Rights-based Rehabilitation:

How can disabled people be involved in shaping services?

By Harriet Amy Jane Cooper

Submitted for the degree of Doctor of Philosophy (PhD)

University of East Anglia
School of Health Sciences

December 2020

I certify that the work contained in the thesis submitted by me for the degree of PhD is my original work except where due reference is made to other authors, and has not been previously submitted by me for a degree at this or any other university.

Harriet Cooper, 18 December 2020

Work I undertook for this thesis is featured in the following co-authored, peer-reviewed paper:

Shakespeare, T., Cooper, H., Bezmez, D. and Poland, F. (2018) ‘Rehabilitation as a Disability Equality Issue: A Conceptual Shift for Disability Studies’, *Social Inclusion*, 6:1.

The literature review sections of that co-authored paper drew on an early version of the literature review I had written for *Rights-based Rehabilitation*, and the section discussing ‘Mary’ in that paper drew on data that I collected. The writing in the ‘Mary’ section of the paper was mine. Versions of the material that I contributed to the jointly authored paper are also presented in the thesis, since they are my own original work. That material can be found in Chapters 2, 3, 6, 7 and 8 of the thesis. I attach a copy of the paper as an appendix, with permission from my co-authors and from the journal.

Abstract

Rights-based Rehabilitation explores how disabled people's views and experiences of the rehabilitation process can shape services and help to develop a rehabilitation policy which incorporates disability rights. The *UN Convention on the rights of persons with disabilities* includes the provision of 'comprehensive habilitation and rehabilitation services' (United Nations, 2008: n. pag.). Yet the World Health Organization identifies a lack of involvement of disabled people in the design, delivery and evaluation of rehabilitation services (2011). In reviewing the literature, I found minimal evidence of the involvement of disabled people in the shaping of research on rehabilitation.

Funded by the CLAHRC East of England's Patient and Public Involvement (PPI) Theme, the research agenda was informed by a project advisory group made up of disabled people who have been through rehabilitation. The group has advised on issues including the production of accessible participant information leaflets, recruitment and data analysis.

The study involved 36 participants living with long-term physical and sensory impairments in the East of England. Data collection included semi-structured interviews, focus groups and a creative writing group. The latter generated new insights into the role of creativity and narrative in facilitating agency in rehabilitation. I analysed transcripts from the fieldwork abductively and iteratively, looking for key themes. The themes which emerged most prominently were:

- the question of what it means to be involved in rehabilitation, including the importance of relationships;
- the significance of being able to take up agency in rehabilitation, and the role of narrative in this process;
- the temporality of rehabilitation experience and its connection with being valued.

The thesis makes a distinctive contribution to our understanding of disabled people's lived experiences of rehabilitation through its close analysis of new qualitative data, its deployment of PPI and its use of creative writing as a research method.

Access Condition and Agreement

Each deposit in UEA Digital Repository is protected by copyright and other intellectual property rights, and duplication or sale of all or part of any of the Data Collections is not permitted, except that material may be duplicated by you for your research use or for educational purposes in electronic or print form. You must obtain permission from the copyright holder, usually the author, for any other use. Exceptions only apply where a deposit may be explicitly provided under a stated licence, such as a Creative Commons licence or Open Government licence.

Electronic or print copies may not be offered, whether for sale or otherwise to anyone, unless explicitly stated under a Creative Commons or Open Government license. Unauthorised reproduction, editing or reformatting for resale purposes is explicitly prohibited (except where approved by the copyright holder themselves) and UEA reserves the right to take immediate ‘take down’ action on behalf of the copyright and/or rights holder if this Access condition of the UEA Digital Repository is breached. Any material in this database has been supplied on the understanding that it is copyright material and that no quotation from the material may be published without proper acknowledgement.

Table of Contents

Chapter Four

Chapter Five

Chapter Six

Chapter Seven

Chapter Eight

Chapter Nine

Acknowledgements

First and foremost, I would like to thank the participants who gave up their time to take part in this study and who so generously shared their rehabilitation stories with me. This thesis is dedicated to them.

I am grateful to the National Institute of Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care (CLAHRC) East of England for funding this project under their Patient and Public Involvement (PPI) Research Theme in 2015. Thank you to the University of East Anglia for underwriting my funding beyond the life of the CLAHRC, when I returned to study on a part-time basis following maternity leave.

A very big thank you to my fantastic supervisory team: Fiona Poland, Tom Shakespeare and Swati Kale, who have supported me in different and complementary ways during my work on this project. When I came to this project I was an early career researcher schooled in the humanities, with a PhD in cultural disability studies. I have learnt a huge amount from working with my supervisors, not just about research design in the social sciences, but also about knowledge production in general, and about communicating research to different audiences and institutions.

Heartfelt thanks to my project advisory group, for their invaluable input into crucial decisions about research design and accessibility, as well as for their support with promotion and data analysis. I'd like to thank in particular Colin Bell, Stuart Ross and Caroline Fairless-Price, as well as Penny Parker, who represented Equal Lives on the advisory group. Many thanks to Linda Watson and Colin Bell for helping me devise project information that would be accessible to people with aphasia. Thank you also to members of the wider patient and public involvement group, which met early in the project and helped me to make the initial decisions about the focus of the research.

I am grateful to Andrea Stöckl for acting as a contact person for the study, and to Bridget Penhale for her advice about safeguarding in the research process. Many thanks also to Hannah Zeilig and Tessa McWatt, who helped me to think about how to get the most out of the creative writing groups I convened. Thank you also to: Equal Lives, Headway, Norfolk Community Health and Care NHS Trust, the UEA Research Office, the UEA PGR team, the Norfolk and Suffolk Primary and Community Care Research Office, the Health Research Authority and the CLAHRC East of England team. I am also grateful to the many local groups and third sector organisations that publicised my project.

Thank you to my family, and especially to Nick, for being there for me and supporting me throughout my work on this project.

Chapter One
Introduction

1.1 A research need

In the introduction to *Disability Rights and Wrongs Revisited* (2014), Tom Shakespeare describes the impact of his experience of becoming paralysed, in 2008, on his life and on the way he thinks about disability:

> This change in my life expanded my understanding of disability greatly. For example, for the first time I now understood the significance and value of rehabilitation, which has been a very neglected topic in disability studies. (pp. 6-7)

Here, emphasis is placed on the relative neglect of rehabilitation as a topic of study in disability research, as well as on the role of the lived experience of increased disability, and rehabilitation, in the development of insight into an under-researched issue. These observations highlight a research need that my doctoral project has sought to address: how do disabled people experience rehabilitation, and how can their views and experiences be used to shape services?

Although disabled people's lived experience has long been valorised as an important component of disability research (see Barnes, 1996; Shakespeare, 1996a), and disabled activists have been pivotal to developing a concept of 'emancipatory research' (Oliver, 1992), research undertaken under the banner of 'disability studies' rarely examines disabled people's experiences of engaging with rehabilitation services. The research I present in this thesis explores the rich and varied texture of disabled people's accounts of their own lived experiences of rehabilitation: from physiotherapy, occupational therapy and speech and language therapy; to engaging with medics, psychologists, and sensory rehabilitation teams; as well as a with variety of other practitioners and services.

In this introduction, I begin by offering some background about the research need I described above, so as to contextualise the research questions I have formulated to address it. I then briefly explain my own interest in undertaking this research, exploring the extent to which I regard myself as an ‘insider’ (Sherry, 2008) in the contexts of the disability movement and medical sociology. Subsequently, I provide an outline of the chapters in this thesis.

1.2 Background, rationale and research questions

Since the 1970s, the UK disability rights movement has sought to redefine disability in terms of social and environmental barriers to participation (seen as oppression), rather than in terms of a functional deficit (UPIAS and The Disability Alliance, 1976; Oliver, 1983). This work to promote a ‘social model of disability’, whereby disabled embodiment or mental illness were no longer experienced as barriers to full inclusion in society, has not always been seen by disability activists as compatible with engaging with rehabilitation (Oliver, 1990, 1993; Abberley, 1995; Davis, 1995; Finkelstein, 2004). Rehabilitation has tended to be associated with a medical model of disability by these authors, and has thus been regarded as oppressive for disabled people. As a result, disabled people’s experiences of rehabilitation are under-researched in disability studies (Shakespeare, 2014). Yet the *UN Convention on the rights of persons with disabilities* (UNCRPD) makes direct reference to rehabilitation rights (United Nations, 2008). Article 26 of the Convention, entitled ‘Habilitation and Rehabilitation’, calls upon all states to ‘take effective and appropriate measures […] to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life’ (United Nations, 2008, n. pag.). This includes the provision of ‘comprehensive habilitation and rehabilitation services’. Yet in many countries, the process of fully implementing rehabilitation policies has ‘lagged’ due to a number of ‘systemic barriers’ (WHO, 2011, p. 104). Among these barriers, the World Health Organization (WHO) cites ‘absence of engagement with people with disabilities’ in relation to the design, delivery and evaluation of rehabilitation services (2011, p. 105). Although some researchers are undertaking work which promotes communication and engagement between the rehabilitation professions and the disability community (for example French, 1988; Crisp, 2000; Hammell, 2006; Bevan, 2014; Swart & Horton, 2015; Bezmez, 2016; Stewart & Watson, 2020), more dialogue between these two groups could help to ensure that disabled people are more fully involved in developing policy and practice (Abberley, 1995; Hammell, 2006; Bevan 2014). For Shakespeare (2014), the commitment to a 'strong' social model has hampered the development of disciplinary alliances (for example, with medical sociology) that could lead to research promoting the human rights of all disabled people (see also Shakespeare & Watson, 2010, 2001).

Thus, on the one hand, disability researchers have tended to overlook rehabilitation experience, and have not always regarded medical sociology as an important sibling discipline from which to learn. On the other hand, rehabilitation researchers have not always involved disabled people in the design, delivery and evaluation of rehabilitation. This study addressed this under-researched niche at the intersection of disability studies and rehabilitation science, both by finding out about disabled people's experiences of rehabilitation and by involving disabled people in decision-making about the design of the project. By doing research at the intersection of the two disciplines, assumptions on both sides can be challenged about what rehabilitation is for, and who decides what rehabilitation is: this could help to make rehabilitation more relevant to the patients who undergo it.

This doctoral study, *Rights-based Rehabilitation*, was funded in 2015 by the Patient and Public Involvement (PPI) Research Theme of the National Institute of Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care (CLAHRC) East of England, as part of a programme of research designed to better understand how to involve patients and members of the public in shaping research. This project specifically sought to understand rehabilitation and research on rehabilitation from the perspective of disabled people who have lived through rehabilitation. From the outset, I therefore sought to involve disabled people with a variety of impairments, from a wide range of walks of life, in the design and delivery of the project, and also to build relationships with the wide variety of stakeholders who could maximise the impact of the work and therefore the voices of disabled people who contributed.

The research questions I worked with in this project evolved over the course of the first year of my work on the project, and were honed in response to conversations with PPI colleagues and supervisors, as well as in response to what I found in the literature, and my evolving understanding of how to promote inclusion in health sociology. The research questions needed to reflect the focus on examining the lived experience of rehabilitation as it is understood and recounted by the study participants. The questions were also designed to explore how far, and in what ways, disabled people’s accounts of rehabilitation services depicted arrangements that met their needs and took account of their rights. The research questions should also seek to know how disabled people envisaged best practice, or what services would look like if they were involved in shaping them. Therefore, the research questions for this project are as follows:

- **How do disabled people who have been through rehabilitation describe their experiences? What is rehabilitation like for people in this group?**
- **How can disabled people’s views and experiences of the rehabilitation process:**
    - **shape rehabilitation services, and**
    - **help to develop a ‘rights-based rehabilitation’ policy?**

A related project objective was to involve disabled people in the design, delivery, and dissemination of the project; this work has been achieved via patient and public involvement, and its route to doing so and the consequences are discussed and reviewed at various points throughout the thesis.

1.3 My status: An insider?

From the start of the project, I have sought to reflect on my own relationship to the topic of my research and to evaluate how my own views, lived experiences and academic knowledge may be shaping my approach to the project; I have developed my capacity for reflection both by drawing on my own critical resources, and through dialogue with my research team and project advisory group. Mason (2018, p. 18) advocates for 'active and practical reflexivity' in qualitative research: reflexivity is about bringing a spirit of inquiry to all aspects of the research, and acknowledging that designing research is likely to be a 'shifting endeavour' (p. 17). For Mason, as for other qualitative interpretative researchers, practicing reflexivity helps a researcher to explore the basis of her interpretations and to better understand their status as knowledge. By reflecting, the researcher is able to provide an account of her own reasoning practices, decision-making and the judgements she has made; this facilitates a more robust research process. She is also able to explain what she learnt through her research practice. In this project, I sought to reflect on my own position in at least three ways:

- I have reflected on my own position in relation to the subject of my research, where I have a certain kind of 'insider' status in relation to rehabilitation (see Sherry, 2008; Woodward, 2008; Corbin Dwyer & Buckle, 2009). I have hemiplegia, a mild physical impairment that was caused by a birth injury, and, as a child I had various experiences of 'habilitation' (WHO, 2011, p. 96). As an adult I have also engaged with rehabilitation services. My childhood habilitation for hemiplegia was a profoundly intrusive experience, impinging much more on my life than the effects of my relatively mild impairment itself. Indeed, it was partly through reflecting on my experience of habilitation that I first came to disability studies, finding it to be an emancipatory academic (and activist) space. My personal experiences of (re)habilitation left me with strong negative feelings about it; in writing my monograph (Cooper, 2020; see also Cooper, 2015), I began processing these feelings and gave an autoethnographic account of my rehabilitation. My feelings about rehabilitation shifted in the course of that writing process: the process helped me examine and work through my experience, equipping me with a reflexive awareness of my own particular prejudices, and their genealogy within disability studies. Reflexive activity helped me to be able to identify, name and own my own changing feelings about rehabilitation, so as to be able to think about how these might be affecting my interpretative practice.

- I have worked reflexively in building relationships for this project, including in my work with supervisors, PPI members and colleagues from the funding body. This work has involved reflecting on relationships of power, authority and control in research, as well as on other issues such as the priorities of different stakeholders.
- I have explicitly explored my changing position in relation to the disciplines of sociology and health services research, where I may be *becoming* an insider, but where, having gained earlier, and longer, familiarity with humanities in my academic background, I always feel I have more to learn. I have already gained a doctorate in medical humanities / disability studies (Cooper, 2015), building on my undergraduate degree in literary studies. The doctoral thesis I present here represents a second programme of PhD study, undertaken for a variety of reasons, foremost of which was my desire to engage with other disabled people, to hear their stories and to use my skills as a researcher to amplify their voices. It has been exciting for me to be schooled in a different methodology, as well as to bring some of my own ideas to bear on this process – specifically in relation to the fieldwork I conducted using creative writing.

1.4 Chapter outline

The thesis begins with three chapters which review the literature in the main fields in which my project intervenes:

- the rehabilitation science literature (Chapter Two),

- the disability studies literature (Chapter Three), and
- the patient and public involvement literature (Chapter Four).

Drawing on evidence from these scoping reviews and narrative reviews, Chapters Two and Three develop the case for research that will explore disabled people’s lived experiences of rehabilitation from a disability rights’ perspective. Later in Chapter Three, the existing qualitative evidence about disabled people’s lived experience of rehabilitation is synthesised. Chapter Four turns to the history and theory of patient and public involvement (PPI) in research in the UK, engaging with some of the key intellectual debates and sociological traditions that have informed the development of this relatively new sub-field of health services research. This ends by discussing how and what I learned about the sometimes vexed relationship between PPI as an institutional practice, and user-led research as an concept emerging from social movements. The lessons I took from exploring the tensions in the history of PPI informed my decisions about how to integrate PPI into my methodology for the project.

Chapter Five describes the methodology for this project. I explain my use of a pragmatic approach, which involved analysing the research problem and diagnosing of it as a ‘type’ of problem: this groundwork could then inform decisions about what kind of study design would be suitable. I set out relevant epistemological and ethical considerations, and explain how the chosen fieldwork activities would yield data to answer the research problem at the heart of this project. The chapter also discusses the decisions I made about how to do patient and public involvement.

The subsequent three chapters (Chapters Six to Eight) present the data analysis, with each chapter focusing on a theme which emerged as prominent in the process of analysis. Chapter Six examines the question of how participants conceptualised ‘involvement’ in rehabilitation. Chapter Seven takes up the issue of ‘agency’, examining participants’ accounts of what enabled them to become actors in their own rehabilitation processes. This chapter also explores what it meant to participants to narrate their rehabilitation, attending particularly to participants' views on what the creative writing fieldwork activities enabled for them. Chapter Eight considers the temporality of rehabilitation, since participants consistently drew my attention to their experiences of the effects of time's passage, or the effects of their sense of time as a limited resource, on the stability of their identity. The final chapter of the thesis, Chapter Nine, discusses the contribution of the thesis to wider knowledge, in terms of how my findings augment, amplify and modify the existing evidence base on the lived experience of rehabilitation, how they help to characterise a notion of 'rights-based rehabilitation' and what they tell us about the contribution that PPI may make to rehabilitation science. In this chapter, I consider the implications of my research for developing a rights-based rehabilitation policy and practice which includes disabled people in its design and delivery.

Chapter Two
Rehabilitation science literature: A scoping review

This chapter presents a scoping review of the rehabilitation science literature. It opens by discussing the aims, approach and scope of the review, before offering a working definition of rehabilitation. Then it gives a more detailed insight into the method I used to carry out the review, before a discussion of my findings, structured around the three thematic areas identified in the aims section. Finally, I summarise my findings and offer some brief reflections on the limitations of the review.

2.1 Aim, approach and scope

My aim in reviewing a proportion of the recent rehabilitation science literature was to generate qualitative insights into the field's treatment of three conceptual areas which are linked to 'rights-based rehabilitation', given the focus of this doctoral project on disabled people's lived experiences of the rehabilitation process. The three areas were:

1) the models of disability and rehabilitation that this literature tends to use,
2) its characterisation of research participants, and
3) its representation of participants' voices in the research process.

I chose to focus on these three themes in the literature so as to compare the representation of these issues in the rehabilitation science literature and in the disability studies literature. This would enable me to substantiate the contribution of *Rights-based Rehabilitation* to existing academic debates within these fields. At the outset of the project, my knowledge of the two fields led me to hypothesise that whereas the disability studies literature would tend to work with the social model of disability[1] as its baseline, the rehabilitation

---

[1] That is, as mentioned in the introduction, the idea that 'disability' can be understood as created by disabling social, structural and environmental barriers, in contrast with 'impairment' which is the preferred term for discussing the body's functioning and its medical conditions (see UPIAS & the Disability Alliance, 1976).

literature would tend to use a biomedical model, or biopsychosocial model of disability, the latter being the model used by the World Health Organization (WHO) in its International Classification of Functioning, Disability and Health (ICF) (2001). My understanding of the different disciplinary protocols associated with the two fields also led me to hypothesise that the involvement of patients in shaping research processes would be more likely to be seen in the disability studies literature than in the rehabilitation science literature, in which research agendas would be shaped by emerging scientific evidence about how to improve function and health. Rehabilitation science is a multidisciplinary field, covering a range of different health professions (*Clinical Rehabilitation* website, 2020), and, whilst the remit of each journal differs slightly from each other, this literature is generally for clinicians, therapists and researchers working in rehabilitation (see for example, *International Journal of Therapy and Rehabilitation* website, 2020), who need to stay up to date about the best available evidence for the treatment of a variety of long-term conditions.

I considered a scoping review (Arksey & O'Malley, 2005; Guilcher et al., 2012) to be suitable for reviewing both the disability studies literature and the rehabilitation science literature, for reasons I detail here. Arksey and O'Malley (2005) seek to distinguish what they call the 'scoping study' from a full systematic review. These authors note that they were writing at a point when a wide range of new terms were emerging to define processes for reviewing literature systematically, but contend that terminology is often used loosely. They observe that the so-called systematic review poses a 'well-defined question' of a literature composed of studies with comparable designs, but that a scoping review is used to explore a broader topic which may have been investigated through a range of types of study (p. 20). Relatedly, the systematic review examines studies whose quality has been assessed, and seeks to answer a specific question, whereas a scoping study asks a more general question of a body of literature, and does not assess the studies according to pre-given quality criteria before deeming them appropriate for inclusion. A scoping study may be appropriate for *Rights-based Rehabilitation* because I am not examining the rehabilitation science literature to evidence intervention designs, nor to compare the quality of different studies into a particular condition. My research questions are relatively non-specific, in seeking to depict rehabilitation science literature concerns, including its conceptualisation of disability, how it characterises research participants and the attitudes it portrays towards patient involvement in research. Although the factors that were important in sorting and classifying the disability studies literature (reviewed in the next chapter) were different, the overall approach I used there was similar, in that I sought to build an overview of how literature across the field tended to characterise disabled people's rehabilitation, rather than asking a very specific research question. Together the findings of these two literature reviews would help me to understand how my own project could and perhaps should intervene in both fields, bringing new knowledge to each about disabled people's lived experience of rehabilitation.

Arksey and O'Malley (2005) observe that scoping reviews are often iterative: the process of doing the review refines the review process and sometimes creates a slight shift of focus. In my case, I found that, although 'research design' was not a criterion I was using to include or exclude studies from the review, it was useful to examine relevant qualitative studies in more detail – both in this review and in that of the disability studies literature. This enabled me to map the small, but growing literature which does bridge a gap between disability studies and rehabilitation science in focusing on the meanings given to the experience of rehabilitation by disabled people. These papers demonstrated how this project could complement and develop existing research. I undertook a thematic synthesis of the qualitative evidence from both literatures which did therefore focus on disabled people's lived experiences of rehabilitation. This synthesis is presented at the end of the next chapter.

