroke and how severe – not sure if this was in response to question asked or volunteered – didn't know that had had a stroke until worked out that on stroke ward – what information received based on luck of finding the consultant and then that they had the time – discussions generally ad hoc although they did take place – information giving only by the medics, not by the nurses, only given therefore when staff available	Anne; Jim; Martin; Paul; Steve
Thinks that may have been given some leaflets about stroke but not really certain – so much paper given to one, not really sure what is in it all – lots lost – not really concerned as not really interested in reading them – access to information on the ward if wanted it – assumption though that if told something once that one would retain it – instead needed to reiterate	Martin; Paul; Rachel; Stewart; Tony

Knowledge about outcomes and that might not be as before – didn't realise how frightening stroke would be in respect to not knowing what recovery might be – didn't know how much worry there would be about the degree of recovery that might occur	Martin; Roger; Stewart; Tim; Tony
Little visibility of what recovery is, what it looks like, what it might be, what drives it, how much occurs/how little occurs, why, when - both on a general level and person specific – don't know why things come back/recover as they do – no experience of being in a similar situation to draw upon – although hopes that will get better, doesn't know when this will happen or how soon and doesn't know to what extent it will be – knows that it won't be to a high level so won't be returning to previous activities soon – waiting for the lightbulb moment/the lightning bolt when the brain will work out what it needs to do to get UL recovery – trying to will the mind to work out recovery – gets sad when it doesn't – the knowledge that unlike in other aspects of life, perseverance might not be enough – unknown about why recovery has occurred as it has done, had hopes about rehab but no real idea except had been told it was a good place to be – why the body suddenly came back to functioning with relatively little effort on his part, unknown	All
Not knowing specifically how long UL recovery would take, that recovery could take so long, that recovery might not be complete, that despite work, effort and perseverance full function might not rtn – the knowledge of how hard life is if one handed/without two functioning ULs – how even little things that shouldn't be hard, are hard and can't be done – the importance/ necessity of working hard in rehab – message not communicated strongly enough – no discussion of timeline of recovery; no idea about the expectation of recovery in the arm – how much or how long; no talk about what improvement might be available – imagine that it will improve slowly over time and that this will drop off, but don't really know	Adam; Gordon; Jim; Martin; Paul; Tim
Never thought that would be in the position to be having to learn basic life skills again such as walking and that one might be dependent on others for things like personal care – learning to be dependent	Anne; Jim; Martin; Paul; Roger; Stewart; Tim
Invitational	
Knowledge gained about stroke – not looking back to learn about what occurred, if anything happy to look forward – likes learning by hearing about experiences of others, e.g. Andrew Marr as can relate and associate with this – stories of others who haven't given up but have kept going – that others couldn't do certain activities such as walking but achieved it, so hope that one might achieve it too – makes it seem more possible that it might occur – information on internet less helpful, too dense/theoretical/ abstract	Gordon; Martin; Roger; Tim
Dis-invitational	
Not knowing what happened when had his stroke; desperately wanting a dummy's guide; wanting to see scans of brain as feels that this will help him understand – knows that scans were done and asked to see them but never allowed	Adam

Acute Setting	
Visible - based on what was seen, what was understood, conceptions, what made sense or how sense was made of the situation	
Care being kind – staff busy but as able, gave kind care	Anne; Liz; Richard; Steve; Tim
The life-saving qualities of the acute setting – people and place – acute wards focus on dealing with acute situations, rehab words different in nature because dealing with remedial things – acute ward saved life but then rehab wards doing the getting better	Martin; Paul; Roger; Stewart; Tim
Being in acute setting felt like waiting for no apparent reason – not clear why there; wanting to get going with recovery but nothing happening – not able to drive own activity – the frustration of the acute setting and the lack of input – lying waiting to get better – ad hoc input giving signs of what would be possible if more input given – when occurred were good but were intermittent and not consistent – even if couldn't have done much in the acute setting, would have liked to have been able to keep muscles stronger so that could have arrived at rehab in better shape, even if exercises could have been done in bed – current state and level to muscle wasting resultant from limited input in – therapeutic value of sitting out in a chair compared to being in bed	Jim; Martin; Paul; Roger; Steve; Stewart

Progress (largely physical) made in acute setting – aware of what achieved/ what hadn't achieved – sense of what drove early progress was determination and persistence as tried to push boundaries – not prepared to just sit and wait – wanting to be doing more/wanting to get back to normal/to experience normal aspects of life again – as much as could, drove own activity – begged for more	Jim; Martin; Paul; Steve; Tim
Being imprisoned/being trapped - fettered to unfettered when got to rehab – desperately wanted access to wheelchair so could get around – bedrails – blood pressure cuff – no chair – doors to ward locked	Jim; Martin; Paul; Roger; Steve
No confidence in what was happening in the acute – wanting to know what was going on because could not see any structure or organisation to what was happening – so chaotic and busy, seemed purposeless (once had stabilised individual medically) – so frustrating to be in a purposeless place – frustration of seeing things being done incorrectly/inefficiently and not having the capacity to intervene and change/address things as would have done before	Martin; Paul; Stewart
Hard place for staff to nurse as pts at their most dependent and most demanding – don't get to see the nice bit when they get better	Stewart's wife Richard's wife
Staff up against the odds with little equipment and resources	Richard's wife
Invisible – based on what was not seen, what was not understood, conceptions/misconceptions, what did not make sense	
Invisibility of active rehab in the acute setting – seemed to just be sitting/lying and waiting – didn't seem any point to being in hospital – what did have was fine but just not enough of it and not done so in any sort of systematic way – no notion of when physios would come – disturbing because realised that if was going to make any progress with recovery then input needed to be given in a systematic and structured way – stress and anxiety related to whether would be seen each day by physios or seen at all – impact emotionally of this unknown – desperately wanting to be seen so could get back strength/back to normal but unknown if they would come	All
No encouragement to use more affected side as part of everyday activities on the ward	All
Little tangible sign of improvement – in fact the reverse as felt that getting weaker	Martin; Paul; Roger; Stewart
Lack of support for emotional well-being – even when asked and begged for this nothing given – mood did pick up by end of stay but only because started to get rtn of activity	Martin; Paul
Mixed visibility of acute stroke management more generally – part of picture but not whole picture, e.g. thrombectomy (not named), inserted something, sucked out, best chance of success, swallowed it up, internally, no marks – had detailed scan but no idea of results	Anne; Liz; Martin; Roger
Limited understanding of other comorbidities – e.g. loose bowels resultant from bowel that might have got a bit twisted when had fall from stroke	Martin; Roger
Invitational – based on what was visible/invisible, what was then conceived as invitational	
To be able to leave the acute setting and get some fresh air – having one shower, wonderful – feel more normal again, being released, able to decision make, have some control	Anne; Liz; Jim; Steve
Care in acute setting kind – if asked, they would do what they could – up against the odds because of the busyness	Anne; Richard; Roger; Stewart's wife; Tim
Dis-invitational – based on what was visible/invisible, what was then conceived as dis-invitational	
The noise and busyness of the acute ward – other people being so unwell – being incontinent – falling out of bed – shouting out – intrusive into personal specie/butting into conversations with family – difficult being with other people when used to being on one's own	Anne; Liz; Paul; Rachel; Roger
Moving between wards and leaving staff who had got to know; frightened of unknown	Jim; Liz; Tim
Being disorientated and not knowing where one was – asking staff for help to orientate but not helped – not helpful to be asked what wanted when in a state of delusion and confusion – to not be comforted when confused and distressed – just wanting to hear a reassuring human voice, not necessarily more than this – remembering people who had died, weird times	Jim; Paul; Stewart
Being told to go back to sleep actually meaning stop ringing the bell and stop being a nuisance; frightened	Stewart
Pts need reassurance that someone is in control/in charge – their lives and futures depend on this, so need the reassurance – need to know that things will happen as planned – best chance of successful outcome	Martin; Paul; Steve; Stewart Richard's wife Tim's wife