2.2 Defining rehabilitation

The WHO defines rehabilitation 'as set of measures that assist individuals who experience, or are likely to experience, disability to achieve and maintain optimal functioning in interaction with their environments' (2011, p. 96; see also Stucki et al, 2018). I have used this definition in this literature review, because the WHO is an internationally recognised organisation whose concepts are widely used in the health sciences, as well as in healthcare and medical education contexts. It was necessary to adopt a narrow definition in order to direct decisions about how to select papers for review. It should be noted, nonetheless, that some researchers in disability studies contest this definition, given its lack of attention to the perceived oppressive nature of rehabilitation (Oliver, 1990; Abberley, 1995; Finkelstein, 2004). In this project as a whole, participants' own definitions of rehabilitation were also of interest to me, since I sought to understand what a 'rights-based' version of rehabilitation would look like from a range of perspectives. Therefore, my decision to adopt the WHO definition should be understood as one driven by a pragmatic need to be selective in the review process, while seeking to remain open to alternative conceptualisations of rehabilitation, and to the dynamics of discursive power which facilitate the dominance of medicalised definitions of the term. The term 'rehabilitation' is used in a range of social contexts in powerful ways, and has its own rich metaphorical life which impacts on how it is understood within the sociological and humanities literatures.

The WHO (2011) divides rehabilitation measures into three broad categories, that is, 'rehabilitation medicine', 'therapy' and 'assistive technologies'. This review included all three categories, although in the disability studies literature, research relating to assistive technologies is not always regarded by authors and editors as being related to rehabilitation. This framing in itself sheds light on some assumptions made within the field, which will be discussed in the review of the disability studies literature. I excluded vocational rehabilitation from my working definition, even though it is arguably one of the later stages of other forms of rehabilitation (Hay-Smith et al., 2013). Drug rehabilitation and the rehabilitation of prisoners were also excluded. It should be noted that whilst this narrow definition was operationalised for the disability studies review in the next chapter, I took a somewhat different approach for the rehabilitation science literature, where it might be expected that all research had some kind of connection with health-related rehabilitation. This approach involved making judgements on a paper-by-paper basis about the extent to which health-related rehabilitation was the central concern of the paper, if there was any doubt about this. This is discussed in more detail in the course of this chapter.

When rehabilitation takes place in childhood, and is associated not with *re*gaining function, but with being helped to achieve it for the first time, the term 'habilitation' is sometimes used, as the WHO (2011, p. 96) notes. Where individual articles draw this distinction, I work with these two terms, otherwise I use rehabilitation as a term for both kinds of intervention, as the WHO (2011) does.

2.3 Detailed method

I selected the following three journals for review on the basis of their reputation as leading international journals within the field, anticipating that they would feature a range of qualitative and quantitative research, representing major contemporary research interests:
1) *International Journal of Therapy and Rehabilitation*
2) *Disability and Rehabilitation*
3) *Clinical Rehabilitation*.

My supervisory team included a clinically qualified physiotherapist, Swati Kale, who was able to draw my attention to criteria that I should consider in selecting journals that would represent the broad spectrum of research currently being published within the rehabilitation sciences. These criteria included the geographical scope of each journal and its disciplinary focus. Drawing on my colleague's advice, and on my own research, I judged that the chosen journals represented a cross-section of the variety of research currently being published within the rehabilitation sciences, whilst all being multidisciplinary rehabilitation journals (as opposed to focusing on one profession, for example, physiotherapy). I will briefly characterise the three journals here before discussing my approach. *Clinical Rehabilitation*, published by Sage (one of the leading publishers of highly ranked journals), describes itself as the 'leading journal in its field' (*Clinical Rehabilitation* website, 2020) and emphasises its scientific credentials. It prioritises research which discusses the 'effectiveness of therapeutic interventions' and the 'evaluation of new techniques and methods' (*Clinical Rehabilitation* website, 2020). Such statements suggest that the journal may be aimed at senior clinicians and healthcare commissioners as well as researchers. The *International Journal of Therapy and Rehabilitation* has a similar remit to *Clinical Rehabilitation* but its target audience appears to be health professionals who are therapists. On its website (2020), it specifically refers to occupational therapists, physiotherapists, chiropodists and podiatrists, as well as radiographers, speech and language therapists and orthoptists. This journal also highlights its international focus in the second sentence of the description of its remit (*International Journal of Therapy and Rehabilitation* website, 2020), noting that this 'enable[s] the sharing of practices and developments worldwide', as well as awareness of the cultural factors influencing healthcare. This is a distinctive feature of the journal's self-presentation which differs from that of *Clinical Rehabilitation*.

The focus of *Disability and Rehabilitation* is slightly different from both other journals in that it describes its remit in terms of seeking to 'encourage a better understanding of disability and to promote rehabilitation science, practice and policy aspects of the rehabilitation process' (website, 2020). Disability is mentioned first, suggesting that the journal is as interested in disability itself as it is in rehabilitation. Furthermore, the generic reference to 'rehabilitation science' alongside references to 'policy' and 'practice' suggests that the journal does not prioritise highly technical, scientific papers but is instead more focused on the implementation of new approaches. This journal also notes that it welcomes 'both quantitative and qualitative research', whereas neither of the other two journals make reference to qualitative methods in the descriptions of their remits.

Initially, I had intended to focus on articles on neuro-rehabilitation in this review, yet a hand search of *Clinical Rehabilitation* revealed that the sample would be too large to look at every article in detail. Therefore, in order that the review was at once manageable in scope and also representative of the literature, two impairments were selected as the focus, one being an acquired impairment (spinal cord injury) and one an impairment that is usually congenital or which begins in childhood (cerebral palsy).

For each journal, I undertook word searches electronically on the journal archives online. In each case, I searched separately for ‘spinal cord injury’ (SCI) and ‘cerebral palsy’. The term had to appear in both article title and abstract, in order for the article to be included. The publication date parameters were January 2011 to December 2018. The main features of each article reviewed in this process were:

- the model of disability and of rehabilitation adopted by the authors,
- the characterisation of research participants in the articles, and
- the presence or absence of patient voices in the shaping of the research.

For each paper, I analysed the type of study under discussion, classifying papers using categories including ‘qualitative’, ‘experimental’, ‘observational or evaluative’, ‘literature review’, ‘mixed methods’, ‘case report’. This helped me to understand, broadly, what kind of research is being published in each journal in relation to each impairment, which enabled me to understand the scope and orientation of each journal, the kinds of models of disability and rehabilitation that its articles tend to deploy, and, to some extent, the characterisation of research participants.

The review process also involved scrutinising abstracts and method sections and carrying out an ‘all-text’ search for each set of papers on the following terms: ‘consent’, ‘participatory’, ‘action research’, ‘public involvement’, ‘patient involvement’, ‘service user’, ‘community’ and ‘community engagement’. This activity enabled me to gain insight into the characterisation of research participants and to explore the presence or absence of patient voices in the articles.

2.4 Findings and discussion

	Cerebral Palsy	Spinal Cord Injury (SCI)
International Journal of Therapy and Rehabilitation	15	10
Clinical Rehabilitation	33	17
Disability and Rehabilitation	106	93
TOTAL	**154**	**120**

Table 1: Rehabilitation science review: number of papers by impairment published in three key journals between January 2011 and December 2018.

Table 1 shows the number of papers published in each journal which focused on cerebral palsy and spinal cord injury respectively. Because this is a scoping review, I was interested in obtaining an overall picture of the kind of research published in this field, rather than in selecting specific papers which would reveal something specific about the success of an intervention or approach. Therefore, it is not particularly meaningful to discuss numbers of papers identified as 'relevant' to my research, since the overall picture is what is relevant. Nevertheless, it is undeniable that as far as my research goes, I can learn more from papers that adopt an approach that is comparable with the one intended for this project, or, to a lesser extent, from papers that offer something very distinct and different from what I intend to do. While the details of my methodology for the project were defined iteratively as I developed my knowledge of existing rehabilitation research, I knew early on that I would be using qualitative methods because I was interested in understanding the nuanced meanings that disabled people attributed to their rehabilitation experience. Therefore, it was helpful to understand the kinds of qualitative fieldwork activities that had been used in other rehabilitation research, as well as to be able to see the prevalence of qualitative research within the sample.

In the course of this review, I make reference to 36 papers from *Disability and Rehabilitation*, three papers from *Clinical Rehabilitation* and three papers from *International Journal of Therapy and Rehabilitation*. This is partly a reflection of the fact that *Disability and Rehabilitation* publishes a much greater number of papers than the other two journals, but is largely a reflection of the fact that on the whole, it was the papers published in *Disability and Rehabilitation* that tended to provide material about the lived experience of rehabilitation, or about public involvement in research, and therefore could be discussed individually in terms of what they could offer my project.

2.4.1 Models of disability and rehabilitation

The journals differed in terms of the models of disability and rehabilitation that their published papers tended to use, as well as in terms of the kinds of research designs employed:

- ***Clinical Rehabilitation*** mainly carried papers reporting on quantitative studies, which were predominantly randomised controlled trials. Disability and rehabilitation were conceptualised almost exclusively in functional and medical terms.
- ***International Journal of Therapy and Rehabilitation*** mainly carried studies of a similar character to those in *Clinical Rehabilitation*.
- ***Disability and Rehabilitation*** carried many more research articles using qualitative methods than the other journals, as well as papers which conceptualised disability as multifactorial, and which placed a notable emphasis on the psychosocial aspects of disability. This trend was much more pronounced in the literature on spinal cord injury than that on cerebral palsy in *Disability and Rehabilitation*, where quantitative methods were common, and studies were evenly divided between those using a multifactorial model of disability, and those using a functional model. This trend might reflect the perceived importance of physical rehabilitation in childhood for maximising functional potential, or the perceived complexities of doing qualitative research with minors.

Only 16% of the articles on cerebral palsy reported on qualitative research compared with 39% of the articles on spinal cord injury (SCI). As previously noted, *Disability and Rehabilitation* is distinguished by its interdisciplinarity, while the other two journals tend to present themselves as publishers of scientific, rather than social scientific, research. *Disability and Rehabilitation* also publishes a much larger number of articles than either of the other two articles, which may also account for the diversity of its output.

The interdisciplinarity of *Disability and Rehabilitation* meant that more expansive and flexible definitions of rehabilitation were used by this journal than by the other two. Within the SCI literature from *Disability and Rehabilitation*, some papers examine SCI patients' engagements with physical activity (Perrier et al., 2013; Smith et al., 2013), while others examine issues of access to IT (for rehabilitation), to healthcare or to the workplace (Goodridge et al., 2015; Mattar et al., 2015; Hay-Smith et al, 2013); another paper examines childbirth experience (Tebbet & Kennedy, 2012). Other studies focus on pain management (Hearn et al., 2015; Löfgren & Norrbrink, 2012), which, while part of rehabilitation, may be highly impairment-specific.

In general, *Disability and Rehabilitation* conceptualised rehabilitation as much more than simply the process of regaining function. So, for example, one paper regarded vocational rehabilitation as the final step in a long re-integration process (Hay-Smith et al., 2013), and did not see it as separate from health-related rehabilitation. Many other papers focused on the mental health of SCI patients, on quality of life, on community reintegration, or on behavioural interventions designed to help individuals at a psychological level as much as at a physical level. From the evidence I gathered, it appeared that in this set of papers, psychological rehabilitation was not seen as separate from, or inferior to, physical or functional rehabilitation in this set of papers, but seen as integral to the success of rehabilitation as a whole.

2.4.2 Characterisation of participants

I found that study authors' presentation of their participants depended greatly on the nature of the research and its conceptualisation of disability. For example, the cerebral palsy research in *Clinical Rehabilitation* tended to characterise children with cerebral palsy as a homogeneous group, differentiated mainly in terms of the category into which they fall in the Gross Motor Functioning Classification System, or the improvements they make as a result of a particular functional intervention. Two of the papers claimed that the intervention measures being tested make rehabilitation 'fun' (Herrero et al., 2012, p. 1112) or 'joyful' (Hamed et al., 2011, p. 163) for the children, however, no evidence is cited for this claim. In these papers in *Clinical Rehabilitation*, the advancement of scientific knowledge seemed to be being privileged over the attempt to obtain shared knowledge about the lived experience of undergoing particular interventions. In general, in the articles published in *Clinical Rehabilitation* and the *International Journal of Therapy and Rehabilitation* which used quantitative methods, a functional model of disability was used.

By contrast with the characterisation of participants seen in most articles in *Clinical Rehabilitation* and the *International Journal of Therapy and Rehabilitation*, the qualitative research published in *Disability and Rehabilitation* placed emphasis – to varying degrees – on disabled people as the bearers of experiential knowledge of disability and rehabilitation, both in relation to cerebral palsy (Maggs et al., 2011; Cussen et al., 2012; Lindsay & McPherson, 2012; Moll & Cott, 2013; Brunton & Bartlett, 2013; Dew et al., 2014; Lauruschkus et al., 2015) and, to a much greater extent, in relation to spinal cord injury (Hirsche et al., 2011; Nygren-Bonnier et al., 2011; Papadimitriou & Stone, 2011; Jannings & Pryor, 2012; Löfgren & Norrbrink, 2012; Tebbet & Kennedy, 2012; Van de Velde et al., 2012; Chun & Lee, 2013; Hay-Smith et al., 2013; Perrier et al., 2013; Smith et al., 2013; Bourke et al., 2014; Clifton, 2014; Mattar et al., 2015; Fritz et al., 2015; Goodridge et al., 2015; Hearn et al., 2015; Norrbrink & Löfgren, 2016; see also relevant quantitative research: Colver et al., 2011; Gannotti et al., 2011; Nadeau &

Tessier, 2011). For example, Moll and Cott (2013) present insights gleaned from qualitative research with adults with cerebral palsy, who report on the problems of a ‘rehabilitation’ that is conceived of wholly as ‘normalisation’. Such an ethos, which is based around a focus on mimicking ‘normal’ bodies, does not offer people with cerebral palsy what they may need to be able to manage their bodies as they age (Moll & Cott, 2013). This article is unusual within these three journals in terms of its questioning of received ideas about rehabilitation.

As the overview in the previous paragraph suggests, a small number of the qualitative studies published in *Disability and Rehabilitation* are extremely relevant to my project, because they explore participants’ lived experience of rehabilitation. I shall briefly mention four of these studies, which focus on spinal cord injury, chosen partly because they are typical of the qualitative studies published in this journal, but mainly because they offer findings that are relevant to a discussion of the features of rights-based rehabilitation. I present a full qualitative synthesis at the end of the chapter on the disability studies literature. To begin with, it is worth noting that such studies could easily have been published within the *Scandinavian Journal of Disability Research*, which is one of the journals reviewed with the disability studies literature. That there is an overlap in terms of the output of the two journals underscores the problem of a strict delineation of one as ‘disability studies’ and the other as ‘rehabilitation science’.

1. An interview study of the lived experience of spinal cord injury rehabilitation (Bourke et al., 2015) drew on Bury’s (1982) influential concept of biographical disruption in its analysis, highlighting three key thematic areas which emerged as important in participants’ attempts to restore ‘biographical continuity’: ‘*[t]he importance of information*, *regaining control* and *restoring a sense of personal narrative*’ (Bourke et al., 2015, abstract). The article concludes by noting that ‘participants in the present study experienced a significant disruption to their biographical narratives following a SCI’ and argues for the importance of paying attention to ‘psychosocial adjustment’ (p. 301).

2. The concept of biographical disruption is also a central theme in Papadimitriou and Stone's (2011) study of temporality in the experience of traumatic SCI. The study involved interviews and ethnographic observations undertaken in an inpatient rehabilitation facility as well as interviews with community-dwelling adults. The analysis focuses on participants' relationship with the idea of the future and the past, arguing that they felt disconnected from both: unable to imagine how the future will be, and lacking a past in which they have been disabled. They characterise participants' relationships to their pasts as follows: 'that reservoir of possibilities that until recently informed their understanding of themselves and where they were going, is dramatically disconnected from their present situation and may even seem to mock them in their attempts to envision a future' (Papadimitriou & Stone, 2011, p. 2127).
3. In another small-scale qualitative study involving 12 participants, Jannings and Pryor (2012) focused on the experiences of patients with spinal cord injury who are able to walk, noting that this ability sometimes led to their needs being overlooked, and to them being perceived as '"normal"' (p. 1825). The authors highlighted the relevance of peer support programmes to this patient group.
4. Chun and Lee (2013) focused on feelings of gratitude in their paper which represented part of a larger study on the lived experience of SCI. They note that, in line with other research in this field, serious accidents and illnesses were experienced as 'unexpected turning points for the participants' (p. 16), also highlighting that '[p]eople's effort to see their world positively in the midst of trauma should not be understood as a distortion of reality, but a revision of what is possible and normal' (p. 16). This contextualisation of the meaning of gratitude – as a feeling that happens in response to unanticipated life events – is relevant to researchers undertaking interviews with people who have been through rehabilitation, as it deepens our understanding of how lives are understood and valued in the aftermath of a sudden alteration to embodied experience.

2.4.3 Patients' voices

In the reviewed articles, the rehabilitation science literature lacked evidence of patient and public involvement. The all-text word searches around key terms relating to PPI (discussed in the 'Detailed Method' section) brought only one article to my attention, which was Norrbrink and Löfgren's (2016) study of the 'needs and requests' of both patients and physicians in relation to the management of pain in spinal cord injury (p. 151). Even here, it did not appear that a formalised PPI process had been used, but simply that the researchers were using an 'emergent design' (p. 152) – an inductive approach to analysis – and that 'patient involvement' in the process of pain management had come out as a key theme (p. 154).

In the process of hand searching and classifying studies according to design, I became aware that certain papers did indicate ways in which research participants were involved in determining aspects of the study design, such as data analysis, interview piloting or member checking of transcripts (Papadimitriou & Stone, 2011; Byrnes et al., 2012; Van de Velde et al., 2012; Kim & Shin, 2012; Chun & Lee, 2013; Guilcher et al., 2012; Huang et al., 2013; Moll & Cott, 2013; Shikako Thomas et al., 2013; Smith et al., 2013; Bourke et al., 2014; Dew et al., 2014; Goodridge et al., 2015; Norrbrink & Löfgren, 2016). In the context of paediatric rehabilitation, superficial parental participation in the research was occasionally reported (Dickinson & Colver, 2011; Fatudimu et al., 2013; Riyahi et al., 2013; Badia et al., 2014; Chiarello et al., 2014; Almasri & Saleh, 2015; Mei et al., 2015). In the papers I searched, there appeared to be some relationship between qualitative research and involvement of stakeholders in the research process, yet involvement usually seemed to take place on a small-scale, and in ways that appeared relatively *ad hoc*. For example, Bourke et al. (2014) note that, in terms of preparing the interview schedule, 'a colleague who lives with tetraplegia was asked to comment' (p. 297). Whilst it should be noted that this step was reportedly taken in addition to a decision to draw on the first author's personal experience of the impairment in question, the consultation does not appear to be the result of a formal patient involvement process. Yet this paper is not atypical of those which do deploy forms of public involvement. In another example, Papadimitriou and Stone (2011) refer to asking two participants to check the themes that researchers were finding in the data (p. 2123). They state that the goal of this process was to ensure that the researchers' interpretations were kept 'close to the participants' intended meaning' (p. 2123), but they do not describe how participants were briefed to undertake this checking process or whether there was a procedure in place for registering agreement or disagreement. The fact that the authors refer to this process in the passive voice and place the named theme at the start of the sentence suggests that it might have been difficult for a participant to disagree with the focus on temporality, because of the way this is framed as something that has been decided upon in advance: 'Temporality themes that emerged from interviews were member-checked by two participants…' (p. 2123). It is also unclear whether there were any procedures in place to manage or reflect on the impact of differences in status and power between research participants and researchers. Given that this is not a methodological paper, I do not consider these points as conclusively evidencing shortcomings, as it is possible that such questions have been addressed by the authors elsewhere. However the framing of these issues here suggests that the tensions that often emerge in patient and public involvement are not being foregrounded by these authors.

Whilst I may have overlooked individual examples of planned public involvement, since I was looking at a large number of articles and focusing on word searches and abstract searches, my review suggests that patient and public involvement is rarely foregrounded in these articles; it is not characterised as a formalised or expected part of the research process.

2.5 Does a notion of 'rights-based rehabilitation' exist in this literature?

Just two papers of those examined here, both of which were published in *Disability and Rehabilitation*, referred to rights in their abstracts. In one of these, a reference to advocating for the rights of disabled people was mentioned in passing: this was in a qualitative paper exploring the challenges of living with spinal cord injury in Botswana (Löfvenmark et al., 2016). The other paper explicitly used a rights-based approach (Colver et al., 2011); it explored whether disabled children in Europe were able to access the environments they needed, and drew on the framework of the *UN Convention of the rights of persons with disabilities* in constructing the study, which was conducted using a questionnaire. Yet whilst this study focused on rights, it did not look specifically at rehabilitation, but rather at disabled children's access to 'the physical environment, transportation, information and communications' (Colver et al., 2011, p. 28). A word search on 'rights' across the output of *Disability and Rehabilitation* as a whole did produce some more general articles on this issue, but the lack of articles referencing rights within the three journals for my date parameters suggests that the issue of disabled people's rights in relation to rehabilitation is barely present in the rehabilitation sciences literature.

2.6 Strengths and limitations of this review; future research

The review cannot claim to be comprehensive in its treatment of these themes in the rehabilitation sciences literature because it focused on only three journals, and within these it focused on the representation of two types of impairment: cerebral palsy and spinal cord injury. However, the selection process that set up the scope and focus for this review nevertheless sought to reflect the range of types of journals in the field of rehabilitation science, and I judged my inclusion criteria to be appropriate for my aims, since I did not intend to ask a specific question of the field and to find a specific answer, but rather to gain an understanding of its dominant orientation and preoccupations, as well as to understand whether a notion of rights-based rehabilitation could be said to exist in this literature. My systematic approach in this review has enabled me to generate evidence about the three themes that were my focus, and to use this to make some observations about the field's orientation towards disability and rehabilitation. In being clear about my scope and aims, I provide context to allow the reader to judge the picture I present of the rehabilitation sciences literature.

A future literature review would need to focus on all the qualitative studies, producing a detailed taxonomy of their approaches and findings. This would provide a more detailed picture of which aspects of the lived experience of rehabilitation receive most attention, and which receive the least. In the next chapter, I offer a synthesis of qualitative evidence about the lived experience of rehabilitation across this literature and the disability studies literature, but due to time constraints, this work focuses on key themes identified via titles and abstracts.