Staff having information that may be helpful for the pt but not sharing it – doesn't help to have information withheld, esp if confused – people have had a massive shock and change to their lives with lots to come to terms with and lots of doubts – not helpful to leave them with more doubts that could be relatively easily addressed	Martin; Stewart Richard's wife Tim's wife
Being trapped – locked in/ imprisoned – attached to machine monitors so having to be dis-attached – ward door locked, so needing to ask permission to leave – no freedom of mvt – beholden to others – not in control – not being able to feel fresh air, to do normal things, to make own choices	Martin; Roger; Steve; Stewart
Spending most of time in bed, no chair to sit out into, when siting out uncomfortable – no access to any independence – little encouragement to use affected side, encouraged to feed oneself but that it – ward too busy/staff too busy – frustration with some of the explanations about why things were as they were regarding the system and amount of therapy input – not knowing why it was that input was so low – ward was just a ward with little invitational about it in respect to recovery – needing to drive own rehab forwards – default option to lie/sit which meant that not getting better and closer to DC	Anne; Jim; Martin; Paul; Roger; Steve; Stewart
Nurses seemed to have almost an entirely passive role – not really involved with pts at all – not even sure that they knew name – not seen and known as individuals	Jim; Martin; Paul; Roger; Steve; Stewart
Not being able to progress rehab at pace that wanted to; asking and asking for therapy input, asked anyone and everyone, but still not given - even begging consultant – being told that they didn't have the staff – extremely low point – not doing anything to aid recovery which felt so instinctively wrong	Jim; Martin; Paul; Roger; Steve; Stewart
When seen by physio in the acute setting, given one or two small bed exercise and then told that they have to go – receiving bits and pieces of physio but perception that not enough – knew that lying in bed all day wasn't the right thing – not just of no value but making the situation worse – frustration with the system as wanted to get going, wanted therapy, really wanted to get on with recovery, but not enabled to – asking but not received	Martin; Paul; Roger; Steve; Stewart
No physio at the weekend which made them even worse than the weekdays where at least a chance of seeing someone and getting something	Martin; Steve Stewart
New people being brought in and needing to be prioritised	Martin; Paul; Steve
Frustration and real anger at the system and people involved with the scanning unit – all hope and life taken away when told that couldn't get the scan that was all that was needed to get out of acute setting and into rehab – to be told that this was because couldn't take the seven steps needed when knew that with just a little bit of help from the system that this would be possible– led to active learning resistance in a real drive to prove the people operating the system wrong and showing he could walk	Martin
Not knowing when the transfer date would be for rehab – carrot dangled but not tangible enough – going but not going – emotionally hard, esp as desperate to go – if bed hadn't become available in rehab would have self-discharged from acute – couldn't stay there any longer not doing anything in such a manmade constrained environment	Martin; Paul; Roger; Steve; Stewart; Tim
Not knowing where being transferred to for rehab	Jim; Martin; Paul; Richard

Rehabilitation unit	
Visible	
Sheer difference in care and everything (facilities, provision of input) between the two sites – acute and rehab – arriving in rehab was being released and being given the opportunity to get better – arriving in rehab saved mental health – knew that as soon as got to rehab and saw it, that would get better – would learn to walk (which associates with being better) – relief when therapy started so could feel that heading in the right direction – actually doing stuff to enable one to get better – and is getting better – better than last week or the week before – positive action – game changing to be able to receive the rehab that did – a place with a purpose – reassurance gained from this that the place had the right goals – time before in the past – need to look ahead – good mind-set, feeling that doing all right emotionally despite all the changes and everything that has happened – loving it there in rehab, really loving it – progressing in leaps and bounds – mentally and physically with the latter driving the former	All
Being given the time and space to try things out – freedom to make own choices – not hemmed in – the importance of gaining aspects of independence – electric chair, bed transfers, personal care,	Anne; Jim; Martin; Paul;

walking – doing anything and using everything that could to be independent – gaining mobility – gaining some control back over life and not being entirely reliant and dependent on others – less frustration – needing to escape from confines of dependency and lack of signs of recovery – needing to be in a different environment where recovery might have a chance of occurring and not to stay in the place where no sign of this – need for normal; to feel normal, do normal things – things that knows, things that likes – to be more adult again – need for independence – need to expand boundaries	Roger; Steve; Stewart; Tim
To come in not being able to walk and to leave walking, the sign of progress made – the importance of moving out of the wheelchair – freedom and normality of being able to walk – able then to make more of own choices during day – perfect to be able to walk again even if with quad stick – similar feeling from moving from push wch to electric but better	Martin; Paul; Roger; Stewart; Tim
Wouldn't have been able to cope emotionally if hadn't been able to walk – to say the words, I can't walk – other people don't understand – walking is so normal so had to get walking again – fearful that would not be able to walk again – wanting to walk down the street so could take dog out – wanting to walk indoors enough to be able to open own front door and invite people in – the emotion and joy then when walked in the walking harness – so thrilled and so important as had thought might not ever be able to walk again – shared the video taken at the time with all the wider family – emotion so powerful, perhaps more so than other things experience in life as partner had never seen pt cry like that before – until did take first few steps wasn't confident that would be able to, but when did, knew that could progress from there – being able to walk is the visible path to leaving – walking symbolising recovery	Martin; Paul; Roger; Stewart; Tim
Equipment as visible signs, e.g. walking hoist – even though in a walking harness, massive leap forward – feeling of relief and release when walked – if one can stand up then can start putting one foot in front of the other – first walking with the support of the bars and then without bars	Anne; Martin; Paul; Roger
With physio, built more confidence in what could do – became more relaxed so walking got better – with each therapy session, gained confidence to do more; didn't trust left side initially but learning slowly to trust it again – physios, the ones who move the recovery forward – enjoyable as everything happening quickly	All
Frustration and embarrassment of being one handed and not being able to do basic tasks – importance of having a functional arm to give function in life and from this have purpose – without two functioning arms, no purpose in life as not able to work and work defines one – reason for being – being good enough isn't good enough – how much one's job and roles in life define one and give purpose and how these go if no longer able to work/do the activities that defines one – learnt that can't be previous self	Jim; Martin Paul; Tim
The impact of loss of strength to be able to do everyday ADLs – getting not just balance back but strength back – perception of arm looking wasted – amazed by how quickly it has wasted and horrified by the look of it – needing to get stronger – muscle wasting leading to weakness impairing function – wanting to build muscles up, wanting them to be stronger – need to build stamina and strength – by building up strength, able to walk better – able to do more in rehab than acute setting because able to build up strength – easier to get up and get going when one has more strength – arm getting a bit better as able to lift more weights = sign of improvement	Jim; Liz; Martin; Paul; Rachel; Roger; Stewart; Tim
Exercises if going to do them need to feel and look like exercise – feel that working up to and beyond limits – building strength because this is the limiting factor – being strong equates to being better – being the person that was before – wants to be this person	Jim; Martin; Paul; Stewart; Tim; Tony
Knowing an arm is there because can feel the pain – can't really feel the arm but can feel the ongoing ache/pain – have to then actively think where the arm is so that can move it safely and it doesn't get left behind – has shoulder pain but doesn't know why this is occurring – when the pain bad, need to stretch in the hope of reducing the pain – the desire for someone to help with this, to have the expert handling to gain some relief – not able to gain this same sensation alone	Jim; Martin; Paul; Tim
Having staff who can look at the problem and know what to do – not knowledge that patients have – have ideas because of their expertise and professionalism – appreciate this because this is what one doesn't have oneself – always new ideas within therapy sessions to get you a bit further – the importance of specialist care where people know what they are doing and can direct things rather than general wards where the correct guidance isn't provided potentially putting one at risk – the belief in the staff that they will get you better	Anne; Liz; Jim; Martin; Paul; Richard; Roger; Steve; Stewart; Tim
The opportunity to drive forward one's own progress – get the maximum from what was offered – the need to do/be active when in rehab – if people don't do and don't put in the effort, they won't get better – if want something then need to work at it – the need for continuing to practice – small steps forward practically and metaphorically – only way to get better/stronger – key in rehab is the sheer hard work – not a passive pt in a bed but an active pt working hard – would be easy not to do	Anne; Jim; Martin; Paul; Roger; Steve