2.7 Summary and conclusions

This review has offered a time-bound snapshot of three themes in three rehabilitation science journals: *Clinical Rehabilitation*, the *International Journal of Therapy and Rehabilitation* and *Disability and Rehabilitation*. The literature I reviewed frequently used a functional model of disability, but this was not consistently the case for papers in *Disability and Rehabilitation*, where a multifactorial model was often deployed, especially, but not only, in qualitative studies. This journal also allowed a much more expansive definition of rehabilitation, including work on access and on vocational rehabilitation, whereas articles published in the other two journals tended to use a more strictly health-based or function-based definition. The characterisation of the research participants also varied, and appeared to depend on the type of research and the aims of the research, but, in general, research participants were described as homogenous groups and were seen as relatively passive within research processes. This suggests that, although there was a small number of studies which explored participants' views of rehabilitation, overall there continues to be a lack of evidence in this field focusing on disabled people's perspectives on the process. Moreover, there was a dearth of evidence of formal patient and public involvement in these studies, even in the qualitative studies in which research participants were characterised as more actively involved in shaping research agendas. From this evidence, it would appear that formalised patient and public involvement activity is not yet normalised in the field of rehabilitation science, and this is likely to mean that most research is being conceived and designed by people who do not have lived experience of the condition, service, or intervention that is being studied. As such, the focus of the research that is mostly being undertaken might not necessarily be what the patient groups in question would consider to be most helpful in improving their lives. The findings of this review therefore demonstrate the potential for the *Rights-based Rehabilitation* study to advance this field, both by generating new knowledge of disabled people's lived experiences of rehabilitation, and by considering what the role of PPI might be in the rehabilitation sciences. This review indicates that it will be useful to investigate how PPI is being implemented elsewhere in health research, so as to develop a suitable and sustainable involvement strategy for this project that helps to ensure the relevance of the research to disabled people. In revealing how differing definitions of 'disability' and 'rehabilitation' have a bearing on a given research project's characterisation of participants and on researchers' perceptions of the role and status of the participant, this review also suggests that, in order to place disabled people's views at its centre, the project should adopt an approach that facilitates exploration of how disabled people themselves define and utilise terms such as 'disability' and 'rehabilitation'.

Chapter Three
Disability studies literature: A review

3.1 Aims, scope and approach

My aim in reviewing the disability studies literature was primarily to understand how rehabilitation has been characterised within this literature. I also wanted to find out what, if any, empirical research has been undertaken exploring disabled people's views and experiences of the process. These objectives would help me to establish how the knowledge produced through the *Rights-based Rehabilitation* study might intersect with, and develop, an existing body of thought in disability studies.

The review presented here is in two parts. The first part is a narrative review, discussing the characterisation of rehabilitation by prominent thinkers in disability studies, describing how differing conceptualisations of disability have contributed to a range of perspectives on this subject. To research this review, I began by drawing on my existing knowledge of the shape of the field of disability studies, including its key thinkers and sub-disciplines. My understanding of the contours of disability studies has developed over a number of years of work as an academic in the field, and has been shaped by reading the work of key thinkers including, among others, Colin Barnes, Lennard Davis, Rosemarie Garland-Thomson, Dan Goodley, Alison Kafer, Robert McRuer, Anna Mollow, Mike Oliver, Jasbir Puar, Katherine Runswick-Cole, Tom Shakespeare, Carol Thomas, Tanya Titchkosky, Shelley Tremain Simo Vehmas and Nick Watson. These thinkers have all played important roles in moving the field of disability studies forward, by posing critical questions, or taking the discipline in a new direction. Rehabilitation has not been a subject of study for many of these authors; it has tended to be overlooked by disability researchers (Shakespeare, 2014). I refined my knowledge of how rehabilitation is treated in disability studies by returning to key texts to explore the representation, or absence of representations, of rehabilitation, and by reading more widely in the field. One of my supervisors (Tom Shakespeare) has been writing and researching on disability since the

1990s: he introduced me to authors in the field who were new to me when I began work on this project, and whose work I also drew on in producing the narrative review.

The second part of this review is a scoping review, which followed similar principles to those set out in Chapter Two on the rehabilitation science literature, and drew on the scoping review method used by Arksey and O'Malley (2005). Drawing on my own knowledge of disability studies from my previous doctoral work in the field, and on conversations with my supervisory team, I selected four major, international, peer-reviewed journals that, between them, feature a wide range of sociological and humanities research on disability, and are publications with global reach. Together, the journals publish most new sociological research on disability emerging in the global north (and beyond), and are also the best-known journals in the field.[2] The selected journals were:

1) *Disability and Society*
2) *ALTER: European Journal of Disability Research*
3) *Disability Studies Quarterly*
4) *The Scandinavian Journal of Disability Research.*

As these journals do not all use impact metrics, it is difficult to know exactly how they compare with other journals. I undertook a hand search of all journal issues published between January 2011 and December 2018. I scrutinised paper titles to create a longlist of articles which addressed rehabilitation as a theme; in cases where I was unsure of the relevance of the paper, I also read abstracts. Articles on the longlist were scan-read and only articles in which rehabilitation was more than a passing theme were included in the final shortlist. Articles were excluded if, for example, rehabilitation arose tangentially in relation to a research question around access to healthcare more generally, or if assistive technologies were under consideration in

---

[2] *Disability and Society* was, in 2018-2019, subject to scrutiny with regard to position it takes on trans issues, as the journal's editor-in-chief is a high-profile campaigner for organisations which promote scepticism around trans identity. Many members of the editorial board resigned in protest in 2019 with concerns about this editor's stance and her influence over the content of the journal. I too signed a petition committing not to publish in *Disability and Society* until this issue has been satisfactorily addressed. This issue came to light a long time after the journal was selected for review.

relation to (for example) environmental barriers to participation, rather than rehabilitation. However, distinctions between what counts as barrier removal and what counts as rehabilitation are not always clear cut, and decisions about inclusion were not necessarily straightforward. For example, it was not clear-cut whether assistive technologies such as wheelchairs contribute to the processes of rehabilitation, whether they should be regarded as facilitating barrier removal, or whether they do both in practice. In making decisions, I followed the definition of rehabilitation in the *World report on disability* (WHO, 2011, p. 96), which places emphasis on individuals achieving 'optimal functioning in interaction with their environments', and on the inclusion of assistive technologies as a category of rehabilitation. Therefore, I usually included papers which discussed assistive technologies, but where necessary I highlighted the fact that the authors themselves distanced their work from the paradigm of rehabilitation, or that the focus of the paper was on barrier removal (at the societal level) rather than rehabilitation (at the individual level).

Given that I went on maternity leave during my PhD studies, and thus elongated the period of study, the literature review was updated during the course of my research, with the hand search from January 2016 - December 2018 taking place at a later date than the search for January 2011 - December 2015. This circumstance has had some impact on the analysis process, because for the later papers, I was more established as a researcher in this field, and more easily able to taxonomise and evaluate the relevance of each paper. Where necessary, I have drawn attention to the impact of my level of experience as a researcher upon the synthesis of the information I present here. Due to time constraints, it was not possible to repeat the hand search for the earlier part of the archive: hand-searching is a thorough, but time-consuming, practice.

3.2 Narrative review of currents of thought on rehabilitation in disability studies

Within disability studies, rehabilitation has long been a controversial theme, with certain early members of the UK disabled people's movement expressing hostility towards it, seeing it as unwanted intrusion in the lives of disabled people (for example, Oliver, 1990, 1993; Abberley, 1995; Davis, 1995; Finkelstein, 2004). Rehabilitation tends to be associated with the medical model of disability by these authors. Their sceptical attitude may have exercised a powerful influence over the trajectory of disability research, as Shakespeare (2014) suggests, in that a version of the social model of disability (understood by this group as *the* emancipatory paradigm to be used by disabled researchers) became connected with a characterisation of rehabilitation as a framework for perpetuating a notion of disability as a personal tragedy, as a state in need of a cure (see especially Oliver, 1993). Indeed, Shakespeare (2014) refers to the lack of research into disabled people's experiences of rehabilitation, of which he started to become aware following his own experience of the process in 2008. I will briefly discuss the key issues raised by rehabilitation-sceptics such as Oliver, before exploring some of the other currents of thought in disability studies on rehabilitation.

In his 1993 inaugural professorial lecture, entitled 'What's so wonderful about walking?' Mike Oliver, one of the founder figures of the disability movement in the UK, spoke of rehabilitation as 'the exercise of power by one group over another' and highlighted the concern with 'normality' within rehabilitation practices (p. 14, p. 15). Oliver (1993) characterised rehabilitation as a coercive practice, referring to patients as rehabilitation's 'victims' (p. 14). Another early member of the disabled people's movement, Paul Abberley, interviewed occupational therapists (OTs) in 1995, concluding that the social model of disability was largely being incorporated into their work at a rhetorical level. In his indictment of OT practice, he argued that a commitment to holism in OT practice functioned as an excuse for failure on the part of the professional because it tends to render the patient responsible: '[h]olism seems […] to be employed […] as a protective device to account for failure' (p. 230). Abberley distinguishes this form of holism from that of 'structural social science' which explores the interplay of structure and agency, arguing that holism in occupational therapy 'corresponds to a humanistic notion of unique and valued persons' (p. 228). This paper explores what is at stake in the attempt to institutionalise the social model of disability within the allied health professions.

It highlights the difficulties associated with a particular strain of thought which emerged in the accounts of the occupational therapists interviewed, and which has a tendency to downplay structural constraints and inequalities.

The work of thinkers such as Abberley and Oliver from the 1990s captures something of the struggle to preserve the radical values of the disability movement, and to prevent these from being co-opted and neutralised by discourses of professionalism. Nevertheless, it is possible to critique this work for engaging only minimally with the views of disabled people themselves: Abberley's (1995) paper reports on interviews with allied health professionals rather than patients, and Oliver's (1993) inaugural lecture analyses poetry and lyrics, but not patient testimony, and by its own admission, represents the views of its author.[3] Shakespeare (2014) argues that disability studies needs to be grounded in empirical evidence of disabled people's lived experience if it wants to influence social policy, and is critical of the emergent field of critical disability studies for a perceived failure to attend to the most pressing question in disability studies: how do we change the social conditions of disabled people's lives for the better? Vehmas and Watson (2014), whose work is discussed in more detail shortly, are also concerned about this issue.

Whilst Oliver describes his work as sociology, it bears many of the hallmarks of the hybrid discipline of cultural studies in its interest in ideology and cultural forms. As such, it is canonical lectures such as this that have pioneered the development of a field of critical disability studies which frequently deploys cultural analysis rather than empirical social research methods in its quest to deconstruct 'the normal' (see for example Kafer, 2013; McRuer, 2006; Davis, 1995). Critical disability studies has developed out of cross-disciplinary engagement with other fields focused on the study of identity: feminism, queer theory, critical race theory (Goodley, 2011), as well as drawing on the work of canonical critical theorists such as Judith Butler, Jacques Derrida, Michel Foucault and others. The field is diverse and it is therefore difficult to make

---

[3] In its discussion of cultural texts, this lecture could be more readily understood as an early example of 'cultural disability studies' (a humanities discipline), than as sociology.

generalisations about its scope, except to say that most of its proponents advocate a shift in focus for disability studies, away from disabled bodies/minds and towards the constitution of ‘the normal’ (Davis, 1995).

Thinkers aligned with the tradition of critical disability studies who have written about rehabilitation include Puar (2017), Mollow (2012) and McRuer (2006). These theorists are interested in what McRuer (2006, p. 112) refers to as the ‘cultural grammar of rehabilitation’, that is, the ways in which the notion of rehabilitation takes on a particular set of meanings in a given sociocultural context. In his influential book *Crip Theory* (2006), McRuer draws on the work of disability theorist and historian Henri-Jacques Stiker, whose reading of rehabilitation in a Euro-American context examines its affective charge in the aftermath of World War One, which left many men physically disabled (McRuer, 2006, citing Stiker, 1999 [1997]). Rehabilitation came to be associated with a return to identity, bodily integrity and wholeness (McRuer, 2006, citing Stiker, 1999 [1997]), yet McRuer suggests that the fantasy of being re-integrated is always accompanied by the risk of slippage into rehabilitation’s opposite: degradation.

Meanwhile, Mollow’s (2012) contribution to our understanding of rehabilitation’s ‘cultural grammar’ is to revisit queer theorist Lee Edelman’s (2004) term ‘reproductive futurism’ with disability studies in mind. Edelman’s coinage connects a cultural investment in the idea of the future with an attachment to a particular fantasy of the family and the child, which he associates with heteronormativity. However, Mollow notes that the disabled child cannot represent ‘the future’ in an uncomplicated way, because the disabled child functions semiotically as a reminder of mortality and human fragility. Mollow (2012) argues that the cultural value placed on rehabilitation in childhood is bound up with a desire to erase this reminder, curing the disabled child and re-incorporating him or her into mainstream, future-oriented culture.

More recently within the critical disability studies tradition, Puar (2017) has argued that the term ‘debility’ is more helpful than ‘disability’ because the former term allows us to think in terms of the intersecting forms of risk that are borne by bodies in accordance not only with embodied disadvantage but also with economic, racial and geopolitical disadvantage. For Puar, the term disability may cultivate a mode of thought that individualises impairment, seeing it as the property of an individual body. These connotations of the term disability, and the way it is often used in disability studies for referring to particular individuals, maintain a framework for imagining disability as that which is exceptional, uncommon, and special (Puar, 2015, 2017). This mode of thought, which Puar (2017) associates with North American disability studies in particular, risks obscuring forms of 'disability' that may not easily be visible as such, for example forms of debilitation which affect large groups or whole populations (Puar discusses Palestine in this regard). Within this context, Puar argues that bodies that can be recognised as 'disabled' are ones that have already been 'retrieved' for rights (e.g. for rehabilitation), but that this recognition is often predicated on the non-recognition of other bodies, which do not easily fit into the 'disabled' category and so do not appear as such, even though they may be subject to much greater degradation and disadvantage. Puar (2017) is also critical of a privatised rehabilitation industry which profits directly from, and coexists symbiotically with, the industries of war and the arms trade, again drawing on the example of Palestine. What we see in Puar's work is not hostility towards *rehabilitation* in any straightforward sense, but rather an attempt to undo an entire rhetorical structure – the language of disability studies – which is shown to reinforce unequal access to disability rights via its particular linguistic investments, even as it purports to do the opposite.

What aligns these approaches from critical disability studies, in spite of their different takes on rehabilitation, is their focus on what we might describe as 'cultural grammar', using McRuer's (2006) term. They focus on culture as a framework which inflects our understanding of rehabilitation, both restricting and enabling our understanding of it, and providing rich layers of context for us as we examine the term 'rehabilitation' and try to get to grips with it. This is the strength of such an approach; yet a possible weakness of this approach, as diagnosed by Vehmas and Watson (2014), is that it does not gives us a clear ethical code, nor a practical understanding of how we should act in relation to particular dilemmas that disability may throw up. They give the example of a pregnant woman who finds that a pre-natal test shows that her unborn child will have a severe long-term condition and is likely to die before the age of four. Vehmas and Watson (2014) argue that in this instance, if critical disability studies simply highlights ableism in relation to how the impairment in question is socially constructed, it will not be taking into account numerous other factors that could and should influence this woman as she reflects on the results of the test. They contend that, like the social model of disability, critical disability studies is quick to critique social arrangements but does not help us with the ‘lived, embodied and visceral experiences of having an impairment’ (p. 641), which may involve wanting to avoid unnecessary pain, and maximise function, by engaging with medicine and indeed with rehabilitation services. In this sense, critical disability studies can also be said to have a ‘strong normative dimension’ (Vehmas & Watson, 2014, p. 641), even though it rejects normativity in relation to embodiment. Its version of normativity tells us what is ‘good’ and ‘bad’ about social arrangements vis-à-vis disability (Vehmas & Watson, 2014). The logical conclusion of the rejection of normativity is that it becomes unacceptable to discuss impairment as undesirable (Vehmas & Watson, 2016; Vehmas & Watson, 2014; Shakespeare & Watson, 2010), yet as Shakespeare and Watson (2010) argue, it is possible to allow that there are undesirable aspects of impairment without devaluing disabled people’s identities.

There is more common ground between advocates and critics of critical disability studies than this overview might suggest: for example, Kafer (2013) aligns herself with critical disability studies, but calls for an understanding that many disabled people want and need access to good medical care; she does not want to reject medical models entirely. There are also thinkers such as myself, who do not feel entirely comfortable with the idea of belonging to any ‘camp’ and have sympathies with, and criticisms of, each. It is easy to caricature each camp in ways which fail to recognise the diversity and nuance of thought in each, and more important, I think, to attempt to place a particular concept in its cultural context when discussing its merits and limitations. For example, when arguing for the need to move beyond the social model of disability, Shakespeare and Watson (2001) emphasised its importance as a *stage* in the process of disabled people's emancipation and suggested that it was partly its success as a political concept that had caused problems for it. Its embeddedness within the operational practices of organisations made it difficult to speak of the model's failure to bring disabled people's medical needs and rights into view. Shakespeare and Watson acknowledged that their 2001 paper represented a shift of position, away from their former (1997) defence of the social model of disability.

Critical disability studies has had an important role to play in the development of a new 'critical' field of thought on rehabilitation, spearheaded by Barbara Gibson, who uses the term 'critical' in this context in the philosophical sense of 'questioning the taken-for-granted' (Gibson, 2018, p. 2). Gibson, who trained as a physiotherapist and is now an academic, draws on critical theory to ask questions about the purpose of rehabilitation, about whom it is supposed to be 'for', and about who defines quality of life (Cooper, 2017; Gibson, 2015). With the rise of crossover publications linking rehabilitation science and (critical) disability studies (Hammell, 2006; Bevan 2014; Gibson, 2015), it appears that the two fields may be becoming more receptive to each other. Gibson's (2015) *Rehabilitation: A Post-Critical Approach* effectively inaugurates a new field of critical rehabilitation studies. In the UK, such work is being taken forward by members of the Critical Physiotherapy Network. Whilst the ideas and the ethos of critical disability studies have influenced some rehabilitation professionals, this cross-fertilisation remains a niche interest, and it would be difficult to deny that in order to influence an evidence-based curriculum within the allied health professions, empirical data about disabled people's lived experiences is likely to be more effective than a critique of ideology.

This brief narrative review of the treatment of 'rehabilitation' across disability studies reveals a good deal of hostility among certain disability studies activists and academics towards it and its perceived norms. While the emergence of a Critical Physiotherapy Network and other developments suggests this situation is now changing, this history may account for the relative lack of empirical research which explores disabled people's views and experiences of rehabilitation (Shakespeare, 2014). I now turn to the results of the scoping review of the subject in four highly regarded disability studies journals, to see how rehabilitation is characterised there.

3.3 Scoping review: Findings and discussion

	Number of articles searched (2011-2018)	Number of articles shortlisted	Shortlisted articles as a percentage of those searched
Disability and Society	720	18	2.5%
ALTER	173	8	4.6%
Scandinavian Journal of Disability Research	229	27	12%
Disability Studies Quarterly	418	7	1.6%
Total	**1540**	**60**	**3.9%**

Table 1: Articles searched and shortlisted from the disability studies literature

As Table 1 reveals, fewer than 4% of the total papers searched focused on rehabilitation. It seems reasonable to assume that a good proportion of disabled people engage with rehabilitation at some point in their lives, which makes this percentage seem small. I will briefly review the salient points emerging from the sample of papers selected from each journal. The question of categorisation, and the issue of whether or not a sub-topic 'counted' as rehabilitation, or should instead be described as something else, was always in play in the review process.

3.3.1 Scandinavian Journal of Disability Research

The *Scandinavian Journal of Disability Research* (*SJDR*) carries a higher proportion of research into rehabilitation than the other journals reviewed in this part of the literature survey. Of the journals searched, *SJDR* carried the highest percentage of articles in which clinical rehabilitation was a major theme. This is perhaps unsurprising when we consider that, as the journal of the Nordic Network on Disability Research (NNDR), *SJDR* appears to place emphasis on work analysing and comparing welfare state systems, including health services. If we compare this journal's self-presentation with that of *Disability and Society*, the latter immediately draws attention to a focus on discrimination, human rights oppression and changing conceptualisations of disability on its website, whereas the language used by *SJDR* is more neutral, referring to disabled people's experiences in different environments and different societal contexts (see journals' websites, 2020). In its statement on 'Focus and Scope', *SJDR* notes that 'empirical work is very welcome', with the proviso that such work engages with the conceptual debates and/or the implications of research findings. On its website, NNDR (2020) refers to *SJDR* as a 'scientific journal': it seems unlikely that the other three journals discussed here would be described in that way.

Whereas for the other three journals, quantitative or experimental data relating to rehabilitation was almost entirely absent among the shortlisted papers, *SJDR* carried 7 papers which used quantitative approaches (Lerdal et al., 2012; Solheima et al., 2012; Törnbom et al., 2013; Järvikoski et al., 2015; Tingvoll & McClusky, 2015; Bøttcher et al., 2016; Damgård et al., 2016). In terms of the variety of study designs presented, *SJDR* resembles the journal *Disability and Rehabilitation*, which I have categorised as belonging to the rehabilitation science literature, and which was discussed in the previous chapter. This similarity suggests that whilst in some cases there are clear distinctions between the literature of rehabilitation science, and that of disability studies, in other cases there are blurred boundaries and overlaps.

There were too many shortlisted articles (27) to focus in detail on the sub-topic of each in this review, though prominent themes included:

a) the use of assistive technology in rehabilitation
b) home adaptation

c) evaluating the (Scandinavian) concept of the Individual Plan (for service delivery).