much in rehab, to stay late in bed, unit would enable this and much of what body wants to do; instead has to find the inner drive to get up and get going – letting oneself down if not doing enough – blame/ punishment - the importance of determination and how if one has this then able to do – have to put the effort in if want to improve – using gym and equipment more than just timetabled sessions to build up strength – building up the stages of recovery one by one – master one bit to automatically and then move on to the next, when movement automatic then know that have recovered enough	
Trying to use LLs to do things but easier just to wait until the physio sessions – knows that this is a cop out but easy to put doing ex to one side – does try the few bed ex but quickly stops as feels that not doing anything – better to wait for the experts – not wise to take risks that might jeopardise time in rehab – does enough in the day so doesn't feel that wants/needs to do any more – easy just to sit and be lazy and watch TV – things that could join in with but no desire to – lots of spare time just to sit	Anne; Martin; Rachel; Roger; Tony
Limiting use of UL because might be messy, embarrassing, awkward – knows that should but easier and better not to – frightened to use it for fear of it going wrong	Anne; Rachel; Tony
Fear not just that might not get better but greater (or equal) fear that might get worse – fear of being back in the acute setting again – knows that couldn't cope if had another stroke – couldn't go through it all again, esp being dependent – would rather end life – searching for reason for the stroke that would be changeable – self-blame – rationalising why presenting as is, citing own actions that might have meant that arrived in the position that was in – desperately wanting to do something different from before so that event might not happen again – desperation to do anything that could to prevent another stroke from happening – worried about BP, hydration and bladder function – couldn't cope if these went off and had to return to acute site again – really not wanting to go back	Liz Martin; Paul; Tim; Tony
Also learnt that mustn't get too tired as this will mean that not able to get as much out of therapy sessions – recovery taking time – build up slowly – the exhaustion of doing such simple everyday tasks as dressing which aren't helped by getting so frustrated/needing to find ways to calm down and not get irritable – the importance of rest – proper rest, not just being in the day room with others, but properly resting quietly – turning mind off as well as body off as otherwise all day using up energy	Anne; Martin; Richard; Roger; Tim
Cognitive approach to rehabilitation – 'I feel like I'm going back to school' – to be relearning everything again – forgets things like a child – needs to concentrate hard so that doesn't forget – fear of not being able to understand, and therefore do, what being asked to do – sheer concentration needed within rehab is exhausting – trying to tell limbs to work that don't want to is mentally, even more than physically exhausting – slowly finding though that able to take the information on board – feels that if concentrates enough recovery should be possible – if recovery not occurring then own fault as not concentrating enough – coordination between mind and body – reduced speed of connection between mind and body/slow rxns – if does ex in the right way will target key muscles that didn't even know had but has to really think about this – the lack of automaticity of mvt and how recovery is about regaining this	Martin; Roger; Tim
Has learnt that has to be patient, has to be calm, has to not want things too much (although of course does) – has been able to do this because each day feels that is achieving – learn that can't do things the same way as old and has to learn things anew – life not as it was before	Anne; Martin; Richard; Roger
Learning from others in rehab and passing knowledge on to others; see others who are walking or trying to walk – modelling what end outcome might be – some people achieving desired goals so might achieve them too – seeing someone walking in the bars and then walking without the bars – sign of progress that seems sensible and logical	Martin; Paul; Roger; Tim
Others who are worse off than one – awful that there are people in such terrible states	Liz; Roger; Tony
Learning in rehab not like any other kind of learning that done before – trying to put in the effort – energy that would have put into work, now put into recovery – recovery about doing something for self rather than as would more commonly have done, for others – investing in self now – has had to do new learning before as an adult so used to it – on that occasion, although very different as cognitive learning, was massive and hard undertaking, was frightened on that occasion, same as felt on embarking on rehab, but overcame this, so drawing on that again – frightened that wouldn't be able to learn, that wouldn't succeed – frightened still now that unless on really good form may not be able to give the 100% that needs to give – self-blame if not 100% such as from trying too hard, from making himself too tired	Martin; Roger; Tim
Has learnt that at a different stage of life – older – more difficult to get new info into an already crowded brain – less flexibility of mind	Anne; Richard; Roger