A noteworthy aspect of this journal's approach to research, and of the themes presented in the shortlisted articles, was the shared emphasis they gave to patient involvement in research and service development. A majority of shortlisted papers drew attention to the expertise of service users, but even so, several of the studies were interested in service users' perspectives only in terms of feedback on pre-given bureaucratic arrangements, or they defined service users as having 'needs' which had to be met. Other studies did reveal a genuine interest in seeking to understand rehabilitation experiences from the point of view of the service user, for example the research of Arntzen et al. (2015) with stroke survivors, Brodersen and Lindegaard's (2014) work with the users of assistive technologies and Hoogsteyns and van der Horst's (2013) case study of arm prosthesis users. One study had a sophisticated conceptualisation of expertise in rehabilitation as a relational formation with various implications in terms of power (Slettebø et al., 2012). The study examined three forms of power in the development of individual healthcare plans: power of knowledge, power of language and power of definition (the latter being the ability to define the Individual Plan, by combining both forms of power). The article concluded by emphasising the importance of empowering and supporting clients to be heard in these processes of definition. Meanwhile, Bekken's (2014a) article foregrounded the difficulties for researchers in accessing children's voices and their expertise about rehabilitation. This observational paper did not seek to speak for the child studied but rather to highlight that the child's use of toys in the rehabilitative setting was significant and meaningful. Parental expertise was the subject of two papers (Ylvén & Granlund, 2015; Ekland Nilsen & Jensen, 2012). In the hand search of papers published between January 2016 and December 2018, I collected several articles presenting research on service user involvement (including those piloting or analysing innovative approaches), which I ultimately excluded from this scoping review as they were insufficiently focused on rehabilitation. Yet these papers informed my thinking for the narrative review on public and patient involvement in research, presented in the next chapter.

Most of the shortlisted papers from the *Scandinavian Journal of Disability Research* tended to start from the premise that rehabilitation is a given if one is disabled, rather than interrogating rehabilitation as the natural response to disability, as was more commonly seen in the other disability studies journals. When rehabilitation is a theme in an article in this journal, it is generally treated as necessary, rather than being the subject of critique. Yet there is a caveat to this generalisation, because a solid minority of papers did offer critical positions on rehabilitation. Furthermore, of the seven shortlisted papers published between January 2016 and December 2018, three of these used ethnographic approaches (Bezmez & Yardımcı, 2016; Breimo, 2016; Glintborg, 2016) and one undertook a critical discourse analysis of two recent Norwegian White Papers relating to rehabilitation (Røberg et al., 2017a). All of these latter four papers offered analyses which highlighted tensions and contradictions in contemporary rehabilitation discourse, with a particular focus on how concepts of personalisation and person-centredness have (or in some cases have not) been incorporated into practice and negotiated in healthcare relationships. Although the following observation has no statistical significance, it came to my attention that these papers appear to demonstrate (within this sample) a slight overall shift of position, when compared with the shortlisted papers published between January 2011 and December 2015. The later papers more often held stances which were critical of how the notion of 'person-centredness' is being mobilised in rehabilitation practice, towards ends which do not necessarily serve patients. For example, discussing the social and economic context in which the 'individual plan' has been implemented (a personalisation technique used in Norwegian rehabilitation services), Breimo (2016, p. 73) notes that: 'each user must form their lives in a tension between the requirement that they make their own choices and strong normative pressures about what this life should look like'. In this analysis, the patient is apparently free to choose but is in fact constrained by factors such as the need to return to work (Breimo, 2016). This author is critical of the '*contractualization* of service production', which appears to promote ‘empowerment’ of the patient while masking the real inequality of power which exists between the patient and the institution (Breimo, 2016, p. 72, citing Andersen, 2003).[4] This might be understood as part of a ‘critical’ turn in the literature on user involvement, which has been gathering momentum in recent years following a period of optimism about its effects in the 2000s (Barnes & Cotterell, 2012a, b). This trend will be discussed at greater length in the narrative review of patient and public involvement in Chapter Four.

3.3.2 ALTER: European Journal of Disability Research

ALTER is a smaller journal than either *SJDR* or *Disability and Society*, and in my experience it is less well-known among the UK disability studies community. Just eight articles were shortlisted, which equates to just over one article on rehabilitation per year. Most of the shortlisted papers focused on qualitative or ethnographic research, with the main exception being a large-scale mixed methods study discussed in several papers as part of a special issue of *ALTER* (Desjardins et al., 2014; Grasso et al., 2014; Kehayia et al., 2014). The large-scale project discussed in the *ALTER* special issue was called ‘A Rehabilitation Living Lab’, yet, in spite of its name, it focused on making a shopping mall fully accessible and was thus arguably as much about environmental barriers faced by disabled people as it was about rehabilitation understood in the terms of the definition used by the WHO (2011). Both the dual focus here, and the incidental nature of the theme of rehabilitation across the articles shortlisted from *ALTER*, illustrates an approach to rehabilitation which sees it within a wider context, as just one aspect of the experience of disability. There is a sense across these articles that rehabilitation is not an ‘intervention’ for particular ‘impairments’ which will then ‘resolve’ these, but rather that it is one way of working with disabled people among many to improve the quality of their lives. The focus on breaking down disabling barriers in the Rehabilitation ‘Living Lab’ project, for example (Desjardins et

---

[4] The paper by Andersen is not included in my reference list, due to the fact that it is in Danish and I have therefore not been able to read it. Breimo cites the reference as: Andersen, Niels Åkerstrøm. 2003. *Borgerens kontraktliggørelse* [The Contractualisation of Citizens]. København: Hans Reitzel.

al., 2014; Grasso et al., 2014; Kehayia et al., 2014), suggests a conceptualisation of disability as an experience that is at once bodily and social. The design of this research poses conceptual questions about the relationship between barrier removal and rehabilitation measures: when is a technology ‘rehabilitative’ of a person and when does it ‘habilitate’ an environment, making it fit for use? The project deliberately frames these concepts as intertwined: the decision to situate the ‘lab’ in a mall reflects a project ethos which recognises that: 1) public spaces are often inaccessible, 2) disabled people need assistive devices to support their rehabilitation and to enable them to access to public space, and 3) non-disabled members of the public, or from the business community, may not be aware of access issues, and the Rehabilitation Living Lab promotes awareness (Kehayia et al., 2014).

Another conceptual, definitional question is suggested by a reading of Keyes et al. (2015): what is the difference between rehabilitation and care? The paper examines the helpfulness of an ‘ethics of care’ model of intersubjectivity for thinking about disabled people’s assistive relationships and care experiences. As the authors explain, the ‘ethics of care’ philosophy favours a model of human interdependence over one of autonomous individuals; within disability studies there has historically been a preference for conceptualising caring relationships within a paradigm of independent living, such that personal assistance, for example, must be seen in transactional terms (pp. 238-9). The term ‘care’ has inherited negative connotations in disability activism (see also Watson et al., 2004; Shakespeare, 2000). This seam of thought has already provoked a good deal of thought within disability studies: for example, Shakespeare (2000) draws on the feminist ethics of care literature to emphasise the need for a concept of interdependence when theorising help in relation to disability, and Watson et al. (2004, abstract) have sought to create a ‘discourse bridge’ between perspectives on care from feminism and disability studies, by drawing on the idea of interdependence. Keyes et al. (2015) argue that the resistance to thinking in terms of ‘care’ in disability studies is highly justifiable, arising as it does out of a history in which disabled people have come to be seen as carers’ burdens, and as powerless, and without the capacity to speak for themselves (p. 239). Drawing on the catchphrase ‘empowerment through care’, Keyes et al. (2015, abstract) contend that an ethics of care approach to health and social care can be empowering, because it involves overhauling the concept of personhood used in the social model of disability, which views people as independent individuals. The ethics of care approach demands attention to interdependence and relational autonomy, proposing that the idea of the independent individual is a myth. Although this article does not discuss rehabilitation specifically, it does explore the question of whether and how service users are empowered in their encounters with social care assessment processes, and highlights the relevance of models of personhood to these debates. As such it makes an important contribution to my own thinking about how ‘rights-based rehabilitation’ could or should be conceptualised. But it thereby also poses further questions for this literature review around what to include and what to exclude; arguably this study has been discussed within my work on *ALTER* only because of a relative lack of work pertaining directly to rehabilitation within that journal. Similar work from the *Scandinavian Journal of Disability Research* is unlikely to have been included simply by virtue of the existence of work there that pertains more directly to clinical rehabilitation.

As with *SJDR*, the hand search of articles published between 2016 and 2018 produced more articles on debates around user involvement and person-centred approaches to rehabilitation, and the question of what it means to implement and embed such modes of working (Hanga et al., 2017; Røberg et al., 2017b; Löve et al., 2018). One of these was a case study of Estonian health services, exploring barriers and opportunities for introducing person-centred approaches (Hanga et al., 2017). Another paper explored the tensions around promoting disabled people’s autonomy in the reshaping of services in the Icelandic context (Löve et al., 2018). A third article featured interviews with rehabilitation professionals (Røberg et al., 2017b), undertaking a discourse analysis of the data which highlighted the tensions between discourses of patient-led care, discourses of goal-setting, and discourses of constraint. The limited data in this scoping review suggests that ‘involvement’ is starting to become a more prominent theme in these journals in the latter half of the 2010s.

3.3.3 Disability and Society

Disability and Society is published in the UK and, as would be expected, it carries a disproportionate number of articles focusing on the UK context. It is nevertheless an international journal, and in my hand search I noticed that the geographical focus tends to be more global in its outlook than either *ALTE*R or the *Scandinavian Journal of Disability Research*. The journal has ten issues per year, each carrying approximately ten research articles, so high number of articles were sifted and reduced to a shortlist of just 18. Thus, research on rehabilitation represents a tiny proportion of the output of this journal. Of the 18 articles shortlisted:

- Seven articles focused on assistive technology, of which four had a paediatric focus (Kwek & Choi, 2016; Darcy et al., 2016; Snell, 2015; McKeever et al., 2013; Jonasson, 2014; Campbell et al., 2012; Wästerfors, 2011);
- Three articles presented personal (or autoethnographic) stories of rehabilitation (Long, 2015; Inahara, 2013; Beauchamp-Pryor, 2011);
- Two articles examined paediatric rehabilitation (Bekken, 2014b; Gaskin et al., 2012), including a study of children's perspectives (Bekken, 2014b);
- One article explored families' experiences of adapting the home for disabled children (Morgan et al., 2016);
- One article considered parent's views on using personal health budgets for their disabled children (Hutton & King, 2018);
- One article discussed the role of disablist thinking in promoting unrealistic expectations around walking in a Turkish rehabilitation hospital (Bezmez, 2016);
- One article looked at the role of stroke clubs in promoting re-integration into the community post-stroke (Brookfield & Mead, 2016);
- One article reviewed the role and benefits of service user involvement in the delivery of medical and health education (Unwin et al., 2017);

- One article presented a small-scale study of the work-life of disabled occupational therapists, written by a disabled occupational therapist (Bevan, 2014).

It is noteworthy that almost half of the articles identified for closer inspection focus on the (re)habilitation of children. Perhaps this reflects an implicit valuing of a utilitarian model of the distribution of resources and rehabilitation technology, whereby young disabled people are seen to be the worthiest recipients of interventions, costly assistive devices, and of follow-up in social research. Or perhaps it is indicative of the uncertain status of children within discourses of disability rights: children may not always be seen as agents, or as bearers of rights, but may instead be seen as having ‘needs’ which can and should be met by health and social services (see Runswick-Cole et al., 2018; Curran & Runswick-Cole, 2013). Perhaps, from the vantage point of this journal, it is possible to position children as being somewhat outside the orbit of the social model of disability; this may now change with the emergence of ‘disabled children’s childhood studies’ as a distinct sub-field (Runswick-Cole et al., 2018; Curran & Runswick-Cole, 2013).

Another point of interest in the shortlisted literature is the role of lived experience in shaping healthcare practice, highlighted by Bevan (2014) and Unwin et al. (2017). As with the other disability studies journals, service user involvement in teaching, learning and research is a key theme in *Disability and Society*, and in the course of my hand search I noticed a number of articles on this topic which, whilst not directly relevant to a discussion of rehabilitation, do nevertheless highlight that the involvement of disabled people in shaping research agendas is a high priority for this journal.

Autoethnographic work emerges as a distinctive feature in *Disability and Society* but less so in *SJDR* or *ALTER*. One such article is a philosophical paper about speech language pathology, written by an academic with cerebral palsy (Inahara, 2013), who has difficulties making her speech intelligible to others. Inahara reflects on the intelligibility of speech as an intersubjective phenomenon, seeing it as the joint responsibility of the speaker and the interlocutor (see also Oliver, 1990). This reframing of pathology has implications for speech therapists: the author contends that they may need to consider the social context of speech more in their work with clients. Another paper in this set examines the relationship between choosing ‘cure’ and its effect on one’s identity as disabled or non-disabled (Beauchamp-Pryor, 2011). This is an autoethnographic paper about the experience of having surgery to correct a vision impairment, and its impact on the author’s sense of belonging within the disability community. The third paper in this category (Long, 2015) was an account of the author’s experience of ceasing to be able to obtain a drug she needs to treat her long-term debilitating condition. This paper describes how the changes to the funding and structuring of health and social care in England have had a significant negative impact on a disabled person’s ability to access the rehabilitative medicine they need in order to maintain a decent standard of living. The strength of feeling expressed in the paper suggested that issues of funding and resourcing of services might be an important context for the present project. Drawing on this autoethnographic case study, I built my topic guide for the focus groups to allow an opportunity to discuss experiences of access to support and resources (see Appendix 7); in the interview topic guide I also facilitated discussion about what participants felt could have been improved about rehabilitation (see Appendix 7).

3.3.4 Disability Studies Quarterly

In this journal, I identified seven articles which had a connection with the theme of rehabilitation, and, in addition, a whole special issue on mediated communication. The special issue contained 21 articles, excluding the editorial. The editorial (Brunson & Loeb, 2011) notes that the articles mainly examine the issue of mediated communication via media theory, specifically the work of Marshall McLuhan (1964), famous for drawing attention to the need to analyse the character of the medium through which messages are communicated. On the basis that the special issue explores supported communication through a media theory framework, rather than in relation to rehabilitation, I have excluded it from this review.

That only seven articles were identified which considered rehabilitation in any detail suggests that this theme is given little attention within this journal, probably because the idea of speaking about rehabilitation is understood as traducing the model of disability within which the journal perceives itself to be operating. *Disability Studies Quarterly (DSQ)* carries both articles on sociological research and articles by academics in the humanities, and can be broadly understood to situate itself within the field of 'cultural disability studies' (Shakespeare, 2014, p. 47). The articles I identified were from a range of disciplinary and theoretical perspectives. Four of the seven articles used social research methods, including observation or interviews or both. The other three articles analysed discourses or histories of rehabilitation in particular contexts: one examined the website and related materials for a cochlear implant programme in Canada (Edelist, 2015), another considered the effects of the medicalisation of disability on perceptions of the same in Africa (Ndi, 2012), a third was a history of prosthesis (Hawk, 2018). Of the four articles that used social research methods, all used qualitative methods. One used structured interviews (Matt, 2014); one described using 'a background questionnaire, a semi-structured personal interview, and field notes' (Schneider and Young, 2010: n. pag.); the other two used observation as well as informal conversations (Bertilsdotter Rosqvist, 2012; Cohen 2012).

It is notable that, of the four journals examined in this review, *DSQ* carries the most literature that is overtly critical of the concept of rehabilitation. The papers by Ndi (2012) and Edelist (2015) both take a critical view of rehabilitation, seeing it as bound up with processes of normalisation and social control. In both cases, rehabilitation is associated with cultural imperialism: for Ndi, this is the imposition of Western thought, and particularly Western medicine, in Africa; for Edelist, this is the imposition of a hearing culture upon children with congenital deafness. The paper by Cohen (2012) describes how rehabilitation was understood in fieldwork undertaken in Columbia, where it was seen as an activity symbolising integration within a politically divided and war-torn country. Here the concept of rehabilitation takes on particular significance at the level of both the physical body and the body-politic. Cohen's careful ethnography highlights the cultural significance of prosthetics in various Columbian institutional settings, where re-learning to walk can be understood both to *displace* attention from the ongoing conflict which creates a group of war-wounded people, and to *focus* attention on this issue.

In Bertilsdotter Rosqvist's (2012) study of people with Asperger's Syndrome, ambivalent attitudes towards rehabilitation emerged. When training, or adaptation, could take place on the terms of the participants, it was to be welcomed, but when it took place on the terms of the dominant (neurotypical) culture, it was felt to be oppressive. Meanwhile, in the research undertaken by Matt (2014) and Schneider and Young (2010), rehabilitation is implicitly desired or seen as positive by the parents of disabled children (Matt, 2014) and by women affected by MS (Schneider & Young, 2010). Where Matt's interviewees in Nicaragua had not made use of rehabilitation services for their children, this was found to be because transport costs to reach the clinic were too high, not because parents were unwilling. The women with MS interviewed by Schneider and Young in Canada wanted to receive lifestyle advice from their doctors, which would assist with their rehabilitation.

In some of the articles I reviewed from *Disability Studies Quarterly*, medical discourse itself was an object of study. Two articles (Ndi, 2012; Edelist, 2015) maintained a suspicion of the medicalisation of disability, seeing this as oppressive for disabled people. They examined the structural inequalities that arise out of the dominance of medical knowledge. Cohen (2012) focused on the changing meaning of the phantom limb in Columbian medical discourse, as well as exploring the perspectives of prosthesis users amongst those who either do, or do not, have a phantom limb experience. The article did not emphasise the expertise of any one group but was interested in the views of both patients and medics. In a sense, this article also drew on a notion of knowledge as existing within a particular discursive framework, since it understood the new-found recognition of the value of the phantom limb experience in Columbian medical practice as indicative of a political paradigm that values integration: the phantom limb is viewed as helping the disabled person to adjust to, and integrate, the prosthesis within the body.

3.4 Summary: Characterisation of rehabilitation in the four selected journals

Most of the literature reviewed in this chapter did not convey a view of rehabilitation as a 'given' if one is disabled, but instead queried whether rehabilitation should be the natural response to disability. With the exception of some of the literature published in *SJDR*, where rehabilitation was discussed in the literature, it was generally the subject of critique. Yet, as the scoping review revealed, rehabilitation was the subject of only a tiny percentage of articles that I reviewed, suggesting that it is not currently a major preoccupation of the field of disability studies.

In the *World Report on Disability* (WHO, 2011), assistive technology is treated as a 'rehabilitation measure' (p. 97), yet within the disability studies literature I reviewed, a distinction is usually drawn between articles in which 'assistive technologies' are discussed and those which frame their focus in terms of a consideration of 'rehabilitation'. Across the board, social studies focusing on assistive technologies were much more prevalent in these journals than social studies exploring experiences of rehabilitative therapies, suggesting that the former are more in keeping with the political position of these journals. Within disability studies, it would appear that assistive technologies are perceived as interventions which remove environmental barriers, whereas rehabilitation is perceived as an intervention upon the body/mind of the disabled person. If I had included all of the studies on assistive technologies, the review would have been flooded with articles that were not about rehabilitation but about access. In itself, this difficulty of classification shows that the boundary between the two categories is fluid. Yet this may also be indicative of the different cultural connotations of rehabilitation and assistive technologies, and of the varying levels of acceptability of older and newer technologies. Today, in the UK at least, the wheelchair has come to be a powerful symbol of disability rights and liberation, with its image often used to symbolise 'access', although as Stewart and Watson (2020) note, for many years the medicalisation of the wheelchair, and its association with a notion of disability as individual tragedy, inhibited the development of improved wheelchair technology and design. Wheelchairs do enables a certain kind of rehabilitation to take place or to have taken place, yet this aspect of the significance of the wheelchair is rarely the focus in the body of literature I surveyed (but see Papadimitriou, 2008). By contrast, the cochlear implant is an example of an assistive technology whose connotations are currently much more closely linked with rehabilitation and cure: Snell (2015) observes that some members of the Deaf community regard it as undermining their culture because it normalises modes of communication associated with hearing, and potentially jeopardises Deaf cultural forms, if more and more children have cochlear implants at an early age.

Another prevalent theme in the disability studies literature was the personal account of rehabilitation, which emerged particularly strongly in *Disability and Society* (Beauchamp-Pryor, 2011; Inahara, 2013; Bevan, 2014; Long, 2015). As we saw, these papers tended to offer critical accounts of aspects of the rehabilitation experience and its effect on the author's life or identity. We might question why personal accounts seem to be one of the preferred forms for discussing rehabilitation in this literature, and speculate on the role of the ongoing dominance of versions of the social model of disability in this field, as well as a rejection of the medicalisation of disability. Is a sociological study of rehabilitation experience perceived to be re-conceptualising the place of the 'medical' in disability studies in ways which threaten the integrity of the field?

3.5 Strengths and limitations of this review; future work

My own familiarity with critical disability studies gave me a sense of the contours of that sub-field, and its history and position within disability studies more generally, when researching this review. This was both a strength, in the sense that the review could be written with a deeper sense of the academic context for authors' representations of rehabilitation, but it also means that the narrative review in particular is written from the standpoint of someone who has been immersed in the critical disability studies tradition for some time and who has greater familiarity with that sub-field of disability studies than with other contemporary developments. The systematic selection approach used for the scoping review was helpful in countering the possible over-representation of critical disability studies in the narrative review, as was my awareness of how my own schooling in critical disability studies might be shaping my own hostility towards rehabilitation as a product of a medicalised view of disability.

Another difficulty I encountered in reviewing this literature, as previously mentioned, was the question of how to categorise assistive technology. It was difficult to be entirely consistent as journals and authors take differing approaches in the disability studies literature, and I had to be guided by authorial framings of issues to a large extent. But, this framing in itself tells us something about the scepticism with which rehabilitation is regarded in general in this literature; there may be a desire to separate assistive technology from rehabilitation because of the way the latter term is seen to ‘contaminate’ the author’s credentials within the field. Future work would track the emergence of critical rehabilitation studies in more detail and depth than I have been able to here. This field could be a fruitful avenue for supporting the implementation of findings emerging from studies such as *Rights-based Rehabilitation*.

3.6 Synthesis: Key themes emerging in the qualitative studies across the rehabilitation science and disability studies literatures

As I was working on the two scoping reviews, I became aware of the emergence of key themes in the qualitative papers which cut across both literatures (rehabilitation science and disability studies). Although undertaking a thematic synthesis of the qualitative research had not been part of the initial plan for the scoping review, I was working iteratively in the review process, responding to what I found (Arksey and O’Malley, 2005). Whilst in many respects, as we have seen, the rehabilitation science literature and the disability studies literature were divergent in terms of how they viewed rehabilitation, there were nevertheless some striking synergies between certain qualitative studies, especially between the papers shortlisted from the *Scandinavian Journal of Disability Research* and those exploring experiences of spinal cord injury published in *Disability and Rehabilitation*. The presentation of key themes here should be understood within the context of the limited terms and scope of my review; it offers a snapshot of what was emphasised within the qualitative papers that I reviewed, but should not be regarded as an authoritative picture of research into lived experiences of rehabilitation. Most research discussed here followed an impairment-specific approach, but research findings could have wider relevance to the disability community.

I synthesised the qualitative research by creating headings for themes which emerged in two or more papers. I scanned titles, abstracts and where necessary the whole paper (if I needed more information about the paper's relevance to my study in terms of the way it deployed qualitative methods, or in terms of its focus on the lived experience of rehabilitation). In order to be scanned, a paper had to be listed in my bibliography as one to which I referred by name in one or other scoping review. I limited the process in this way because of time constraints, deciding that this was a fair inclusion criterion because it necessitated that a study already had some characteristics that made it relevant to my own research questions. I included qualitative research studies only, and focused on those papers that described disabled people's own views and experiences, excluding papers about parents' views, or discourse analyses of policy literature, for example.

3.6.1 Time

- The experience of time emerges as a key theme in some qualitative research into rehabilitation experience. Bury's (1982) concept of biographical disruption is particularly relevant to rehabilitation for acquired impairments (Papadimitriou & Stone, 2011; Bourke et al., 2015). Papadimitriou and Stone (2011) present qualitative data demonstrating that the patients with spinal cord injury they interviewed felt disconnected both from their projected futures, and also from a sense of the past, because they did not have a past as people with disabled identities. Bourke et al. (2015) presented three superordinate themes which emerged in their interviews with four participants with tetraplegia following spinal cord injury: 'acquiring information [about

SCI]', 'regaining control', and 'restoring a sense of personal narrative' (article section headings). The temporality of illness is a major theme in medical sociology, with concepts such as 'biographical disruption' (Bury, 1982) and 'narrative reconstruction' (Williams, 1984) having been influential in that field, so it is probably not surprising that it is also important in relation to rehabilitation experience. For Bury (1982) and Williams (1984), the onset of illness is seen as a disruptor of identity and selfhood; it is an experience which necessitates the 'reconstruct[ion] of a sense of order from the fragmentation produced by chronic illness' (Williams, 1984, p. 177).

3.6.2 Shifting identities, questions of belonging

- As the above discussion of the 'time' literature illustrates, rehabilitation may involve negotiating a shift of identity. For example, the decision to choose a 'cure' might alter how one perceives oneself or relates to others within the disability community (Beauchamp-Pryor, 2011). Identity shifts have also been a key theme in the sociology of illness, drawing on Charmaz' (1983) influential paper on the concept of 'loss of self'.
- The management of the shift from inpatient to outpatient rehabilitation can be critical to a patient's recovery of a sense of self (Arntzen et al., 2015).
- It may be helpful to regard rehabilitation as a 'learning trajectory' (Aadal et al., 2014, p. 358) in which participants perform active roles and are members of a 'community of practice' (2014, p. 360).
- For congenital and lifelong impairments, an emphasis on nourishing bodily self-awareness and on learning how to manage the ageing body may be more appropriate than an emphasis on normalisation (Brunton & Bartlett, 2013; Moll & Cott, 2013).

3.6.3 Feelings, especially loss

- The experience of psychological loss associated with acquired impairment should not be underestimated (Clifton, 2014), and the opportunity to work through grief (Clifton, 2014) or to be encouraged to explore gratitude (Chun & Lee, 2013) may be helpful. The management of hope in the rehabilitation process may be important, and it can be helpful for rehabilitation professionals to have some insight into factors that can influence hope (Soundy et al., 2014). Shakespeare (2004) has also emphasised the need for disability studies to be able to accommodate lived experiences of emotion associated with disability, including loss and frustration. Frustration is highlighted in the paper by Jannings and Pryor (2012) in their discussion of the lived experience of re-learning to walk for patients with spinal cord injuries, as well as by Norrbrink and Löfgren (2016) in their paper on patients' (and physicians') experiences of managing neuropathic pain in spinal cord injury.

3.6.4 Agency-autonomy

- An emphasis on agency rather than autonomy may help rehabilitation patients to adjust and to be more comfortable with themselves (Löfgren & Norrbrink, 2012; Van de Velde et al., 2012; Bezmez, 2016; Norrbrink & Löfgren, 2016; see also Papadimitriou, 2008). For Van de Velde et al. (2012), patients with spinal cord injury could be supported through the rehabilitation process if professionals helped them to reconsider their 'internalised ideal of independency' (p. 491). Löve et al. (2018) criticised the limited conceptualisation of service user autonomy in services for disabled people in Iceland.
- The issue of maintaining or regaining control of one's life during rehabilitation was highlighted (Bourke et al., 2015); in the paper by Hearn et al. (2015), overcoming pain was framed in terms of control over one's life.

3.6.5 Sociocultural significance of rehabilitation

- Disabling assumptions are an important factor in the rehabilitation process, for example, the privileging of re-learning to walk as *the* central activity in rehabilitation (in this case, in the Turkish context) plays a role in patients' perceptions about what their future will be like (Bezmez, 2016; Bezmez & Yardimci, 2016; see also Oliver, 1993).

- In Cohen's (2012) study of rehabilitation norms in Columbia, the emphasis placed by medical professionals on the importance of a phamtom limb experience in successful rehabilitation appeared to mediate phantom limb experiences.

3.6.6 Relationships

- Family relationships are an under-researched component of the rehabilitation process which may be integral to its success, or may help individuals re-access rehabilitation through the life-course (Berthou, 2012; Dew et al., 2014; see also Bezmez & Yardimci, 2015).
- Peer support plays an important role in rehabilitation (see for example Hanga et al., 2017; Brookfield & Mead, 2016; Bourke et al., 2015; Jannings & Pryor, 2012).
- Disabled occupational therapists have some of the most developed insights into how best to work with disabled people (Bevan, 2014), yet they face barriers to their full inclusion within the profession (see also: Bulk et al., 2017; French, 1988). A qualitative study of the experiences of disabled healthcare professionals (Bulk et al., 2017) also concluded that disabled people experienced marginalisation within these professions. This particular study was ultimately not included in the reviewed papers because it was not felt to be sufficiently connected to the topic of rehabilitation, but it certainly speaks to the issue of disabling stigma in the healthcare professions.

The scoping review of the disability studies literature offered in this chapter indicates that the topic of rehabilitation may be under-researched in the field, given how infrequently it appeared in articles surveyed across four major international journals. The narrative review I presented also supports this conclusion, noting that early figures in the UK disability movement such as Oliver (1990, 1993) were suspicious of rehabilitation, seeing it as a set of practices that medicalised disabled people's experience. Rehabilitation is not a dominant theme in critical disability studies; however, where it is studied, theorists focus on the ‘cultural grammar of rehabilitation’ (McRuer, 2006, p. 112) and consider histories of rehabilitation.

On the evidence of the narrative and scoping reviews, existing sociological work on rehabilitation is fragmented, with larger-scale empirical work on this theme often being allied with medical sociology and the health sciences, and researchers with commitments to disability studies often starting from a position of scepticism towards rehabilitation, seeing it as medicalising disability in ways that may be oppressive. Although this review did uncover some empirical research exploring disabled people’s views and experiences of the process, these papers tended to focus on home adaptation, or the use of assistive technologies, or to offer autoethnographic accounts of rehabilitation. There were very few qualitative studies of lived experiences of inpatient and outpatient rehabilitation. These findings suggest that there is a need for a study of rehabilitation experience that simultaneously draws on key concepts and methodologies from medical sociology, while also operating from within disability studies, learning from scholarship within this field on how best to design inclusive and accessible research and services.

When synthesised with the rehabilitation science literature, a series of themes emerged in the qualitative papers across both fields: the temporality of rehabilitation; shifting identities; feelings about rehabilitation; agency and autonomy; sociocultural aspects of the process and relationships in rehabilitation. This synthesis helped me to characterise the small body of work on the sociology of rehabilitation that is emerging at the intersection of the rehabilitation sciences and disability studies. I was later able to draw on this synthesis, alongside the two literature reviews I had undertaken, in order firstly to decide how best to design *Rights-based Rehabilitation* and later to interpret the study’s findings in their academic context.

Chapter 4

The history, theory and practice of patient and public involvement in research: A narrative review

4.1 Introduction and aims

Funded by the Patient and Public Involvement Research Theme of the National Institute of Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care (CLAHRC) East of England (2014-2018), the *Rights-based Rehabilitation* PhD study was conceived with the aim of involving disabled people with lived experiences of rehabilitation throughout the design and delivery of the project. When I started work on the project as the lead researcher, I was relatively unfamiliar with the field of patient and public involvement (PPI) in health research. To inform my decisions about how to involve people in my project, I began by reviewing the history, theory and practice of PPI in research, defining the aims of this review as:

1. to examine academic and policy literature on the history of ideas of public involvement, and on theoretical debates relating to this topic, to inform my decision-making about how to involve members of the public in the project, and
2. to develop my thinking on the philosophy and practice of PPI, in order that my overall approach to my research would be shaped by an understanding of the histories and theories of inclusion in social research.

This approach would enable me to be able to discuss the role, or potential role, of PPI in rehabilitation-related research.

4.2 Approach and scope

To delve into the history of PPI as a policy idea, and to understand the thinking and activism from which it emerged, I read a range of noted and widely-cited titles, including books, academic papers, policy statements and reports on the topic. I drew on my knowledge both of influential authors within this field (for example, Peter Beresford, Marian Barnes and Phil Cotterell, Mike Oliver, Paulo Friere) and of key policy organisations (INVOLVE) to identify the relevant literature. I located relevant books by undertaking word searches on library catalogues; I searched under the term ‘patient and public involvement’, as well as using the terms: ‘user involvement’, ‘co-production’, ‘action research’, ‘participatory research’ and ‘emancipatory research’. These sub-fields of sociology and related disciplines were often referenced in conjunction with PPI. In the course of this work, I became aware of the relevance of longstanding, foundational debates on the relationship between agency and social structure in sociology. Questions about who is empowered to act, and how, and under what conditions, are relevant not just to considering how social action happens in the world, but also to researchers’ own practices. Although the structure-agency debate might seem purely about theory, it has been influential for researchers seeking to elucidate key concepts in health sociology, such as health promotion (see, for example, Veenstra & Burnett, 2014) and health inequalities (see, for example, Williams, 2003). It is also suggested that the history of patient-centred care and of patient agency in contemporary healthcare discourses can be linked with a particular turn in later twentieth century academic sociology (Armstrong, 2014). These ideas are briefly outlined later in reviewing how ‘agency’ is viewed in health policy discourses.

To ensure that I was engaging with the most up-to-date work in the field, I also looked closely at the output of two major medical sociology journals, *Social Science and Medicine* and *Sociology of Health and Illness,* in the course of my review process, to explore the extent to which the presentation of PPI has become a normalised part of academic writing in a field that has been deeply shaped by changing ideas about patienthood. I undertook ‘AND’ searches on the terms ‘voice’ and ‘involvement’ in the journals, using the date parameters Jan 2011 - December 2018 for these searches, producing 14 articles from *Social Science and Medicine*, and two from *Sociology of Health and Illness*. I read abstracts and shortlisted six of the articles from the former, and one from the latter publication. I drew on these articles in the writing of this review, although only three papers are referenced directly. The relative paucity of articles in this literature which discuss user involvement is notable. It is possible that medical sociologists with an interest in PPI publish on this aspect of their work in journals that specifically treat that issue such as the *Journal of Health Services Research and Policy*; however if that is the case, it demonstrates that PPI is not yet normalised as part of 'method' in social sciences research.

The literature on PPI raises questions about ethics and methodology in social research, in particular in the context of medical sociology, as well as opening up debates about democracy and citizenship. Its history is bound up with the history of the emancipatory struggles of minority groups such as the disabled people's movement. I have sought to trace many of these key issues in this review, but, since it was necessary to be selective in terms of the literature I read, I focused on the policy history which gave rise to patient and public involvement in health research as we know it now, and on key debates in sociology, health sociology and disability studies that make up the intellectual hinterland for the comparatively new field of PPI research. I chose these focal points so that my review could help me to make practical decisions about how best to design the PPI in my study, and so that I was addressing issues which are central to my research problem. In the context of this chapter, these themes include the role of the patient in health service design and research, and disabled people's inclusion in research.

4.3 Chapter outline and terminology

The review begins with a brief recent institutional history of the concept of public and patient involvement in health service contexts, starting with its UK origins in Community Health Councils (Barnes & Cotterell, 2012a). I then examine specifically relevant conceptual fields which have influenced the formation of PPI as a discourse and a practice in a series of sub-sections: 'agency and patient agency in sociology', 'co-production', 'participatory action research' and 'emancipatory research'. Subsequently, I look at the question of what PPI contributes to health research, focusing on PPI as an institutional practice; I also examine its reported benefits for researchers and members of the public, and explore suggested best practices for implementing it. I then consider some critiques of PPI, before briefly explaining how my learning from this review influenced the decisions I made in this doctoral research project.

The issue of how to define PPI, alongside related terms such as 'co-production', is interrogated throughout this review. The field of PPI is a field of competing, and sometimes contested, terms (Tritter 2009): Wilson et al. (2018) note that three terms, 'participation', 'engagement' and 'involvement' are often used interchangeably in UK research contexts, although these authors define only 'involvement' as pertaining to the inclusion of members of the public in research design and delivery. PPI is a jargon-laden field; indeed INVOLVE, the UK body which supports 'public involvement in research', includes a 'jargon buster' on its website (INVOLVE, 2020a). It should be noted, to begin with, that patient and public involvement names an institutional and institutionalised process, albeit one that started within social movements, and so it makes sense to begin with an institutional definition. INVOLVE defines 'public involvement in research' as:

> research being carried out **'with'** or **'by'** members of the public, rather than **'to'**, **'about'** or **'for'** them. This includes, for example, working with research funders to prioritise research, offering advice as members of a project steering group, commenting on and developing research materials, undertaking interviews with research participants (INVOLVE, 2020b, emphasis in original).

The emphasis on prepositions as central to the definition of public involvement suggests a concern with the *process* of research, rather than the product. It also reveals a sensitivity to the ways in which those with an interest in the research are positioned in relation to it. The statement echoes one of the early rallying cries of the disability rights movement, 'nothing about us without us!' (see Charlton, 2000), which has been used to highlight the marginalisation of disabled people, and the way in which we have often been spoken 'for' or 'about', rather than having had our own voices heard. This echo creates a linguistic connection between PPI as a policy initiative, and grassroots social movements fighting for rights and representation. A similar, but modified, example can be found in the 2012 UK government policy initiative on public involvement, ‘Liberating the NHS: No decision about me, without me’ (UK Government Department of Health, 2012). As Beresford (2013) notes, this use of the terminology individualises a concept that was once a rallying cry for collective action. The tension between the goals and practices of social movements and their institutionalisation within the UK National Health Service (NHS) and the National Institute for Health Research (NIHR) has been the subject of much discussion within the field, and will be an ongoing theme in this review.

4.4 A brief history of patient and public involvement in the UK

Researchers tracing the history of PPI often begin by exploring an upsurge of interest in ideas such as co-production and citizen participation among academics and policymakers, which they locate in the 1970s (Needham & Carr, 2009; Barnes & Cotterell, 2012a). Co-production is a term that is often used in relation to patient and public involvement today, but which long precedes the formation of PPI as a policy term: it can be defined as what happens when ‘people who use services collaborate in the production of services’, although the actual implementation of co-production is potentially ‘complex’ (Needham & Carr, 2009, p. 16). According to Needham and Carr (2009, p. 2), the concept of co-production ‘dates from the 1970s, a time when movements to challenge professional power and increase citizen participation in community affairs coincided with efforts to reduce public spending’ (see also New Economics Foundation, 2008). These authors draw attention to a flurry of interest in co-production in the USA at this time, as a mode of ‘harnessing the input of people who use services’ (Needham & Carr, 2009, p. 2). A 1980 article from the journal *Public Administration Review* exemplifies this trend, appearing to focus on the potential of co-production to decrease bureaucracy in its conclusion that ‘[w]e have too often come to expect that agencies can change people and have forgotten that people must change themselves’ (Whitaker, 1980, p. 246).

Another early paper by an American author, entitled ‘A ladder of citizen participation’ (Arnstein, 1969), is widely cited in the user involvement literature and is regarded as having been highly influential in the development of the PPI field (Tritter & McCallum, 2006). Arnstein was originally writing in relation to urban planning, but the paper has subsequently been referenced in many fields on the issue of participatory democracy. Arnstein offers a hierarchy of types of public involvement in decision-making, presented as a ladder of citizen participation, with the rungs of the ladder titled, from bottom to top: ‘manipulation’, ‘therapy’, ‘informing’, ‘consultation’, ‘placation’, ‘partnership’, ‘delegated power’ and finally ‘citizen control’ (p. 217). The lower levels of the ladder are forms of tokenistic or manipulative involvement, whereas the higher levels represent a real transfer of power. Interestingly for a thesis on rehabilitation, in this model, ‘therapy’ – which is sometimes used as a synonym for rehabilitation – is regarded with suspicion, seen as being one of the non-participative types of involvement. Arnstein (1969, p. 218) describes how,

> under a masquerade of involving citizens in planning, the experts subject the citizens to clinical group therapy. What makes this form of “participation” so invidious is that citizens are engaged in extensive activity, but the focus of it is on curing them of their “pathology” rather than changing the racism and victimization that create their “pathologies”.

There are similarities here with the rhetoric that disability theorist Oliver (1993) uses to characterise rehabilitation, as an ideological edifice which seeks to wield power over its ‘victims’, which was discussed in the last chapter. The linguistic resonances here reveal the need to draw out the connections and distinctions between the various related but different concepts used in this field of citizen involvement on the one hand, and social movements for equality on the other (such as the disabled people’s movement, of which Oliver was an early and prominent member). This review will be tracing these links. The Arnstein quotation exposes a culture in which experiences that could be understood as products of discrimination are instead understood as symptoms in need of cure, describing the cultural context which was soon to give rise to radical social models of minority experience (including disability and mental illness). Indeed, the 1970s was the decade in which a UK disabled people's organisation produced its founding statement that was to lead to the social model of disability (UPIAS and The Disability Alliance, 1976), out of which was to emerge the concept of emancipatory disability research (Oliver, 1992; Zarb, 1992; Campbell & Oliver, 2013 [1996]). I shall turn to this important strand in the history of PPI shortly.

These ideas are the intellectual hinterland of early uses of patient and public involvement in health service delivery in the UK. Barnes and Cotterell (2012a) trace the arrival of PPI in this context back to the 1974 introduction of Community Health Councils. The role of these bodies was to 'represent the "public interest" in health and health services' (Barnes & Cotterell, 2012a, p. xv). According to a 2007 report for the government by the UK Parliamentary Select Committee on Health, Community Health Councils represented the first 'substantial attempt by Government to give users, or potential users, of healthcare services a voice in their design and operation' (n. pag.). When they were first established, there was a great deal of enthusiasm about the radical, inclusive potential of the Community Health Councils (Hogg, 2007), which put the UK 'in the vanguard' in terms of its promotion of patient involvement in service delivery (Tritter, 2011, n. pag.). Subsequently, these bodies, whose status as inside/outside the NHS was always 'ambiguous' (Barnes & Cotterell, 2012a, p. xv), were criticised on the basis that they were not as inclusive of a diversity of voices as they could have been, and on the basis that their remit with regard to primary care was limited (UK Parliamentary Select Committee on Health, 2007). Community Health Councils were abolished in 2003, and have been replaced by a series of different frameworks and structures.

In the 1980s, conceptualisations of PPI altered in response to new political and economic priorities in the UK. The growth of interest in the potential of a free market economy led to a shift of emphasis from collaboration to consumerism in the policies that were developed (Barnes & Cotterell, 2012a; Needham & Carr, 2009), especially after the publication of the Griffiths Report, which encouraged market research in the NHS with health service users

(Griffiths, 1988; Barnes & Cotterell, 2012a). After the introduction of the internal market within the NHS in 1991, this trend was to increase, leading to the introduction of the Patient's Charter within this period. The internal market in the NHS meant that purchasers of healthcare services had to justify their decisions to taxpayers and patients (Oliver et al., 2004). The NHS Research and Development (R & D) programme launched at the same time as the internal market, creating a framework in which research priorities could be set via consultation both with NHS staff and with service users (Oliver et al., 2004). In 1996, the Standing Advisory Group on Consumer Involvement in the NHS Research and Development Programme was formed (Barnes & Cotterell, 2012a). In a review by S. Oliver et al. (2004) of public involvement in NHS research, the term they give to service users throughout is 'consumers', and the authors gloss this term as referring to patients and services users. Whilst their report makes clear that they use this term partly because so-called 'consumer groups' are often consulted in the reviewed studies, they nonetheless deploy the term without discussing its connotations. This, along with its usage in the name of the Advisory Group, suggest that 'consumers' may have been the preferred term for researchers working on PPI at this time, perhaps reflecting an optimism invested in a version of consumer 'choice' associated with free market capitalism (Salecl, 2010). By contrast, today, 'service users', 'patients' or 'members of the public' are much more common terms in the discourse of PPI. This movement away from consumerist language might reflect a sense of disappointment and frustration among advocates of PPI with the way in which emancipatory ideas from social movements have been co-opted and used within a neoliberal policy context that has implemented austerity and cuts to government funding for public services (see, for example, Beresford, 2019). Tritter (2009, n.pag.) observes that an emphasis on patient choice 'may undermine population-based approaches to public health and health policy', and that such language may best serve the interests of an increasingly fragmented, and consumer-oriented, healthcare system rather than meeting people's health needs.