Has learnt how frightening the future is but how this is lessened when achieved things, as gets feedback that recovering – has learned a lot about oneself as a person and what might/might not be able to do – patience and fortitude – determination, practice makes perfect – to keep on until you get it right	Anne; Martin; Roger; Tim
Seeing the depression in other pts – as a fellow pt, able to see this, but not sure that it is visible to staff	Tony
Staff doing a greater amount of care than probably really needed – down to laziness – happy to take up help if offered rather than do the work, even though knows benefits of trying to do more	Paul; Roger; Stewart
The environment of rehab – the room, the door, the TV all amazing – rehab ward able to do what it does because smaller and fewer interventions – able to design a programme and stick to it with fewer interruptions – being in rehab is being in rehab, it isn't being in hospital – having a space that is mine – want to go home but will be sorry to leave it	Anne; Liz; Martin; Paul; Rachel; Roger
Role of nurses to get pts ready for therapy – in as much that this was their role, they did it well – felt that most were aware that were working in a rehab centre and therefore if people could do things for themselves should be able/encouraged to – nurses on the margins of the enabling team – need to be aware of rehab goals and progress being made – some staff less good at communicating with the pts, esp if confused – perhaps some overlap role between nurses and OTs in respect to toileting – staff have complex roles needing to get pts independent	Anne; Martin; Paul; Stewart; Tim
Not to eat a big lunch if an early afternoon therapy session as too full and not able to perform to best – learnt to limit meals as too much	Martin, Paul; Rachel
Importance of showering about being clean – not nice to turn up to physio sessions not clean	Martin
Thank goodness for the NHS and to have such good facilities locally – fortunate for the latter – the importance of never losing the rehabilitation unit – too important – don't let it close – people need to have the opportunity – the luck of living in part of the UK where such a good rehab place exists	Martin; Steve; Stewart; Tim
Thank goodness for friends and family – hard to do alone – importance of support of family – nice for them to see the progress being made – sharing the successes with others – the unquestioning and unstinting support of family – even when so dependent – just got on with it even though so embarrassed to be needing that help – pushing, encouraging, supporting physically and emotionally	Liz; Martin; Paul; Richard; Steve; Stewart; Tim
Invisible	
What rehab looked like – place and process – no idea that such a place existed; no idea what coming to – one doesn't know about rehab until one needs it – no need to know until one needs it – no previous experience to draw upon – no idea that there was such a process at all that took people with disability and didn't necessarily remove it but modified it through a programme of work – had hoped for such a thing but no evidence in acute that there could be such a thing – just desperation to leave acute setting – thought that would probably be given some exercises to build the muscles up – that was only expectation – never realised that would be in rehab for six weeks – that it could be this long	In different ways, all
Even from leaflet about the place and search or internet, little information/feel for the place – only knowledge was being told that it was a good place to be - knew that if it was like the acute setting then would struggle	Roger; Steve; Stewart
No real information about how the ward works – learnt it over time by being there – staff have information about the order of play and how the day works but don't share this with the pts, for example, what time will be woken up and got up etc – some nurses give it but not consistently done – anxious not knowing – clearer for therapy as have the timetable – got dressed but then someone came in (OT) and had to get dressed again; couldn't understand	Anne; Martin; Richard's wife; Tim's wife; Stewart
Time/activities on ward not linked to recovery – except at mealtimes when able to speak with others to compare progress – sharing stories – may be things like going to the loo and brushing teeth help with recovery, but not uncertain – learning routine – not linking ward activity to recovery	Anne; Martin; Paul; Stewart; Tim; Tony
Things doing in rehab and the learning involved not like any other learning done before – exercises done in rehab not like any other exercises that had done before – despite having done lots of sport in youth – haven't really ever been unwell before so hitting hard when the body can't or won't do what one wants – doesn't know if can force things to get better, doesn't think so but doesn't know	Anne; Rachel; Richard; Roger; Stewart; Tony
Does some of own UL exercises but reluctant as not able to see any real benefits – progress too slow to keep doing exercises – different from walking where could see progress	Anne; Jim; Paul; Rachel; Roger
The unknown of what happens if one stops the exercises – if it will seize up – does one need to continue forever	Martin; Paul
Unknown if meant to push through tiredness or give into it – feel the fatigue is different	Anne; Martin; Richard

Both the theory and practice of goal setting – own goals in mind but when set goals with team no shared as not confident – set goal of climbing stairs but with a complete unknown if this would ever be possible and guessed that if it ever was then would be years away – goals that did set not referred to/reviewed – own goal of wanting to be indep more motivational that team goals – common sense that would want to be indep, toilet etc; common sense that would want to be better – no idea what goals to set	Jim; Paul; Roger; Tim; Tony
Unknown about driving – how long not able to and what the process would be of returning to drive again – wanting to get back to driving because of the independence	Gordon; Martin; Paul; Tim
As a relative, although invited to sit in on sessions, not always appropriate/ wanting to give pt space – if not there then left not knowing what occurred – sources of communication about treatment limited – therapy/care invisible unless directly witnessed – by not knowing what is happening within rehab sessions, not able to carry over any practice – not able to do any homework – information generally for relatives about the situation, rehab itself, their role – a bystander who can witness rather than someone really actively involved – need to always ask what should be doing to help – take own notes/pictures so remember what to do – as a carer, only get knowledge if really proactive and persistent seeking it out – does not come unless really asking for it – anxious that without the right information, might do the wrong thing in indep practice/ lifestyle choices	Steve's wife; Tim's wife
Support for points of transition and what the next stages might look like – future stages unknown – both practical but also emotional – help to plan/help to cope – thinks that things have changed but won't really know until gets home	All wives
No idea what the therapy provision will be once at home – hear of others who have visits 2-3 times per week but have no idea - don't think that the rehab unit would just show one the door at the end and let one get on with it, but just don't know – think that they would want to take you in, mend you from the outside, see you could cope and withdraw gradually but just don't know – based on a feeling that has but aware that might be wrong – from the ethos of everyone wanting to help one, can't think that this will stop when get home but don't really know – no sign of a specific ex programme to do when at home – plans to just increase mobility for walking as much as possible but nothing else specific	Anne; Paul; Richard; Roger; Tony
Who to ask if have questions once get home – feel that should see someone but not sure who	Liz
Invitational	
Being invited in/welcomed to look round the rehab unit prior to transfer – reassurance gained for relatives and through them, the pt – reassured that would meet needs – right place to be going to – more than the leaflet could achieve	Steve's wife
Being welcomed on arrival; being made a cup of tea (personal, thoughtful, normal); being given own room – all signs of being valued	Jim; Martin; Paul
The importance of early orientation and laying down the basics – didn't happen in acute – helpful to know who was in charge, what their role was and what the overall ethos was	Stewart
The size of the place of rehab being quite small confers some sense of control which wasn't there in the big, busyness of the acute setting – the stroke takes away so much control – important to gain in any way possible	Jim; Paul; Roger; Steve; Stewart
Being in an environment where can see outside and go outside – much better than being in a ward in a tower block – nice to be able to have the window open even at night – getting the morning light – feels more like home – people take the trouble to make it look nice - lovely place – nice just to sit back and relax really – finding that sitting on my bottom rather a lot during the day but it is nice – so quiet which is lovely	Anne; Paul; Rachel; Roger; Steve; Tim
The importance generally of the very smallest things such as being made a cup of tea – being seen as an adult – a person not a pt – the person that was before – monthly fish and chip night – that someone would have thought of this and given money to make it work – given something back – amazed by the kindness shown by people	Martin; Paul; Richard's wife Roger; Tim's wife
Qualities of the staff delivering the care/therapy: supportive; attentive; humour; professional; trust in the care of the more senior/experienced ones; seeing the pt and their relatives as an equal – inviting them into their space – giving time to a pt or relative – taking their time over them – staff who go the extra mile and think about the pt and all their family – can't do enough for one –always there to help – just take it as part of their job – the ethos of the place of everyone there to help you; will do whatever they can	All
Qualities of staff: see people as individuals, need to make a connection, need to know who to push in what way and to be able to read people and pick up on mood and how feeling, build a rapport/ understand what motivates – importance of knowing when someone wants/needs help and not –	All