INVOLVE, the body which replaced the Standing Advisory Group, was funded by the National Institute of Health Research (NIHR) until 2019, at which point the contract to run this agency appears to have been outsourced to a private company (Boote & Carr, 2019). The role of INVOLVE has been to promote public involvement in health research. In 2001, public involvement was enshrined in law as a duty for NHS organisations (UK Government, 2001; Barnes & Cotterell, 2012a), and is today mandatory in all NIHR funded research. INVOLVE provide a Library of Examples, which is currently still available on their website, and which shows that in recent years, members of the public have been involved in shaping a wide range of projects, from clinical research exploring the relationship between memory and medication in patients with Parkinson's disease (INVOLVE, 2013a) to mental health service evaluations (INVOLVE, 2013b) and qualitative research on patients' experiences of rapid HIV testing in GP surgeries (INVOLVE, 2013c; see also INVOLVE 2013d and e for further examples). As INVOLVE (2012) explains, the mode of involvement depends a great deal on the nature of the research. For example, in the project on Parkinson's disease, patients and carers appear to be consulted just once, in a meeting in a pub, but most of them did not want to be involved further (INVOLVE, 2013a). The lessons drawn from the consultation were, nonetheless, far-reaching for the project and the pub environment facilitated exchange on more equal terms than a research environment might have done (INVOLVE, 2013a). This case study shows that the quantity of PPI may be no substitute for its quality. Moreover, PPI will almost always be constrained by limited time and resources (Wilson et al., 2015).

In this brief historical overview, I have focused on the ways in which concepts of involvement have been institutionalised within UK health research (or health delivery) policy. Yet these concepts of involvement have grown out of social movements and academic research practices. Thus, there are a range of key terms that intersect with, and are used alongside (or sometimes in contradistinction to), 'patient and public involvement'. I now discuss some of these concepts in turn, and their relationship to PPI: 'agency' and 'patient agency', 'co-production', 'participatory action research' and 'emancipatory research'. I begin with 'agency' because of the centrality of this term within twentieth century sociological debates about how social action happens. The recent history of the agency-structure debate provides a cultural context within which to understand the other key terms in this chapter, as well as helping to elucidate the rise of an ideal of ‘patient agency’, which is often being implicitly validated in discourses of patient involvement. Meanwhile, ‘co-production’ is regularly used in relation to contemporary institutional practices of public involvement, but has a longer history outside the academy; given its ubiquity in PPI discourses, it merits closer attention as a keyword for this review to unpack. ‘Participatory action research’ and ‘emancipatory research’ represent intellectual traditions within sociology which have sought to reflect on inclusion and involvement, and which are frequently referenced in histories of user involvement (see, for example, Barnes & Cotterell, 2012b, pp. 144-5).

4.5 ‘Agency’ in sociology and in health policy discourses

As a term in sociological theory, ‘agency’ has long been the subject of debate. The question of how people are empowered to act in or upon the social world, and the ways in which are they constrained or enabled by social forces and structures, is relevant to the question of how PPI should be carried out and by whom, because it helps those who work in the field of PPI to consider the factors that enable someone to act, and the structural and social barriers that make action more difficult. As sociology became established as an academic discipline, various theories were developed to explore the relationship between structure and agency. Determinism, in which activity is seen as determined by structural factors, can be contrasted with voluntarism, which places emphasis on the role of individual agency in bringing about action (Pozzebon, 2008). Meanwhile, co-determinism generally refers to a mid-twentieth century turn in sociology, whereby certain thinkers sought to nuance a structuralist (or determinist) view of social action, by drawing attention to the dialectical tension between structure and agency (Dépelteau, 2008; see also Mills, 2000 [1959]; Bourdieu 1990, Giddens, 1984). In the younger field of relational sociology, the term ‘trans-action’ comes to the fore, to denote the web of social actions which take place between individuals (Dépelteau, 2008, Emirbayer, 1997). According to this reading, ‘power is an effect of social relations’ and not a property of an individual (Dépelteau, 2008, p. 60).

Relational sociology rejects the idea of an ontological distinction between structure on the one hand, and agency on the other; it also seeks to de-reify these concepts, so that agency is not seen as a property that an individual has, but rather as something that always happens within social relations (Dépelteau, 2008).[5] A further development of these debates takes place with the rise of Actor Network Theory (Latour, 2005), which seeks to bring together the natural sciences and the social sciences by throwing into question the function of taxonomies that divide animate actors and inanimate objects in accounts of how things come about in the world (see, for example, Law, 2004). Actor Network Theorists argue that such taxonomies maintain disciplinary boundaries between the natural sciences and the social sciences, but do not necessarily help us to understand the characteristics of the world we are researching.

How do these theories help us think about the changing role of patients and the public in designing health services and research? By situating these debates about agency in their historical context, we can see connections with the rise of a new way of thinking about patients. Armstrong (2014) observes that the turn towards agency among thinkers such as Wright Mills, Bourdieu and Giddens in the latter part of the twentieth century came about within a particular historical and cultural context, in which individualism had begun to be privileged. The related idea of the patient-as-agent can be seen as part of this same historical trend: indeed, the concept of 'patient agency' has not always been dominant (Armstrong, 2014; see also Rose, 1999). The etymology of the word 'patient' reveals that the idea of 'patient agency' should perhaps be seen as a linguistic oxymoron: in the fourteenth century it meant 'enduring hardship without complaint' and 'a person who *undergoes an action*' (Oxford English Dictionary, 2005, my italics). Patienthood is thus etymologically linked with passivity, endurance and 'being-done-to'. In Parsons' (1951) discussion of the sick role, three key features of patienthood

---

[5] Reification refers to the process of falsely attributing of the qualities of a 'thing' to a concept, so that it appears concrete or measurable in some way (Watson, 2015); Watson (2015) argues that reification is often deployed without acknowledgment in classical sociology.

are discussed: ‘helplessness, technical incompetence and emotional involvement’ (cited in Armstrong, 2014, p. 163). In the second half of the twentieth century, the identity of the patient underwent a ‘fundamental reconstruction’ (Armstrong, p. 163), which led to the normalisation of a notion of the patient as actor. The movement towards an emphasis on the patient as actor is, for Armstrong (2014), linked to a range of factors, from the rise of a ‘risk factor perspective’ (p. 167) in medicine and the emergence of medical ethics in the 1970s, which relied on an ideal of patient autonomy, to a wider cultural shift towards more voluntaristic conceptions of social processes in the latter part of the twentieth century. Armstrong situates a discursive shift towards patient agency in medicine within broader processes and practices that transformed health into a matter of personal responsibility and self-management. It is in this context that the idea of the ‘expert patient’ has come to the fore in health policy and education discourses in the UK (Tritter, 2011); indeed, in 2002 the Labour government of the day invested in the ‘Expert Patients Programme’ to deliver courses supporting patients to manage their long term conditions themselves (UK Government, 2013). This programme was seen as an innovative way of empowering patients, but it was also, according to the government’s own literature, a way of implementing budget cuts, especially after it was outsourced to the private sector (UK Government, 2013).

For my purposes in this thesis, an understanding of the nature of the contemporary cultural emphasis on patient agency has helped me to situate and critically evaluate my own practice as a researcher engaging with techniques for patient and public involvement in research. In particular, a discussion of the tensions associated with the notion of patient agency draws my attention to the potentially double-edged nature of ‘empowerment’ within the contemporary political economy of health research and service delivery. Armstrong’s (2014) representation of patient agency as a disguised form of social constraint, rather than as a truly liberatory possibility, connects agency with responsibility, and with a form of work on the self, as well as with the capacity to act (see also Rose, 1999). This critical framing of the issue contrasts with the more positive and celebratory depictions that may be seen in policy literature about patient-centred care or the expert patient (see, for example, UK Government, 2013). To give another example of a tension, the term ‘expert-by-experience’ can be helpful for valuing lived experience alongside academic knowledge, and its widespread use by UK health bodies and charities can be understood as an achievement of social movements advocating for patient involvement (for examples of usage, see NHS Improvement, no date; Care Quality Commission. 2020; Mind, 2020). Yet the concept has also been criticised for commodifying certain kinds of lived experience (Carr, 2019) and for setting up a potential schism around the question of who is entitled to speak from experience (Carr, 2019; Hemming, n. d.). The term expertise-by-experience seeks to redistribute agency by rhetorically valorising an aspect of the research process that has historically been overlooked, and in this sense the term does important work. Yet, being an expert-by-experience may nevertheless be an ambivalent space to occupy in a research team. Turner and Gillard (2012, p. 198) query the ‘service user researcher’ label, pointing out that it ‘automatically discloses a level of personal information that university researchers are not expected to make public’. In this context, Fricker’s (2007) concept of ‘epistemic injustice’ may also be useful for considering how a ‘service user researcher’ is seen and positioned within a research team. Epistemic injustice denotes a ‘wrong done to someone specifically in their capacity as a knower’ (Fricker, 2007, p. 1); within this we might focus in on ‘*testimonial injustice*’ (p. 1), which takes place when the hearer stereotypes the speaker and, in so doing, reduces the credibility of the speaker’s words. While the contemporary discursive valorisation of expertise-by-experience is intended to increase the epistemic capital of the speaker who can claim this subject position, it is possible that it might also leave that speaker exposed, while re-entrenching existing binaries between ‘knowledge’ on the one hand, and ‘experience’ on the other.

Exploring these debates has enabled me to think through the uneven distribution of agency in research relationships, and to consider the persistence of hierarchies of status in university research, even when (or perhaps especially when) patients are involved in it; I have sought to be sensitive to these dynamics throughout my work on this project. Even if I cannot resolve these tensions, being aware of their existence and exploring their mechanics helps me to make small adjustments to my practice, such as, for example, trying to minimise the burden of time associated with particular PPI activities. In the next section, I turn to another term that needs to be used with caution in PPI, and is sometimes over-used: co-production.

4.6 Co-production

Although the use of the term ‘co-production’ pre-dates the term ‘public and patient involvement’ (see New Economics Foundation, 2008), it seems to be more commonly used within institutional contexts rather than in user-led contexts (see, for example, Needham & Carr, 2009; New Economics Foundation, 2008). The New Economics Foundation (2008, p. 9) traces the term ‘co-production’ back to the 1970s, noting that it was coined by a professor in the USA in the 1970s, who was

> asked to explain to the Chicago police why the crime rate went up when the police came off the beat and into patrol cars. She used the term as a way of explaining why the police need the community as much as the community need the police.

Here, a reciprocal emphasis is given to the ‘police’ and to the ‘communities’: the two groups need each other. As this example suggests, the New Economics Foundation defines co-production with reference to the ‘second economy’ of community (2008, p. 10), through which people help themselves and others continually, in ways that are not recognised in terms of financial remuneration. The New Economics Foundation observes that the mid-twentieth-century economist William Beveridge believed that the cost of the NHS would fall over time because ‘spending on health and welfare will make people healthier and more self-reliant’ (p. 9); the New Economics Foundation suggests that this has not happened because of the way in which excessive marketisation has disempowered people, rendering them consumers who expect a service to be delivered to them by professionals, without involvement on their part. This discussion suggests that co-production implies empowerment but that empowerment itself takes its discursive shape within a particular economic and ideological environment: empowering a consumer is different from empowering a citizen.

Scepticism about co-production is longstanding. Back in 1969, Arnstein (p. 222) noted that

> in most cases where power has come to be shared it was *taken by the citizens*, not given by the city. […] Since those who have power normally want to hang on to it, historically it has had to be wrested by the powerless rather than proffered by the powerful.

Arnstein's point reminds us why, when co-production takes place as part of a governmental or institutional initiative, it can provoke questions about the extent to which it is genuinely redistributive of power (see, for example, Williams et al., 2020; Beresford, 2014; Bradley, 2013). Indeed, as Arnstein notes, certain kinds of participatory work enable 'the powerholders to claim that all sides were considered', while making it so that 'only some of those sides' can 'benefit' (1969, p. 216). This is a means of 'maintain[ing] the status quo' (1969, p. 216). Critics have thus sometimes understood the institutional use of co-production as a means of neutralising a political threat by *seeming* to have listened to those who represent that threat. For contemporary health service researchers, these criticisms translate into a need for honesty, transparency and pragmatism on the part of the institutional researcher about the distribution of power in PPI relationships.

What does co-production mean for health research? For INVOLVE (2018, p. 4), co-production in a research context is 'an approach in which researchers, practitioners and the public work together, sharing power and responsibility from the start to the end of the project, including the generation of knowledge'. Whilst asserting that relationships in co-production should be horizontal rather than vertical, the guidance nevertheless recognises that there are power differences between researchers, practitioners and members of the public, and that these will affect the dynamics of working relationships (INVOLVE, 2018). The guidance acknowledges that these differences can be ‘rooted in wider social and economic differences’ and that ‘this inequality needs to be continually addressed in the ongoing relationships’ (p. 7). There is thus a realism here about the tensions involved in co-producing research. Furthermore, this guidance observes that the principle of power sharing in co-production does not mean that there will be no project leader, nor that everyone must necessarily be involved in making every decision. It can still allow for different roles. In the context of my doctoral project, the implications of this acknowledgement of different roles means a recognition that my status and duties as the funded PhD researcher are different from those of any peer researchers on the project: the project will not be ‘co-produced’ in that I have a responsibility to write and deliver this thesis which marks out my role from that of people who have advised me. As doctoral researcher, I also have the power to interpret and selectively use advice I receive from PPI members, and to curate that information in these pages. In this sense, there is a clear inequality between my role and that of my advisors. Researching co-production leads me to be more fully aware of my ethical duty to represent the advice I have received and the decisions I have made in response to this advice as accurately as I can. I now turn to two subfields of sociology that have been influential on the development of PPI (Barnes & Cotterell, 2012b): participatory action research and emancipatory research.

4.7 Participatory action research

Participatory action research is an approach to social research which emphasises the involvement of those communities which the research is designed to serve, and which aims to put research findings into practice. As a sociological practice, it might be understood as a forerunner of the field of PPI, and its ideas have been seen to contribute to the theory and practice of PPI (Barnes & Cotterell, 2012b). The purpose of action research, for Reason and Bradbury (2001, p. 2), is ‘to produce practical knowledge that is useful to people in the everyday conduct of their lives’. They note that action research will be inherently ‘participative’, because ‘human community involves mutual sensemaking and collection action' (2001, p. 2). The emphases on community, and on the sharing of meaning-making practices, are central to this mode of doing research. The field has developed from a range of influences around the globe, including Paulo Friere's work in Brazil with poor and illiterate school children which sought to change the 'authoritarian teacher-pupil model' into a process of 'continual shared investigation' (Koch & Kralik, 2006, p. 13), and the work of mid-twentieth century thinker Kurt Lewin. Reason and Bradbury cite a wide range of schools of thought as being sources of influence upon the development of action research, from experiential learning and psychotherapy, to 'liberating perspectives on gender and race' (2001, p. 3). These authors emphasise that '[t]his is truly a living movement worldwide for which no one person or community can claim ownership' (Reason and Bradbury, 2001, p. 3); this reveals a sensitivity to the distribution of power in conventional research practices, which is one of the reasons why this approach is so often cited in the PPI field, where different groups' access to institutional power is also a key issue.

Participatory action research is an approach which is 'only possible *with*, *for* and *by* persons and communities' (Reason and Bradbury. 2001, p. 2). In Reason and Bradbury's definition, we see 'for' used as one of the liberatory prepositions. This contrasts with the INVOLVE (2020b) definition of public involvement quoted earlier, where 'for' is positioned as one of the negative prepositions, along with 'to' and 'about'. Does 'for' have paternalistic connotations? This preposition has more than one possible meaning in this context: it can refer to something being done without the participation of the recipient, but it can also be used to distinguish who the beneficiary of the research should be. The language of participation is a frequent theme in the literature, and such differences over usage or non-usage of prepositions suggest the high value placed on using inclusionary language, and theorising inclusion, in both action research and PPI.

The focus on prepositions also reveals that this field is preoccupied with the *manner* in which research is done: the question of 'what is PPI?' or 'what is action research?' can never be fully detached from the question 'how do I do research?'. Questions about the politics of participation are always also questions about epistemology. Who is doing the knowing, and for what purpose? How does our conceptualisation of knowledge shape how we think about the very nature of inquiry itself (Reason & Bradbury, 2001)? These kinds of insights are relevant to PPI in that the lived experience of engaging with a health service, or of living with an impairment, may lead to a different view of what constitutes a research priority from that held by an academic researcher.

Action research can be deployed to resolve practical problems. Its techniques were used in a project funded by CLAHRC East of England ('IMPRESS') to find out about and evaluate the implementation of PPI in the CLAHRC's projects (CLAHRC East of England, 2018). The process involved running a series of research 'cycles' through which researchers sought to understand what it was like to do PPI, and then sought to use actions to resolve problems that emerged during the life of the project. This process ultimately led to the formulation of a set of actions to support researchers within the CLAHRC to implement high quality PPI within their projects. Recommendations included the need for more training in relation to PPI, as well as for greater (institutional) support for PPI both before and between projects. The IMPRESS project is an example of how practical, and accessible, action research can be: it seeks to solve everyday problems in ways that help people to make systems work better. The recommendations around transparency, for example, are directly relevant to my project: it is vital that the learning from my doctoral research is shared with the PPI group that helped produce it, both so that they can know how their expertise has shaped the research, and so that they can help disseminate the research findings to a wider audience within the disability community within the East of England and beyond. This may increase the credibility of the research among the groups it is intended to serve.

Like action researchers, PPI researchers often critically analyse research *processes*: INVOLVE (2012) places emphasis on the processes which facilitate involvement (consultation, collaboration, user-controlled research), rather than end products of research. The literature that INVOLVE produces often makes reference to involving minoritised groups in research (see, for example, INVOLVE, 2012). By working with people whose voices are socially marginalised in this project, I have been made aware of aspects of my approach to fieldwork that might make it less accessible, or inaccessible, to certain members of the community whose voices I need to hear. Wherever possible I have sought to reshape activities to improve their accessibility.

4.8 Emancipatory research

Whereas participatory action research has its origins outside of the UK, usually in global south contexts, the intellectual tradition which became known as 'emancipatory research' began among social researchers aligned with the disabled people's movement in the UK (Barnes & Cotterell, 2012b). Like action research, this sub-discipline is often cited as having had an impact on the development of PPI, and in this section I explore its relevance to the PPI field. The main focus of so-called emancipatory research was a question that has also preoccupied PPI researchers: the question of whether and how marginalised voices come to be represented in research. Mike Oliver, one of the early proponents of this tradition, who was also a prominent figure in the development of disability studies in the UK, described this as a question about the 'social relations of research production' (1992, p. 101). He argued that neither traditional positivist research methods, nor the interpretative paradigm, which was at that time still regarded as 'new' (1992, p. 106), had liberated disabled people from their oppression. Oliver's criticism of the interpretative paradigm is that 'while [it] has changed the rules, in reality it has not changed the game' (1992, p. 106). The problem, as diagnosed by Oliver, is that the 'social relations of research production' have not changed, by which he means that much research is still undertaken by a 'relatively small group of powerful experts doing work on a larger number of relatively powerless research subjects' (1992, p. 106). It is these dynamics which have to change if disability research is to become emancipatory. As the INVOLVE definition of public involvement discussed earlier in this chapter shows, some health service researchers and policymakers took up the question of who is researching whom, and who is being researched, as PPI became institutionalised.

Oliver's (1992) critical evaluation of the relationship between research and policy makes an important contribution that PPI seeks to address. He critiques the 'enlightenment model' which assumes that research provides a 'backdrop against which policymakers make decisions' (p. 109), but in which disabled people rarely see improvements in the material conditions of their lives as a result of research. This is an ongoing and pressing issue which the PPI field has sought to tackle, by drawing attention to a need to make health research relevant to service users, by involving them in making decisions about research (Wilson et al., 2015). As Beresford (2019) suggests, it may be difficult to address this issue fully in health research without greater democracy in all parts of the public sphere.

Emancipatory researchers have also interrogated the relationship between the funding of research and the framing and conduct of the inquiry (Zarb, 1992; see also Barnes, 1996). Since the 1990s, there has been widespread discussion of the notion of researcher independence within social research, but this discussion is usually conceptualised more in terms of issues of personal commitment and individual bias, than it is in terms of the constraints and imperatives imposed by funding bodies and funding regimes. Such constraints can sometimes appear relatively subtle and benign, but their effect may still be to alter the light in which a researcher chooses to present a particular issue. In relation to public involvement in research, the requirements of both funders and academic institutions are likely to constrain how it can be carried out. The funder's view of public involvement is likely to affect the level at which PPI is funded and whether it can be funded at all; the attachment of PPI to particular projects can make it difficult for networks to be maintained between funded projects (CLAHRC East of England, 2018).

The choice of the term 'emancipatory' in the name of the approach should be scrutinised in terms of the claims it makes and the hierarchy it imposes. Who is being emancipated and how? The naming of an 'emancipatory' paradigm potentially downgrades certain kinds of participatory research that do not meet its criteria. A possible solution here might be the 'the de-coupling of participation and emancipation' (Danieli & Woodhams, 2005, p. 290), as this seems to resolve the problem of how the researcher deals with the issue of political consciousness-raising as its own form of colonisation in the research process. Whilst this solution could mitigate the prescriptivism, and even paternalism, associated with some forms of emancipatory research, it nevertheless leaves open the thorny question of how the researcher should manage her own political opinions during fieldwork. Danieli and Woodhams (2005) appear to argue for a separation of politics and methodology in their critique of the 'emancipatory' paradigm (2005). Yet, proponents of emancipatory research would argue that it is impossible to disentangle methodological considerations from political and economic ones; indeed, the need for emancipatory research, they would say, is precisely to investigate and reveal these entanglements.