encourages/pushes in a nice way not assuming and jumping in – giving someone the space and time and not rushing them – good staff are those who face and address the problems that a pt has and don't shy away from them – staff who move towards and help/assist and not step away and turn their back on the problem	
Respecting that everyone has different ways of getting through the day – e.g. when to W&D, making food prep (for self and others) – as part of recovery, being given the space and opportunity to problem solve as this is how would tackle new things before can find out more about them as a person – flexibility of the set up so pts can make choices – service adjusting for the individual rather than the other way round – explanations helpful – to know why	Anne; Jim; Martin; Paul; Tim
Information being given by someone that one trusts and respects; being helped to gain knowledge so that not trying to understand everything alone – acts as a good supplement to own researching/learning that doing – have a relationship with; someone who has given their time to you; someone who has shown that they care – a bond with an individual, same bond not needed with others but need a bond with someone – able to ask more and get more support if feel that have a bond – reassurance of being with staff who seem to know what they are doing – able to trust – people know about you as they should do	Steve's wife; Rachel; Tim
Clear explanations about healthcare advice in a way that can carry it out – safe, effective but doable – queries answered about rehab and recovery when have them – people on tap in rehab to do this as needed – therapists good at giving information about recovery – partly in response to questions asked and partly just info given – know quite a lot from reading done before so able to build on this	Paul; Steve's wife; Stewart; Roger
Being provided with a summary document of treatment session so as a relative knew what had gone on – made the sessions visible even though not there	Steve's wife
Timetable – visible, invitational signal that rehab (and through this, recovery) starting; that input will be each day so no need to second guess and not know; others committed to helping get better – someone else in charge and in control in a clear and the right way – taking recovery of individual seriously – don't have to work out what to do as a pt – can pass across the responsibility – whereas the TT in acute (if they had had one) would have had 3-4 days empty, in rehab just one day empty – often two or more things in a day – not having a timetable meant no visibility of anything that was going to help one get better whereas in contrast having a timetable gives reassurance that others have got the situation in hand – a sign of hope that something will happen to improve things – that the outcome might be different from the current situation – the importance of having this timetable straight away as a real sign of intent – importance then of the TT being adhered to – gained confidence that it means something in practice Using the timetable to plan one's day so that can get most out of it and make it work – routine/schedule/timetable – sense of agency – the disempowerment of the stroke in so many aspects of life and the TT giving some of this control back The TT making sense for learning – for recovery, it seemed instinctively that if things needed to be repeated, then needed structure to do this – more than just a few people being nice and doing bits as had been in acute – needed to be more organised and systematic than that – the promise that a TT offers – the reassurance that everyone is working to a plan and everyone knows what this plan is – not ad hoc but with a purpose – physio even at weekend although less intense – if recovery is going to occur then it will only be if it is done in a purposeful way Lesser importance of the TT towards the end when recovery really pretty much complete – the commitment to being seen and having therapy sessions not so important	Anne; Jim; Martin; Paul; Roger; Stewart; Tim
From the start of stay throwing oneself into therapy and getting early positive feedback back – meant that one wanted to carry on – wanting also to do as well as possible both with recovery for own benefit and to pay back all the hard work of the physios/ staff – both for self and for others - pep talk from HCA about how it is up to each person to decide how much wants to get out of rehab and that this will depend on how much effort they want to put in – want help what is going to occur and to understand what needs to do – help to get to the next stage of the ladder – knowing what doing wrong so can do it better - notice every little thing, physical and emotional – able to pick up on these – difficult to know day by day if improving – good to have someone from outside/someone objective/ expert saying this – amazed by amount of tuition received	Anne; Gordon; Martin; Paul; Stewart
Physio hugely invitational – made sense – lots of positive feedback, tangible improvements – structured/logical – hard work but worth it – wouldn't be walking if it wasn't for the physio – absolutely wonderful – not sure if remarkable or normal but wouldn't be where he was without them – would go through any hoop for the physios – anything to try to make the body work – high expectations and no second best – people who really value the quality of the output – someone who really engages with one at a personal level – pushes/encourages in a nice way for this – experience things that wouldn't try/dare to do alone – always something different – never the same and each	All

day a bit more - mixed feelings about being pushed – likes it because that the reason for being in rehab but in essence quite happy to sit – quite happy to give up and rest if given the chance – happy to work hard if supported – needing feedback and encouragement from others to keep going – to have an eye kept on one – to make sure that there was nothing that was being – being able to do something purposeful that couldn't do before	
Being in an environment where there is a rehab gym and where therapy given – feel like the key things that are needed – a place that promised organised remedial work – The fact that rehab started straight away on arrival – being given the timetable – at the start of rehab, the immediacy of rehab being provided – leading to the feeling that outcome may be fine, that there might be a chance – always progressing/moving forward	All
Using the gym – feel better every time that go there – not wanting to give that feeling up – wanting to come back and get that feeling again – needing to come back – important physically and important mentally – being able to access the gym outside of scheduled times – use the space and the equipment – time off ward – banter with other people – shared experience rather than recovery being alone – being challenged/pushed by others rather than having to drive this indep – being guided to use the equipment safely	All
Early and quickly progress with walking; tangible sign of change, that walking might be possible again and therefore other things from there – capturing the moment of the first proper walk so that could share it with everyone via social media – had thought it was unimaginable – psychologically important for the pt and the family – helping people achieve the next stage of their lives	Jim; Martin; Paul; Roger; Stewart; Tim: Tony
The skills of an expert individual, esp to take the pain away – not something that he can do for himself – lovely when someone does this for you – being taken into the hands of experts – doing exercise that understands why, finds beneficial and enjoys – being given opportunities just to see if one can do	Martin; Paul; Stewart
Providing you do as they ask you, should be fine, don't try to be difficult or awkward because that's against their rules and regulations so you are here just to do as you are told really, find that lovely – it's like being in school isn't it, the teacher says do it, so you do it, you don't try to do the other thing or try to be difficult	Anne; Rachel: Roger
All the staff play their part – not just named people – everyone keen that each pts gets better so will contribute to this – the staff are there to get the pts better – will do whatever they can do – most important aspect of rehab – the staff/ people; then the training which is delivered to a high standard by highly trained individuals – different staff have got different ways of teaching – different ways of helping convey information so that able to learn – different characters	Anne; Martin; Rachel; Roger; Tim
Learnt the importance of keeping the humour – to laugh a little – liking to joke and keep some humour which is so important – life too short to be serious – lightens things for both sides – having other people around to jolly one along	Anne; Jim; Martin; Roger; Tony
Value of others to chat to in the dayroom to pass the time but not many others in to do this with – camaraderie between pts – people to get close to – people who are fun – laugh together – help each other out, encourage each other along – pleased when people go home but also sad – nice just to sit and watch what's going on around	Martin; Rachel
Being able to talk to staff about how one feels; share a bit with pts but not able to do that too much – the importance of staff just being able to sit and listen – to sit on the side of the bed and listen – care so personalised and individualised to meet his needs – listened to and responded to	Anne; Roger: Tim
Therapy dog – to touch and stroke – to have the contact - normal for what does at home with own dog	Roger
Good to be able to do small things on ward for others less able – some small sense of purpose and value as a person – trying to be useful as that is what he would have done before – the positive power of being able to help people, real incentive to do what one does – to be able to affect change/have an impact/make a difference – learning the power of being able to give to someone in a way that that person could never achieve if left to themselves	Jim; Martin; Paul; Tim
Had thought that being in rehab for six weeks would feel like far too long but actually fine because everyone so friendly and everyone working with the aim of getting the person better – need to be careful because could see how one could become institutionalised – relaxed rules and regulations so easy to be there – gives a chance to sit and think about what would like future to be – being in rehab for six wks has given hope and optimism – esp when compared to before – lighter of heart – the importance of the first few steps as a visible sign of change – gives hope and the feeling that can get better – love and amazed by the fact that there is a place where one is given a chance to get oneself better	Rachel; Roger