The tradition of emancipatory research has links with that of 'user-led' research and with research by survivors of mental health services (Barnes & Cotterell, 2012b, p. 144; Beresford & Branfield, 2012). Beresford and Branfield (2012) emphasise the importance of 'user-controlled organisations' in building the solidarity and collective strength needed for marginalised voices to represent themselves in the research process (p. 36); they refer to their own involvement in a national service user involvement organisation, Shaping Our Lives (Beresford & Branfield, 2012, p. 33). They note that the earliest manifestos for disability activism are sometimes criticised for being too narrow in their conceptualisation of disability, mostly reflecting the views of a small group of white, male wheelchair users (p. 39). Beresford and Branfield (2012) stress the need to develop inclusive practices for user involvement which recognise the diversity of experience associated with disability and with mental health service use. This observation also applies to the field of PPI: a recent study suggested that PPI work tends to rely on pre-existing relationships with representatives, and that a priority for the field is to explore how a greater diversity of voices can be included (Wilson et al., 2018).

The public and patient involvement agenda has been demonstrably influenced by critiques of the social relations of research production. INVOLVE's literature refers to three possible approaches to PPI: consultation, collaboration, and user-controlled research (INVOLVE, 2012, pp. 21-24). In recent literature, INVOLVE (2012, p. 21) speaks in terms of ‘approaches’ rather than ‘levels’, stating that this shift recognises that research projects often deploy more than one approach at a time. Yet the implicit hierarchy in the terminology derives from Arnstein’s (1969) notion of a ladder of participation, as Oliver et al. (2004) acknowledge in their discussion of the work of the body that preceded INVOLVE. INVOLVE describes ‘user-controlled research’ as ‘research that is actively controlled, directed and managed by service users and their service user organisations’ (INVOLVE, 2012, p. 24), and notes that such research is designed to improve the lives of service users who have expressed their frustration with ‘traditional’ approaches to research. Terms such as ‘controlled’, ‘directed’ and ‘managed’ seek to emphasise a shift of power in research relationships.

If emancipatory research is fundamentally about shifting power relations in research processes from those within research institutions to those outside of them, or at the margins of them, how far is the practice of patient and public involvement in UK health research also about such a shift? Since PPI is an institutional practice, it cannot fully embrace such a shift while current material, social and institutional relations continue as they are, because the institutions that champion PPI are themselves in some ways invested in maintaining their own existing hierarchies, even as they are also committed to becoming more diverse, inclusive and democratic. However, this is more an observation of what PPI is (an institutional practice governed by institutional priorities) than a criticism. Although PPI would not fulfil the criteria of ‘emancipatory’ research, the process of institutionalising PPI (for example within NIHR research) has already brought a much greater diversity of voices into research decision-making (Wilson et al., 2015). In the next section I look more closely at how proponents of PPI in health research explain their rationales for doing PPI.

4.9 Evidence for the impact of PPI

In this section I will discuss several NIHR-funded, or NIHR-backed reports on the impact of PPI in health research in the UK, including documents that offer guidance to researchers (Wilson et al., 2015; NIHR Research Design Service, 2014; INVOLVE, 2012, 2013e; Staley, 2009). In a context in which PPI is still only partially normalised with health services research and medical research, these publications highlight best practice in PPI and promote the advantages of doing PPI, as well as drawing attention to difficulties or tensions that require resources to resolve. A study by Keenan et al. (2019) of the normalisation of PPI within one of the NIHR's programmes for Collaborative Leadership in Applied Health Research and Care (CLAHRCs) found that even within the organisation in question, which had a policy of programme-wide support for PPI, it was not fully embedded within the CLAHRC's research projects. The impact documents to which I refer here (Wilson et al., 2015; NIHR Research Design Service, 2014; INVOLVE, 2012, 2013e; Staley, 2009) may be seen to build the case for PPI within the wider health research community, in a context of much disparity between projects in the extent to which PPI is seen and treated as an important part of health research.

A major theme across the documents concerns the value of the patient perspective and what it adds to research. The NIHR handbook on PPI for researchers (NIHR Research Design Service, 2014) answers the question of the importance of PPI exclusively in these terms, focusing on the role of patients in offering insights into the lived experience of a condition that researchers had not considered. Such insights may be invaluable in shaping research agendas (see also Davies' Foreword to Staley, 2009).

Involving the public in research is understood to influence the quality and relevance of the research (INVOLVE, 2012). PPI may improve the clarity and accessibility of information about research (INVOLVE 2012). Moreover, involvement can also offer researchers feedback on the appropriateness of their methods, and on the relevance of their research outcomes to the public (INVOLVE, 2012). PPI can help to clarify the aims of a project (INVOLVE, 2012). Staley's (2009) review of the impact of public involvement found that it had enabled researchers to better understand the needs of health service users. PPI can lead to increased participation rates in research, because it gives credibility to the research among the public and enables researchers to reach individuals who might otherwise not be aware of the research, nor feel confident to get involved (Staley, 2009).

PPI can have benefits for those involved in research, including PPI representatives themselves and research participants (INVOLVE, 2013e; Wilson et al., 2015). Wilson et al. (2015, p.135) found evidence that PPI could lead to an 'increased sense of self-worth and confidence' among PPI representatives, as well as leading to a 'career trajectory' in PPI for some. Staley (2009, p. 80) found that taking part in PPI 'increased people's capacity for further advocacy work by enabling them to form new relationships with key policymakers and local agencies'. Moreover, Staley (2009) found that in the long term, PPI could help to establish organisational partnerships which would then be well-placed to bring about change.

The arguments for PPI cited so far relate mainly to what Wilson et al. (2015, p. 5) refer to as the 'methodological argument' for doing PPI: that is, that it ultimately 'improves quality within the health service, particularly in terms of service delivery and patient outcomes'. Yet, as noted previously, there is perhaps a more fundamental reason why proponent of PPI see it as a good idea: the perceived need to democratise research (as discussed in previous sections). This is the 'moral argument' for PPI (Wilson et al., 2015, p. 4). As the INVOLVE briefing document (2012, p. 8) states: '[i]t is a core democratic principle that people who are affected by research have a right to have a say in what and how publicly funded research is undertaken'. The two elements are separated out in this analysis, yet, as we have seen, a core element of both participatory action research and emancipatory research is their insistence on the inseparability of the 'moral/political' and the 'methodological'. This is manifested, for example, in the tendency of emancipatory research in particular to highlight the role of the material relations of research production in the shape it ultimately takes (for example, a university's position as the holder of a grant will be an important mediator of the form that public involvement takes). This is not to suggest that researchers ought to be able to resolve these tensions, but rather to highlight the fact that PPI is an attempt to work with these university structures, without necessarily being able to resolve them.

4.10 Implementing patient and public involvement

As the INVOLVE briefing document for researchers observes, '[h]ow you involve people will depend on the nature of your research, as well as the different activities people decide they would like to get involved in' (2012, p. 21). There is no one model of how to do PPI: the goal and purpose of the research, as well as the methodology, will impact on the role that researchers and institutions expect service users to play. Although PPI will vary a great deal from one project to the next, the INVOLVE briefing document makes a number of practical recommendations for researchers doing PPI. These include: involving people from early in the project, being clear about the commitment that is involved, making involvement accessible and resourcing it adequately, providing training and support, being clear about responsibilities within your own organisation in relation to PPI, and recording evidence of PPI activity in your research (2012, p. 13; see also CLAHRC East of England, 2018).

As previously discussed, INVOLVE (2012, pp. 21-24) has had a threefold model for conceptualising how PPI can function in health research, which comprises 'consultation', 'collaboration' and 'user-controlled research'. By way of comparison, the three models identified by Wilson et al. (2015, pp. xxv-xxvi) are the 'one-off model', the 'outreach model' and the 'fully intertwined model'. Wilson et al. conceptualise this hierarchy in terms of the time and resources required in each case, which is a way of acknowledging that the capacity to undertake PPI is linked to funding, and that it will therefore differ between projects according to budgetary arrangements. Furthermore, the terminology used by Wilson et al. (2015) situates ownership of the research within the research institution, which acknowledges that PPI is, first and foremost, an institutional practice. The term 'outreach' implies that it is the institution reaching out, for example.

Because it questions ready-made decision-making, the question of ‘how’ to do PPI inevitably gives rise to questions about leadership and democracy, as well as about inclusion and exclusion. This can lead to some tensions in the instructional literature. For example, in the INVOLVE (2012) briefing document, the pronoun ‘you’ is used to refer to university researchers and the pronoun ‘they’ is used for members of the public. The manual reminds researchers: ‘how *you* involve people will depend on the nature of *your* research, as well as the different activities *people* decide *they* would like to get involved in’ (p. 21, my italics). In another example, the document advises researchers to ‘[i]nvolve *people* at an early stage so that *they feel* part of the research and also have a *sense of ownership* of the research’ (p. 13, my italics). This language may well reflect how PPI processes run in practice much of the time, in the sense that many are indeed directed by academic researchers. However, it does highlight a need to explore how language is being used to create a sense of what ‘standard’ PPI might look like, and how it can signal that certain sorts of PPI are outliers, such as projects being run by service users, or involving peer researchers who are contracted by the university, but who otherwise sit outside traditional structures of knowledge and expertise.

A 2019 paper reporting on the CLAHRC East of England’s IMPRESS study provided qualitative data about the barriers and facilitators to implementing and normalising PPI within the CLAHRC (Keenan et al., 2019). It highlighted researchers’ nervousness about their own understanding of what PPI ‘was’, and what best practice looked like; as a result of this some researchers preferred to opt for tried and tested approaches to PPI rather than thinking creatively about what might work best for their own project. One respondent referred to ‘making it up as I go along’ (Keenan et al., 2019, n. pag.). The study also highlighted the finding that researchers experienced support for PPI within the CLAHRC as operating at a ‘bureaucratic’ level rather than at a hands-on level (Keenan et al., 2019, n. pag.). This identified that the CLAHRC programme may have placed more emphasis on establishing PPI than on monitoring and appraising it within the CLAHRC. The authors highlighted the time-consuming nature of building and maintaining PPI relationships, and its economic value was clearly in question among some parts of the research community. The risks arising from these barriers were that busy PPI leaders might allow the work to ‘slip’ (Keenan et al., 2019, n. pag.), or that formulaic modes of doing PPI might be used. The paper provides insight into the important question of what PPI may be like when it happens, and what those who do it feel about it. This paper suggests that PPI is still experienced as a relatively new part of the research process for many academics, and that it has not been completely normalised.

4.11 Critiques of PPI

The implementation of PPI has been critiqued both by academics and activists who define themselves as working in the PPI field itself, and by those who align themselves with a critical social policy tradition. Critics of the implementation of PPI policy argue that an activist agenda has been co-opted and neutralised by policymakers, such that involvement processes have come to be about shaping enterprising consumers rather than listening to citizens (Beresford, 2014; Carr, 2014; Bradley, 2013; Barnes, 2008; Scourfield, 2007). These voices often became more critical after the advent of austerity as a UK government policy from 2010, and with the associated public spending cuts which especially adversely affected disabled people (Spartacus Network, 2015; Beresford, 2014; Duffy, 2013; We Are Spartacus, 2013). In a society in which the ‘rationality’ of the market is allowed to prevail, it may be difficult for PPI to be conceptualised outside of a framework of consumer choice and consumer satisfaction (Beresford, 2014). A notion of the citizen as consumer is not wholly incompatible with a notion of democratic citizenship, however when consumption becomes the dominant model for understanding material and social relationships, this is indicative of an altered understanding of the connections between the individual and society (Bradley, 2013). This has particular implications for the most vulnerable people (Scourfield 2007). A big question for practitioners of PPI might therefore be: can we use PPI to facilitate a form of co-production of knowledge that enables people to become not just consumers of healthcare but active citizens of a social democracy (see

Beresford, 2019, 2014)? A related question might be: how far will it be possible to bring about such a shift without a change in political and social structures?

The challenges and contradictory effects of ‘entrepreneurial’ personhood on public involvement in research are illustrated in a paper exploring the experience of social housing tenants who participate in deliberative forums with their ‘quasi-public landlords’ (Bradley, 2013, abstract). The paper focuses on the contradictions involved in finding one’s voice in a nominally participatory setting. Bradley argues that Butler’s (1993, 1997) theory of interpellation can explain how tenants who participate gain a voice and yet are compelled via this process to take up a position as responsible consumer-citizens who must then distance themselves from stereotypical social housing tenants. As Bradley writes, drawing on Butler’s work, ‘[t]he recognition inherent in the act of participation inducts tenants into the subject status that conditioned their demands for participation’ (2013, p. 392). For Butler (1997), to able to speak is to belong to a system that regulates both what we can say and how we represent ourselves. This suggests that the ability to have a voice in participatory research is never separate from the ability to make oneself intelligible within a particular system or discourse. Participation is predicated on having access to the tools of participation; but that very access may be also predicated on participants relinquishing or suppressing something of the very ‘experience’ that one might be trying to communicate.

A further criticism of PPI, or perhaps rather, a difficulty associated with implementing it, questions how academics or clinicians can embed participatory research practices in institutions without them becoming something an institution imposes, which in turn can lead to a risk of implementing such practices in a tokenistic way (see Turner & Gillard, 2012). Although university-led participatory research may not be tokenistic *per se,* making public involvement a duty for researchers risks tokenism as researchers seek to fulfil a requirement to involve, while still undertaking the research they had already decided to do. Yet if public involvement is not mandated, it is much more difficult to transform research agendas so that they do include a diversity of voices, including those outside of universities.

Williams et al. (2020) argue that the concept of ‘co-production’ has become ubiquitous in health policy research but that the good practice, which values real citizen involvement, is increasingly rare. The authors argue that structural factors in academia, such as the ongoing lack of prestige associated with the time-consuming work of involving others outside academia in research, play an important role in this. Williams et al. (2020) note that career advancement continues to be linked to publication record in academia, and also that the oftentimes mundane work of maintaining patient and public involvement networks is, in some cases, passed down to the most precarious colleagues in universities.

Other researchers have focused on the questions that PPI may introduce about the status of knowledge. In the two papers I shortlisted in my review of public involvement in the journal *Social Science and Medicine*, a key topic is the tension between evidence-based policy-making and the Foucauldian concept of ‘subjugated knowledges’ (Foucault, 2003), which their authors associate with user participation (Lancaster et al., 2017; Lopes et al., 2015). Lopes et al. (2015) found that macro-level perceptions about what counts as evidence influenced processes at the micro-level in patient and public involvement activities. In this study of stakeholder involvement in the work of health Advisory Committees in Australia, the question of how lived experiences of illness could be articulated in such a way as to be incorporated into official advice was especially problematic. Meanwhile, in their work with people involved in drug policy discussions in Australia, Lancaster et al. (2017) analysed the co-constitution of the discourses of evidence-based policy and consumer participation, finding that such discourses construct the consumer as having a particular relationship with, or lack of relationship with, evidence. For Lancaster et al. (2017, p. 66), the category of consumer takes shape in the context of ‘the structures through which representation is sought’. These expect and require the consumer to offer up a particular kind of knowledge, and to enact a particular kind of oppressed and marginalised subjectivity. This circumstance, the authors argue, may actually be restricting the potential for user involvement to pluralise and diversify the kinds of knowledge that can then be understood as knowledge in health policy arenas. In order for user involvement to be ‘truly deliberative’, they argue, there needs to be a full examination of how the rhetoric of involvement (via such terms as ‘consultation’) participates in an ‘“economy of restriction”’ of users (Lancaster et al., 2017, p. 66, quoting Fraser et al., 2018 [2016]). The critique offered by Lancaster et al. (2017) brings to mind the concept of ‘testimonial injustice’ (Fricker, 2007), whereby the pre-judging of a speaker alters the status of the knowledge that the speaker is seen to bring.

Lancaster et al. (2017) also argue for committee formations that change the status quo in user involvement: ‘consider how […] subject positions might be remade if one ‘scientific’ voice were to sit on a committee alongside 25 people with lived experience of drug use’ (p. 66). In the PPI events I attended in the early part of my PhD studies, mainly run or supported by the CLAHRC East of England, I witnessed events which were structured in this way, with service users and stakeholders from many walks of life outnumbering researchers. However, such events, which recognise and attempt to challenge existing power structures in research processes, have yet to be normalised across the board, as Keenan et al. (2019) point out.

4.12 Strengths and limitations of this review; future work

This review has characterised public and patient involvement in health research as an institutional practice in the UK, with a history and theory drawn from various intellectual traditions and social movements around the world. Influential thinkers in the field of user involvement have indicated directions for exploring some of the debates and tensions around how PPI could or should be implemented, and what it could, should, or might be able to do in terms of democratising access to research. A main strength of this review is its detailed focus on points of tension in relation to the question of how the aspiration to democratise research is translated into institutional practice. A possible limitation of the review is that, due to the size of the field, and constraints on my own time, I was not able to undertake a systematic scoping review of a journal such as *Health Research Policy and Systems*. This might have enabled me to offer a more robust overview of the current state of the field, however, it is also possible that the review of the medical sociology journals I undertook was more enlightening, because it demonstrated how far discourses of involvement have, or have not, been normalised within that literature. Furthermore, I wanted to give a substantial amount of attention to instructional literature published by UK research funders and supporting bodies, because my own project is operating under the aegis of one such funder, and it is important to situate the decisions I make about my own project in relation to the norms expressed in these materials. A further possible limitation of the review is my own tendency towards criticality, in that I am drawn to focusing on work that highlights tensions in the translation of theory into practice. I have sought to remain aware of this tendency have balanced my discussion of critical policy papers with engagement with case studies, government policy documents and instruction handbooks. One of the most useful papers I have examined in this review is Keenan et al. (2019), which engages ethnographically with different practitioners' own understandings of PPI, including their sense of its benefits, its drawbacks and its frustrations. This qualitative investigation into the process of embedding PPI provides an honest account of how it feels, on the ground, to be doing PPI in the 2010s. The lack of strong observational findings suggests that the field of PPI research would be advanced by further ethnographic work to explore its implementation from the perspective of its practitioners, and that more research of this kind is needed if we are to be able to think in detail and in context about how to transform research relations in the 2020s.

4.13 To conclude: Lessons of this review

In this section, as well as giving an overview of the literature reviewed and the key points I have sought to develop about PPI, I briefly discuss what I have learnt about PPI that helped me to make decisions about how to design the research. In this chapter, I examined a diverse range of literature relating to the practice of PPI, which can be roughly categorised into: legislative documents and government policy guidelines; instructional literature from governmental research bodies; papers and book chapters examining the history and theory of PPI, or radical social movements and practices that have informed contemporary PPI discourses; as well as papers and reports examining PPI in practice, some of which are commissioned by health research funders and their subsidiaries. The diversity of modes of speaking about PPI, and different kinds of rhetoric on display in my review, draw attention to the status of PPI as a fragile but highly politicised object of knowledge which different stakeholders seek to capture and define for their purposes. I have suggested that PPI represents an attempt to institutionalise the work of social movements and intellectual traditions that have historically sought to *critique* institutional practices (e.g. emancipatory research), and in this sense PPI may always be an endeavour that is fraught with tension and difficulty. Yet PPI also represents an attempt to democratise research relations in the here-and-now, rather than waiting for the ideal material conditions to arrive, and in this sense the difficulties and challenges it presents are ones that are well worth our time and energy as researchers. PPI requires us to engage directly with the philosophy and ethics of our research: what is it for? Whom does it serve? They offer an opportunity to formulate an ethos for research that simultaneously strives for change while being realistic about what is manageable within our institutional constraints.

Perhaps the most important lesson I took from this review that informed my own approach was the need for a pragmatism when implementing PPI, whereby the researcher is guided by the specific requirements of the research problem, and by a realistic assessment of available resources, when considering how to design PPI for a project. However, alongside the need for pragmatism, I have internalised a sense of the university researcher's responsibility to reflexively consider her power and its effects, and perhaps especially to inquire into the aspects of this power that may not be immediately visible or tangible, but which accrue to her through the current social and material relations of research production.

Another key lesson from this review, which helped me to plan my methodology, is that PPI is time-consuming and resource-intensive, often in ways that are not highly prized by contemporary academia. PPI relationships take time to build and maintain. PPI needs to be planned for, from the outset, allowing time and other budgetary resources; without this, it is much less likely that PPI will be able to take place from the inception of the project. A related lesson of the review is the role of PPI in shaping a research agenda from the beginning: if it is implemented early on in a project, members of the public, and patients with specific experience of the condition or service that is being researched, may be able to offer insights that academic researchers had not accounted or planned for. Doing PPI in this way promotes greater democracy, transparency and accountability in the research process, but it also requires university researchers to enter into PPI in a spirit of openness, responsiveness and humility, and be ready to be challenged about what they plan to do. Implementing such an approach may lead to a more robust research protocol, because researchers will have had to defend their plans and think carefully about how to articulate their research in clear, accessible language. Moreover, it may lend credibility to the research among the public it is intended to serve, because the group or groups who are the subject of the research have been involved in scrutinising what is being proposed. In the next chapter, on methodology, I will be going on to explore how the tensions associated with PPI, which I documented and analysed here, have influenced the decisions I made about how to design my research.

Chapter Five
Methodology

5.1 Research problem and theoretical framework

At the heart of the research problem for this study were the views and lived experiences of disabled people, as well as their agency (or lack thereof) in shaping rehabilitation services. I therefore required methods which put the voices of disabled people at the centre. I used a **problem-solving approach** to think about how to develop this: that is, I sought to diagnose the research problem as a type of 'intellectual puzzle' (Mason, 2018, pp.11-12) and then to enlist methodological tactics that would yield pertinent insights. I diagnosed the research problem I was grappling with as an 'experiential puzzle': I wanted to understand how a particular aspect of life is experienced (Mason, 2018, p. 12). The research problem also has some qualities of a 'mechanical puzzle': I was interested in knowing 'how something works or is constituted' (Mason, 2018, p.12), from the point of view of those experiencing it. I sought to find out how participants make sense of their rehabilitation experience. The study would generate knowledge about how rehabilitation had been for them when it went well, and what it had been like when it went less well, and what factors they saw as contributing to each of these outcomes. The research would inquire into participants experiences of decision-making in rehabilitation. Did they feel that their voices were heard? What would enable disabled people to shape rehabilitation? By seeing the research problem itself as central to determining the strategies of data collection and analysis used, I had necessarily chosen a **pragmatic approach** to designing my study (Morgan, 2014; Creswell & Poth 2016; Mason, 2018). Pragmatists tend to agree that knowledge is socially constructed, but they also think about knowledge in relation to its utility: what is it going to be used for (Kaushik & Walsh, 2019)?