Shared rehab between hospital and home – graded transfer/discharge home – phased return – opportunity to experience being more normal once again, some sense of harmony, taken-for-granted-ness – familiarity of home where in control as opposed to the unfamiliarity of hospital – leaving the rehab unit and going out with family – weekend leave – benefits psychologically as well as practically – importance of doing normal things again – seeing what will have to content with – in some ways like stepping back	Steve; Liz; Martin; Paul; Tim
All the component parts are great of rehab, but it works collectively as a unit – vitally important because wouldn't be able to cope at home, one might think that one could but one couldn't – it's a hub that protects one and allows one the space to get better, when one leaves the protective hub for weekend leave etc, realise limitations, protected from those limitations somewhat when inside	Martin; Roger
Key that need to impress upon people more the importance of time in rehab and working hard would take their time to get things done – have a role to play in one's own recovery but need expert help to do it properly; easy to learn bad habits and need to be guided carefully – learning the wrong thing can have a massive effect going forwards – got to listen to the experts and take on board and do what they say	Martin Steve's wife
Dis-invitational	
Issues with the transfer from acute to rehab – didn't know when going to happen/not able to say farewell – cold/long/late – not expected	Anne; Jim; Liz; Roger; Tim
Rehab unit far away from home and wife who doesn't drive long distances or on the motorway – reliant on lifts from others	Gordon; Roger
Not being expected on arrival – no bed – not being certain as all other people so much older – feeling alone – cried when arrived	Tim, Liz
Being barrier nursed in isolation – loneliness; unclear why when feels well – feels that all unnecessary	Roger; Tim
Panicked that six weeks of rehab wouldn't be enough – that had been lying in bed getting weaker and wanted to build himself up for rehab – anxious as couldn't contemplate how when at such a low level functionally, six weeks of rehab wouldn't be enough	Martin; Richard; Stewart; Tim
Not knowing what to expect/not knowing the routine – others knowing but not always saying	Stewart; Richard's wife
Limited access to doctor – amazed that didn't see a doctor as much as would have thought – used to seeing the doctor daily on the acute site – would wait each day to be able to update on what was feeling/doing – only one who can adjust the medication – should have access to see a doctor at least once a week for a general review/check-up – in rehab, it isn't the doctors but it's the nurses instead who are in charge	Liz; Martin; Tim
Lots of people go back to own rooms rather than being in the dayroom – no one then to really interact with – happy enough to be in room by self but nice to be with others to pass the time	Anne; Martin; Roger; Tony
Not quite institutionalised but not fully able to do own thing – not living life as normal and in control	Liz; Stewart
Overall, being in rehab too nice, helpful, kind, relaxed - message about the importance of working hard needs to be much clearer and stronger – wished that had been pushed more and made to work harder – when with staff wanted to do things that couldn't do in own time – wanted to be exercising	Jim; Martin; Paul; Steve
When doing ADL's, the frustration of not knowing what strategy to use straight away – to try things and to fail and eventually get it right not helpful – being cross not to have thought of alternative method in the first place as wasted time and effort – frustrated when not learning quickly enough – thinks that should be able to do things and then finds one can't	Anne; Jim; Martin; Paul
Seeking help from nursing staff with ADLs as anxious about the timing of mornings and that may miss a physio session – looking at the clock, knowing what time there is to get ready and wondering if it will be long enough – effortful and exhausting – needs planning – often needs more time than is available as everything takes such a long time as so slow – huge frustration if get the timing wrong – frustration esp if miss any physio – frustration too if in bed in the morning knowing that have 9.30 appt and no one around to help/no one coming – wanting desperately to get to the stage where not dependent, where can transfer from bed to chair and get ready independently – ridiculous and frustrating that can't do it – can't even roll over – frustrating when had always been able to do things for oneself – practical and able	Jim; Martin; Paul; Roger; Stewart; Tim
Staff saying that will be back in a couple of minutes and then not returning – better to say realistically how long will be – even if a long time – people can plan if they know the truth – promised things that don't materialise – wanting certainty and not more uncertainty – soul destroying to be told something that then isn't true – the impact of just having to wait and not to know – to be dependent on others	Martin; Paul; Steve; Stewart
Pain experienced when doing indep practice – anxious to do them for fear of making things worse – anxiety that doing indep practice, even in gym/with kit, might go against what doing in therapy	Jim; Martin

sessions – doesn’t want to make things worse – fearful if get exercises wrong or stop doing them will go backwards with recovery – unable to face going backwards to where came from with acute setting – possibly/probably doing too much but feeling that that is better than too little, although not certain on this and waiting to be told off – limited communication about what to do/not do leading to anxiety and concern that may do/may have done the wrong thing and put pt even more at risk – not being shown the right exercises to so – mentally having to constantly check that not worse again	Paul; Roger; Tim
Upper limb tasks don’t seem to have much relevance – not so structured; putting things into things and taking them out – feeling that not really doing anything in sessions, or anyway anything useful or made sense/all common sense, so got no progress – feels that outcome would have been different if had had ‘physio’ on arm – whatever the magical ingredients of physio were wanted these for his arm because feels that if physio made LL better, then the same physio would have made UL better – fed up by the end because what doing in sessions od no interest and don’t make sense – what does make sense is when the OT do the arm stretches	Anne; Paul Roger; Steward; Tim; Tony
Generally having to work hard – knows that has to but doesn’t really want to – esp at time of life – if want to get something then need to work at it but doesn’t want to	Anne; Rachel; Tony
The dis-invitation of goal setting – chose LL related goals and as a result links this to the fact that staff focused on LL and therefore LL recovered, if had set an UL goal then they would have focused on this more and therefore recovery would have been better; hadn’t realised how the system worked, hadn’t realised that needed to ask for UL, hadn’t realised that his choices would have such consequences; blame/his fault	Paul
Supplementary forms of information – leaflets no real appeal, has them to look at but hasn’t – knows the info is there but would rather just ask when has access to people that can ask	Anne; Paul; Rachel; Tony
As a relative to have to be strong all of the time – having to drive forward safe care – notice things that should be picked up by staff and then gets things in place to correct them	Wives of Martin; Richard, Steve; Tim
Volunteer groups not wanted – desperate to avoid	Tony
Other people on the unit – inconsistent behaviours – not people that would spend time with – sad to see other people who are so dependent – sad to see people who are going home to difficult situations	Liz; Tim
Not having more structured therapy sessions/group sessions	Martin; Paul; Tony
Learning that will need help when goes home – dis-invitational is having to work out how to do this/ benefits etc alone with no support and guidance – anxious about whether everything will be ready at home and if things will work out	Anne; Paul
By the end, rehab still good but a bit fed up – keen to go home and move on	Anne; Liz; Steve; Tony

Home

Visible	
Seeing equipment at home – visibility of permanence of what has happened – that now has to live with what one has got – realisation that has done well but seeing the equipment at home for the first time meant that really twigged that hospital life would now be home life – would travel with him – that life will never be as it was before – feeling that life more restricted that pre-stroke, only a small amount but noticeable – because making progress every day when in rehab, didn’t get the sense of restriction which really only came on getting home – aware of not being like was before, of not being perfect – small things which notices cannot do or feels that probably could not do – shown the boundaries of what can do in a way that didn’t get when in rehab – glass three quarters full compared now a glass quarter empty – wider sphere of life has closed in a bit – now in a grp of people that wasn’t before as someone recovering from a stroke - when in hospital knew that had had a stroke but at home, really realised it – woven into his life history	Gordon; Paul Richard; Stewart
Getting the leg back gave confidence that would get the arm back working again – amazed that leg came back so expecting arm to do the same – might not be 100% but will be pretty normal – clear to see LL improvements as can walk further/easier – arm feeling like leg felt before it recovered but no similar signs of improvement for UL – ADLs as hard, dropping items, hurting self, shoulder pain	Adam; Gordon; Paul; Tim
Pleased with aspects of improvement but wanting more – both plsed and disappointed as wants more – wanting normal as end outcome	Adam; Gordon; Paul; Stewart; Tim

Perception of body not being able to do very much – not being able to do what it used to and what he would like it to be able to do	Adam; Gordon; Paul; Roger
Trying to understand current and future outcome – what still able to change to feel that future might be different/better but finding reasons largely related to self about why outcome not as good as could be – when in acute setting, the constraints of the system were a defined reason for levels of recovery or not, in rehab opportunities were offered and therefore outcome based on what did/didn't do, now at home, no opportunities any more so own responsibility again	Adam; Gordon; Paul; Tim
Invisible	
Able to see things in hindsight which couldn't see at the time – esp that the outcome could be as it was – if had known this, thinks that would have done things quite differently and worked even harder than did – cannot afford just to wait because recovery won't come with waiting – in hindsight – how crucial rehab is, not just a nice place to be to help things along but recovery dependent on it – a lot that didn't realise about stroke and recovery which wished had realised – hard to rtn to low place months after DC when recovery no longer occurring and realisation of level of deficit and life with deficit there again	Adam; Gordon; Paul
Didn't know when left rehab that recovery might not continue and might not be complete – knew people in the past who had had stroke didn't get fully better but didn't realise that this was still the case today – as got fully better from previous stroke, thought that would be the same this time and no realisation that it wouldn't be	Adam; Paul
Knowing what to do with the arm to make it better – leg easier because can walk; don't know what to do similarly for the arm – unknown whether to do specific exercises or just try to use it in everyday life as trying both but neither seem to work – the UL ex that were given boring and mundane so less inclined to do them – difficult to see any benefit from doing them – no idea what to do to do things differently – trying to draw upon knowledge of past experience of gym-based exercises to use for recovery – all right for the LL but doesn't help UL which is what really wants to improve – what to do/how to do, not completely invisible, but quite invisible	Adam; Gordon; Paul; Tim
As a patient, anxious that without the right information, might do the wrong thing in indep practice	Adam; Gordon
People like him not represented on pictures or words of leaflet from leisure centre, so no sure if it would be suitable to go or not – how to translate being in the rehab gym to gym in local area	Paul
Knowledge of the future and what it might look like, knowledge of how to support oneself within this if not able to work – not really talked about in any way when in rehab setting	Adam; Paul
Invitational	
Being given something new to do when at home because by doing something new there is the hope that further improvement might occur – improvement not occurring with what doing before so good to have something new as able to sustain hope a bit longer – being given ideas that wouldn't have thought about oneself as perhaps more likely to be more successful	Adam; Gordon; Paul
When being given exercises, actually being shown what to do is helpful	Adam; Gordon; Paul; Tim
Routine of doing exercises when at home – helps to have specific physio times – helps to have the discipline	Gordon; Paul; Tim
Doing exercises in a leisure centre in a way that won't do at home – will do a few at home but not in a structured systematic way – at home, busy doing other things as just gets on with living life – which in of itself has therapeutic value	Stewart
Dis-invitational	
The lack of access to hands on, only so far that one can take oneself and sometimes need help to get further – to be told it is down to you to get better but then no real strategies in place to do this – the lack of access to both kit but also guidance and knowledge – only so much trying and failing that one can do before giving up – the realisation that further recovery might/would not occur – despite all efforts	Adam; Gordon; Paul; Tim
Dis-invitation of being DC immediately/quickly from community physio team – physio reluctant to even come out – massive disappointment because this was the one thing that valued so much as an inpt – the starkness of contrast between being with people who believed you could/would get better and those who didn't– being told that taken as far as one can get when feeling that so much more that needs/wants body to be able to do – that just living life is not enough – wanting to live it as lived it before	Gordon; Paul
Not knowing how to get arm better – not knowing what to do to make it better – doing the same exercises after DC and not knowing what else to do when at home – would have liked more guidance in hospital about what to do at home – desperately wanting a review and someone to check up that	Adam; Gordon; Paul; Tim

doing ex correctly and how to progress them – not knowing what to do because not the professional, wanting guidance from the professional – recipient of the treatment being given to one	
The frustration of trying to use a less than perfect arm/hand – the frustration of not being able to do the very simplest of life activities – the feeling of being useless and dependent	Adam; Gordon; Paul; Tim
The inconsistency of being able to do strength work when exercising but for this not to translate into the arm being able to do more functionally – just as limited	Paul
The dis-invitation of home as an environment in which to carry on recovery – not able to replicate any of the sensations and successes that had in rehab gym	Adam; Paul
After DC, the dis-invitation of no longer being able to carry on using both equipment and space to do the ex that one understands, finds beneficial and enjoys – the psychological impact of this – of not get the feedback on improving and progressing that had before – the sensation and awareness of improving when in the therapy gym – able to push and this led to improvement – wanting to experience this sensation after DC the dis-invitation of not being able to replicate this sensation at home	Adam; Jim; Paul
The feeling that wished that had worked harder – tried to work hard and did do, but wishes that could have done more; wishes that has been told about the importance of doing more; would have worked for all the hrs that were offered as feels time in rehab was the window for improvement – people available and kit available to facilitate this which then doesn't have at home – opportunity lost	Adam; Paul
The dis-invitation of having no role and purpose – not able to return to work when had no plans to stop working	Gordon; Paul
Looking good and seemingly having recovered well in the eyes of others not meaningful as not what he feels – to be told that has done well when doesn't feel this	Gordon; Paul; Stewart
Not seeing oneself represented in the leaflets provided by leisure centre regarding accessibility and exercise for disability – images and info aimed at old people and doesn't feel old – not sure whether to go as not sure sessions aimed at him	Paul
The amount of time that healthcare appts take up on DC home – reason for not being able to engage so much in exercise – allows scope for belief that more recovery might/will come when more time available and therefore able to do more exercise	Paul

Appendix 18 Table constructed to guide analysis – pointers derived from the writings of Paul Atkinson

Pointers to structure analysis	**Additional prompts**
Social definition – alongside the social situation (the something that is socially and analytically specific)	Phenomenon of interest Learning as distinct from rehabilitation unit as a whole
Common or joint activities Mutual attention, undertaking How things are framed – how the actors involved framed things	Patients: Framed in… Staff: Framed in…? Despite working to a common goal, to consider if people working in the same way or differently towards this – is the how the same or different? Motivations/ drivers
Processes of communication that bound them Interaction rituals	Who is the 'them': patients and patients, patients and staff, staff and staff, patients and carers, carers and staff, carers and carers Informal – when, where, how, between whom, why, consequences Formal opportunities – when, where, how, between whom, why, consequences Communication via words: Spoken and Written – e.g. timetables, minutes of case meetings Invitational interactions – intentional or unintentional; Dis-invitational interactions – intentional or unintentional Communication via actions (actions of care, esp physical actions of care, what is meant by that by both parties) – Formal: actions of role/job; Informal: actions of human kindness/care
Collective consequences?	Physical, emotional, wider outcomes of the rehab, of the learning – to the patients, to their family, and to the staff The consequence to pts and family was the enablement of function and what future life would be like Consequence to staff related to pt outcome but this also linked to their goals/targets – local and national
Physical boundaries Performance architecture of the built environment Backstage/frontstage; Upstairs/ downstairs; Visible/invisible	Building; Rooms – bedrooms, dayroom, dining room; Ward; Gym Patient spaces Staff spaces – offices, nursing station, drug room, sluices, laundry room, storage rooms, stairwell, common room, toilets Weekend leave – the going away and out of the space; then the returning Both what physical and symbolic already given up in the acute stage
Symbolic boundaries All boundaries – physical and non-physical are symbolic Segmentation	Boundaries of role Boundaries within roles Associated knowledge/skills; culture/class/status; gender Stability v fluidity of the boundaries Expectations of the boundaries Who constructs the boundaries – what does it say about one grp in contrast to another Ownership of info about self – how much one wants this to be shared/how much choice one has
Crossing the boundaries – both physical and symbolic	Transition from acute to rehab to home – large physical and symbolic crossings Large boundary crossings as well as small but important boundary crossings Transitions – knowns and unknowns encountered; Starting things anew – again and again

Social knowledge – how gained and how used How do they do that and how do they know that? Knowledge in action	Taken as given that we are knowledgeable – fairly high degree of cultural competence – often tacit • Know how to enact their own everyday lives; Can make sense of the activity of others; Have working knowledge of the world around May be learnt self-consciously and then put into practice in an implicit manner; Allows one to navigate through one's world – knowing rules and how to interpret them Local, situated knowledge; typification, taken from grantedness; Understanding of local situated knowledge, social rules and conventions as they guide action – rules need to be interpreted ; Allows one to carry out routine and mundane tasks Process of enculturation or formation of habitus – Alongside is specialised/esoteric knowledge Need to also explore how people make sense of the phenomena – their practical reasoning Knowledge of orderliness – how this is achieved, how fixed or fluid Meaning and intention of rules – what the rules are and rule following – how rules are interpreted and therefore acted upon – how are rules made sense of such that people can account for their actions Also codes – local ways of working developed by those within the situation; working together and working separately How much negotiation/what type – what results/what consequences Awareness states – who has awareness of what: Staff and pts; Staff and carers; Carers and patients Open awareness, closed awareness, suspicious awareness, mutual pretence; Disclosure and withholding How is the exchange of information managed? Does one party have authority of information over another? Where and what is censored? And why? Actions based on suspicious awareness – often act based on what we surmise or predict based on limited knowledge
Social skill – equally how gained and used	Embodied knowledge Embodiment related to cultural competence
Different orders:	Orders of encounter; Orders of face to face interaction; Discursive order of language; Temporal orders; Spatial orders; Aesthetic orders; Sensory orders
What people actually do	
The performance	Dramaturgy – the performance of each of the social actors – how and why, motives, responsibility Degree of collectively and collaboration Ordinary and routine ways that people enact and make visible to others who and what they are Prompted to think about the degree of competition, the creation of values, the public and ceremonial aspects; Reputation Contrastive rhetoric; Performative rhetoric – need for persuasion?
The spoken encounter	Role and purpose of the communication How people shape the narrative and therefore the personal feelings that they express; the symmetry or asymmetry of the encounter What is said; How it is said Are their repairs/corrections from self or others – are repairs allowed/enabled from both sides or only in one direction How do both sides seem to make sense of the other's utterances – what knowledge are they drawing upon – skilled or everyday? How what is said is responded to
Rumour, reputation and legend	Potential of these for social control

The negotiation	Negotiation between pts and staff; staff and staff; patients and patients; carers Within negotiation to consider: Rhetorical and discursive devices; Support enlisted from others; Resources they command; Invocation of power or authority; Expertise and knowledge brought Process not just end point: Number of people involved; Experience of people involved; Who the people represent; Balance of power; Whether negotiation a one off or repeated as part of a process; The stakes of the people involved; Whether the transaction is visible to others; Compromises and coping mechanisms; Work arounds Does the negotiation ‘comply’ with the rules – is there deviance; What does this show if complying or deviant – how does it relate to sense of self
The identities	Not given but made/created – social identities; How formed and negotiated Are there threats to identity – how managed, are they faced? Disease? Setting (the unit) Labelling in both positive/less positive way – often based on motives – how socially created and where come from Changes to identity; Previous ‘careers’ in the broadest sense of term; status passage Turning points – time pre and time post – may be significance of the event itself and/or to the meanings given to life before and after Rites of passage/ceremonial occasions Termed as moral career with moral meaning selfhood and not morality – personhood seen as a career Escape attempt – a refuge when participants can be validated Enculturation; Communities of socialisation In what way does the setting shape the person; Patient, carer and staff Apprenticeship (interesting to explore any resonance to this in other settings with learning in rehab); learning on the job is something that in a way do throughout life, but is rehab a specific form of apprenticeship when learning practical skills, knowledge coping mechanisms, role/identity; Process of becoming; Motive/motivation/responsibility – justifications from people for actions/non-actions; Reference and rationality
Community of practice	Members who have a collective specialised expertise Culturally and socially shaped Often framed around novices entering and gaining skills – often tacit and embedded knowledge
Sense, place and things	Multimodal; Interaction with things as well as people – need to detail the field in fieldwork May well be rules about the look of the place; branding Embodied fieldwork – less common to write about the sensation of touch and feel; Sound and silences; Aesthetics and design Physical spaces and social spaces – use of space and motion within the space; space = physical; place = cultural Staff mvt within but also pt; Time of day and time of wk
The past in the present; memories and social time	Not a place frozen in time but ongoing; temporal phenomena; rhythms History inhabiting and informing the present; What is memorised, what is used to represent the past