In this chapter, **I aim to describe my pragmatic, problem-solving approach:** I explain how I was guided by my analysis of the research problem to develop a suitable set of methods that could yield relevant and distinctive data. To succeed, I needed to work **iteratively and reflexively**, moving between various sites: interdisciplinary academic knowledge, PPI input, ethical sensibility, personal experience, and back to the research problem. I also needed to consider how best to **collaborate** with others, especially other experts-by-experience, to problem-solve in inclusive ways.

Analysing the research problem as an experiential puzzle, in which participants' points of view were at the heart of the research, it made sense to use qualitative methods such as semi-structured interviews and focus groups, rather than either observational methods, or tools for collecting quantitative data. Since I was also interested in what we might think of as the 'emotional truth' of rehabilitation experience ('what did it feel like, and in what ways did this matter?'), and I was seeking to understand the role of this aspect of rehabilitation in people's development of a sense of agency in the process, I also chose to explore how creative writing might be used as within a data collection activity. Drawing on the emerging literature on using creative writing as a method in social research, which is discussed later in this chapter, I judged that using structured writing as a fieldwork activity might offer opportunities for participants to engage with their rehabilitation experience from a new angle, and might facilitate the emergence of data which would complement and illuminate that collected elsewhere in the fieldwork.

The decision to focus on accounts of lived experience as a form of expertise about rehabilitation necessitated a theoretical framework which allowed me to attend closely to the meanings that participants themselves attributed to their experiences. A commitment to this mode of attention also required that I should suspend the desire to jump too quickly into explaining, or making causal connections, but rather should attempt to see the world through the participant's eyes. In the early part of my work on the project, I judged that phenomenology, with its emphasis on description and on questioning when and how we come to deploy categories such as subject and object (Merleau-Ponty, 2002 [1962]), would help me to put my own assumptions on one side, and listen carefully to the sense-making work that the participants were doing.

Papadimitriou (2008, p. 693) argues for phenomenology as an approach that defamiliarises subjectivity and objectivity, as follows:

> Against a view of the human being as subject, encapsulated in a mechanistic physical body detached and distinct from an object-laden environment, phenomenology seeks to transcend the subject-object dichotomy by viewing the human being as an intentionally lived relation, engaging in and engaging social and physical contexts.

This analysis draws attention to a false division between the human being as ‘subject’ and the environment as ‘object’. Papadimitriou’s analysis of SCI patients’ use of wheelchairs finds that rehabilitation can be about a liberating process of becoming ‘en-wheeled’, with the wheelchair becoming ‘part of me’, to quote one of the participants (2008, p. 699). A phenomenological analysis pushes beyond the binaries of subject/object, health/illness, disabled/non-disabled, and by refusing to be limited by these categories, creates the conditions for insight into bodily experiences that may easily be ‘othered’ by conventional taxonomies (see Leder, 1990; Toombs, 1993; Carel, 2008; also Merleau-Ponty, 2002 [1962]). Phenomenology is widely used in the field of qualitative health research, and academics have developed protocols for routinely doing ‘interpretative phenomenological analysis’ (IPA) (Smith et al., 1999; Biggerstaff & Thompson, 2008). However, routinely using any approach within research without analysing the how that methodology can be developed to respond to the research problem, as Mason (2018) advocates, undermines the possibility of producing credible analysis or findings. I found the principle of attending to participants’ own meanings a useful aspect of phenomenology to deploy in my fieldwork and data analysis, but I found the protocols of IPA restrictive and distracting when it came to making sense of the data. The idea of following a strict set of rules created for someone else’s research prevented me from fully realising my pragmatic strategy, and from taking decisions in response to the needs of my particular research question. Nevertheless, the decision to focus on understanding what rehabilitation was like from the point of view of my respondents meant that the philosophical tradition of phenomenology (if not IPA itself) was an important influence on my thinking as I collected and analysed the data.

Because one of the main goals of the research project was to amplify disabled people's voices and to foreground their views, the research problem required analytical techniques that prioritised the meanings and interpretations that participants ascribed to their experiences. I found Mason's (2018, p. 134) taxonomy of three modes of reading interview data ('literal', 'interpretive' and 'reflexive') helpful because it acknowledges that interpretation takes place in a context, structured by the question of what the researcher wants to do with, or get from, the data. As such, this framework supported my pragmatic approach. Mason associates each mode of reading with a type of outcome, while acknowledging that in practice, researchers may use all three modes together to derive data. Here I briefly describe how I thought through the utility of each mode of reading. My stated aim of foregrounding disabled people's own views and opinions led me to seek to work with the data in a 'literal' way; that is, I sought to find out, and then to present to the reader, the key themes seen to arise in the data. However, I also recognised that lived experiences are culturally, historically and psychosocially situated, and that interviews, focus groups and creative writing groups are scenarios constructed by the researcher to yield particular insights. In these scenarios, events will be recounted in particular terms to me because I am perceived to be a member of a certain community (a researcher, a woman in her 30s, a disabled person – although in my case, my disability is not always immediately visible). Furthermore, I recognised that both processes of transcription of interview tapes, and processes of reading, analysis and writing, are processes of mediation, and are not neutral activities, but rather play a role in shaping how the data is understood by readers of the research. Having reflected on these issues, I came to the conclusion that a 'literal' approach would necessarily be inflected by interpretative thinking, and that the challenge ahead was to try to think critically and reflexively about the grounds upon which my interpretations were being based, questioning my own assumptions, and continually returning to the transcripts when interpreting, even as I recognised that those transcripts themselves were constructions. My reasoning could thus be described as ‘abductive’ – that is, involving an iterative movement back and forth from data to theory (Mason, 2018; Blaikie, 2007). This seemed to be a useful strategy for ensuring that I paid close attention to the data whilst being careful to analyse the contextualising role of my personal and academic resources in my interpretative practice.

The question of who has the power to shape and frame knowledge in the research process is not a theoretical nicety but is instead fundamental to the aim this study, that of centring the voices of disabled people, some of whom may be extremely marginalised, and voiceless, in society (see Barnes, 1996; Shakespeare, 1996a; Oliver, 1992). In Chapter Four, I discussed the sociological traditions that have sought to redistribute power in research processes, so as to inform the design of this project. These literatures informed my understanding of the relationship between ethical and moral questions of involvement on the one hand, and methodological questions on the other: I came to understand the two issues as inseparable. I drew on these literatures both to analyse how my own power and my own concerns might impact on the data analysis process, and to think carefully about how to share decision-making power with members of the public who had experienced rehabilitation. It is to this last issue that I now turn.

5.2 Patient and public involvement

In making decisions about patient and public involvement (PPI) in the project, I was guided by both the aspiration in PPI to democratise the research process and also by the need to craft a study whose results would be as relevant and useful as possible for disabled people undergoing rehabilitation in the future (Williams et al., 2020; Wilson et al., 2015) who therefore needed to be involved in shaping it. I also maintained a pragmatic approach here, making decisions on the basis of a) what would enable me to respond to the research problem outlined above and b) what would be feasible and achievable for me as an individual researcher with time-limited doctoral funding. Working with a local disabled people’s organisation and drawing on my own and my supervisors’ networks of colleagues in the disability community in the East of England, I began by recruiting attendees with lived experience of rehabilitation for a roundtable event to discuss my aims and proposed research methods for the study. This event took place in February 2016, just a few months after I started work on the project, and was well-attended by members of the public who had experienced rehabilitation for a long-term condition. The event, which was held at UEA, was publicised via my research team's local networks, and via promotional information sent out by the Norfolk-based user-led disabled people's organisation Equal Lives, which has played an active role in supporting all aspects of my project throughout its lifetime.

The project ultimately had two strands of PPI. Using the classification of PPI developed by Wilson et al. (2015), the strands could both be understood to operate within an 'outreach' model, whereby the researcher has regular points of contact with lay representatives through the course of the research. The first strand of PPI involved the development of a wide network of individuals who might attend occasional events, and was helpful as a means of raising wide awareness of the project. The network I developed early on during the project's life, and the trust I built with colleagues in the disability community, was extremely helpful during the recruitment phase, in enabling me to cascade information about the project and to reach potential participants who might not otherwise have found out about the research. Recruitment went smoothly: I recruited 20 interviewees and enough participants for four successful focus groups between 1st January and 31st May 2017. This may well have reflected the efforts I made to connect with a wide range of advocacy groups and disabled people's organisations from the very beginning of the project.

The second mode of working with the patient group involved the creation of a small project advisory group. Working with this group enabled me to make informed decisions about a wide range of project matters, including the wording of information sheets and consent forms, the schedule for interviews and focus groups, recruitment methods, and data analysis. This is a widely used mode of collaboration (see INVOLVE, 2013a, b, d). One of the members attended as a representative of Equal Lives, which played an active role in setting the agenda for the project. All five members of this small group (including me) had experienced rehabilitation for a different long-term condition. Between us, we had experience of a range of physical and sensory impairments. Two members were male, and three of us were female.

I had planned for members of the project advisory group and members of the wider network to have the opportunity to attend a data analysis roundtable event. The purpose of involving a large group of individuals in the data analysis was 1) to explore how far consensus could be reached about the meaning of particular data excerpts; 2) to ensure the relevance of the results to the wider patient group; and 3) to widen and democratise the research process. In the event, I restricted the data analysis event to my project advisory group, because I became aware of how close knit the disability community was across East Anglia, and it appeared that some of my research participants had come forward via a process of snowballing. It was essential to maintain anonymity during the data analysis process and, in order to achieve this, I took extra precautions when anonymising the data for this meeting, sometimes changing key details about participants' experiences or impairments, in order to make participants unrecognisable.

I also planned that PPI members would have the opportunity to be involved in disseminating results of this project directly via their networks. I had long intended to hold a dissemination event of some kind, or to participate in a community event such as Norwich's annual Disability Pride day, to share learning from the project with members of the public. At the time of writing, the Covid-19 crisis has made face-to-face events problematic, so it currently appears more likely that this activity, and future implementation work, will take place via online meeting spaces initially.

I followed INVOLVE guidance when deciding how to remunerate PPI work. PPI members were able to claim a fee of £30 for each two-hourly meeting they attended, and could reclaim travel expenses. I designed meetings to last 1.5 hours, but usually asked members to prepare by reading a short document in advance.

Throughout the remainder of my methodology section, I refer to the role of PPI members where their input shaped my decisions. Whilst it would not be accurate to say that the project was co-produced, because I was always the lead researcher seeking advice and input from PPI members, the involvement of disabled people with a lived experience of rehabilitation was nevertheless a key feature of my work from its inception. In the next section, I discuss my reasons for deploying creative writing in my fieldwork. This had been an idea I discussed with service users at an early stage of the project, and which I introduced to them because of my own wish to see how arts-based methods might be used to yield insights into the lived experience of rehabilitation.

5.3 Creative writing as research method

When I was planning this study, I became interested in the question of whether using creative writing as a research tool could illuminate aspects of the lived experience of rehabilitation that might not be so easily accessed via focus groups and interviews. I considered this question iteratively, drawing on my existing knowledge as a humanities researcher to decide what else I might need to read, and to do, in order to make decisions about using creative writing in this project. In this section I give a brief overview of the key concepts and issues with which I engaged to develop my approach for this part of the project.

In a report for the World Health Organization, Greenhalgh (2016, p. 7) emphasises that stories are '*sense-making* devices': I wanted to understand what kinds of insights a writing activity would yield for participants in my research. Would the injunction to write 'creatively' or to write fiction liberate participants from anxiously focusing on producing a 'true' account, in such a way as to allow them to focus more clearly on the *meaning* of the experience (see Barone and Eisner, 2012; Leavy 2009)? Drawing on these theories of the use of writing in social research, I hypothesised that the rehabilitation process might have evoked strong feelings which, for some people, could be more easily expressed in fiction than in an account of what actually happened. I also drew on my own experience of writing auto-ethnographically about childhood rehabilitation (Cooper, 2020, 2015) to theorise that the act of writing itself might support participants to make sense of their lived experiences of rehabilitation through the creation of narrative. A fieldwork activity involving creative writing might therefore offer specific kinds of insights into participants' sense-making work that were less easily accessible via focus groups and interviews.

The idea that there may be merit in challenging the '*fiction-nonfiction dualism*' (Leavy, 2009, p. 48) is a relatively new concept in health sciences research, yet it is compatible with a conceptualisation of medicine as a discipline of interpretation, and with the recognition that no two patients will narrate their illness in exactly the same way (Greenhalgh & Hurwitz, 1999). Furthermore, the question of whether and how pain, illness and disability can be represented has been central to the development of medical humanities (Scarry, 1985; Sontag, 2002 [1978]; Frank, 1995; Woolf, 2002 [1930]). My knowledge of this field from previous research was an asset in designing this strand of the fieldwork. There is a growing literature on the use of creative writing in health and social care contexts (see, for example, Sampson, 2004). I hypothesised that the act of taking part in a facilitated writing group, and subsequently of sharing stories, could be liberating for participants, as well as helping to foster a sense of belonging (Nyssen et al., 2016). However, any benefits to participants were incidental and secondary to the primary reason for undertaking the creative writing group, which was to elicit stories and reflections about rehabilitation in a deliberately crafted form, which might offer novel insights into the lived experience of the process.

Several attendees of the PPI roundtable in February 2016 felt that creative writing had merit as a research method on the grounds that it could promote greater inclusion: some participants might prefer to express themselves via the written word. Yet other PPI voices expressed concern that writing might not be an inclusive mode of collecting data, because it would exclude people whose impairment made self-expression via language or writing very difficult, for example people with aphasia. Another of the themes that was explored in the roundtable discussion was whether or not the products of the creative writing should be used as research data. Participants might feel inhibited by the knowledge that their writing would be analysed. I worked closely with PPI members when designing the creative writing element, both in the stage prior to submitting my research protocol for ethical approval, and in the period leading up to implementing the creative writing group. The full details of the procedure I used for this aspect of the fieldwork are described later in the chapter.

5.4 Purposive sample

Sampling is a term which was originally drawn from statistical studies (Emmel, 2013), but which is used with different purposes and effects in qualitative research. Like a quantitative researcher, a qualitative researcher still needs to consider how to select participants and whom or what the selected participants represent. I used a purposive sampling method, in which cases are chosen because of the features they demonstrate, or because they reveal a counter-position (Emmel, 2013; Mason, 2018). In order that the data would provide meaningful information about rehabilitation as a lived experience, I sought participants who identified as disabled, and who had been through rehabilitation.

5.4.1 Using the term 'disabled people'

In my project information sheet, I chose to use the term 'disabled people' but did not give a definition of disability. This may have had implications in terms of who chose to put themselves forward as participants. During the first year of work on the project, when I was working on the sampling strategy, I saw it as important for the wording to draw on the language of 'disability', and thus implicitly on rights discourses that have emerged out of campaigns allied with social model thinking (Oliver, 1983). At that time, I was sceptical about the use of impairment labels in social research; I felt that they taxonomised lived experiences in a way that linked these with an oppressive medical model of disability. I had recently reclaimed the term 'disabled' for myself and I felt it to be emancipatory. Further, as noted in the review of the rehabilitation science literature, most research undertaken within that discipline, including qualitative research, groups people according to their impairment. At that time, I did not want to confer that kind of explanatory power upon impairment labels, but the process of doing this project has taught me that many people find value, solace and belonging in those labels, and that it is difficult to do this kind of research without them (Shakespeare, 2014). I often wonder how the results of my project might have differed had I chosen not to work so explicitly with the language of disability, or had I chosen to work with people with one specified impairment. When I consider my decision to use the term ‘disabled’ now, I believe that it was done partly a way of highlighting my disciplinary proximity to disability studies, and my distance from what I saw as the more medicalising approaches of rehabilitation science. But it was also a way of highlighting the politics of the project, and my commitment to advancing disability rights. Given the framing of the project in terms of ‘rights-based’ rehabilitation, it was an important term to use.

On the information sheet, I did provide some examples of what I mean by rehabilitation, stating that it included, but was not limited to:

- physiotherapy
- occupational therapy
- speech and language therapy
- rehabilitation medicine
- rehabilitation counselling
- wheelchair services or training for use of other assistive devices
- experience of using orthotics and prosthetics
- other type of rehabilitation for a physical impairment
- rehabilitation for a sensory impairment.

I stated that rehabilitation could have taken place at any stage of the life-course (WHO, 2011) and I tried to encourage participants to self-include rather than for me to inappropriately exclude.

5.4.2 Inclusion criteria

In my research protocol, I stated that I would include people with a long-term physical or sensory impairment who have had (or are currently having) inpatient or outpatient rehabilitation. I noted that participants must have a good enough command of the English language or British Sign Language to understand the information sheet, give informed consent, and participate fully in the data collection activities. I included participants with communication difficulties such as aphasia and I made arrangements for their inclusion.

5.4.3 Exclusion criteria

The exclusion criteria given in my protocol were:
1. Children: anyone under the age of 18
2. Individuals without the capacity to provide informed consent
3. Individuals whose primary experience of rehabilitation is for an intellectual impairment (e.g. autism, learning disability) or for a mental health issue (e.g. schizophrenia, bi-polar disorder).

The decision to exclude participants whose primary experience of rehabilitation related to an intellectual impairment or mental health issue was not easy, especially given that I had chosen to use the term ‘disabled people’, which is associated with the social model of disability, and which therefore invokes self-definition. I felt that the rehabilitation experiences of people with mental health issues and intellectual impairments were important and merited research with regard to rights, but I ultimately decided that such research would have more relevance and impact for the communities it served if it was undertaken as part of a separate project, hopefully led by people with lived experiences of the impairments in question. I hypothesised that the inclusion of data about these types of rehabilitation experience might make it more difficult to make comparisons across the data set as a whole, and to find key themes which the majority of transcripts had in common. Indeed, as I shall discuss later in the thesis, I recognise that my decision to include people with a wide range of physical and sensory impairments has had an impact on the specificity of my data, and may mean that my project is not seen to fit easily within the scope of ‘health research’ and is instead classified as ‘social research’.

In compliance with the Mental Capacity Act (UK Government, 2005), I explained in my research protocol that mental capacity was to be assessed on an ongoing basis during the data collection activities, and should a participant lose decisional capacity during an interview or focus group, or appear not to have such capacity on the day, I would respond as necessary, and with sensitivity, to the situation. I stated that I would cease data collection activities if the person appeared to have lost capacity, and would only retain data if permission had been given by the individual in question. In practice the above scenario did not arise.

5.5 Ethics application, promotion and recruitment

In order to maximise recruitment opportunities, I decided to apply to the UK Health Research Authority for permission to recruit participants via the Norfolk Community Health and Care NHS Trust. I submitted my ethics application in summer 2016 and had received permission to begin recruitment by November of the same year. I discuss ethical considerations relating to my project later in this chapter.

In my protocol, I set up the two recruitment pathways, one via the NHS and one via the community. The NHS recruitment pathway operated as follows:
1) a) A patient could be identified as an eligible participant by a member of healthcare staff within Norfolk Community Health and Care NHS Trust. The eligible patient would be given a leaflet informing them about the research by their healthcare professional (Appendices 5 and 6). If the patient consented to be contacted, his/her contact details were passed on to me using a 'consent to contact' matrix (Appendix 20), and I sent out a participant information sheet (Appendices 8, 9, 12, 13, 16 and 17) using the introduction letter (Appendix 21). In practice, no participants were recruited via this method, although one found out about the project via a healthcare professional and contacted me directly.
1) b) Healthcare professionals from Norfolk Community Health and Care NHS Trust were able contact past patients (from 2011 onwards) whom they believed would be interested and eligible. This recruitment pathway proved

unnecessary due to the high level of interest in the project generated by the community recruitment pathways.
1 c) Posters were put up in the wards and waiting rooms in the Colman Centre for Specialist Rehabilitation Services (part of the NCHC Trust), to promote the project (Appendix 4). Interested patients were invited either to contact me directly, or to let a member of hospital staff know that they would like to take part.

The community recruitment pathway took place as follows:
2) a) Participants found out about the research via promotional materials circulated by user groups, charities, and disabled people's organisations (Appendices 5 and 6). The primary partner in this process was Equal Lives (the Norfolk-based disabled people's organisation). Participants made contact with me directly, or occasionally were introduced to me via a contact as someone who had expressed an interest in the study. This proved to be the most successful mode of recruitment.
2) b) Participants found out about the research via someone involved in my PPI network or wider network, and contacted me directly for more information. This tactic also played a helpful role in recruitment.

Promotion for the project was conducted via the websites and social media feeds of Equal Lives, NIHR CLAHRC East of England, Norfolk Community Health and Care Trust, UEA Disability Research, Headway and other user groups and individuals who were willing to post information online. Paper leaflets were given out by many of these organisations. PPI members offered to post information on their personal social media accounts, or to circulate it to friends. Posters were put up in wards and waiting rooms at the Colman Centre for Specialist Rehabilitation Services, and at the offices of Equal Lives and other organisations.

5.6 Data collection procedure

My analysis of the research problem as one which was concerned with meaning and experience led me to decide on the following data collection methods:

1) 20 one-off semi-structured biographical interviews to produce context-specific knowledge about the lived experience of rehabilitation (Mason, 2018);
2) 5 focus groups (each of 5 or 6 people) to explore views and opinions about using rehabilitation services;
3) creative writing group (1 x writing meeting, 1 x sharing meeting; up to 10 participants overall) to explore whether and how the use of a creative format might yield insights into rehabilitation that differed from, and complemented those collected elsewhere in the project.

These three strands would complement each other in terms of the different and specific insights they would yield (Mason, 2018), and I provide a details of each procedure shortly.

I carried out the following steps for all of the research strands. I sought written informed consent from each participant at the start of the data collection activity. I offered participants a choice of three ways of receiving information about the project: a ‘regular’ information sheet (see Appendices 8, 12 and 16) and an easy-read information sheet, designed with detailed input from two PPI members with aphasia (see Appendices 9, 13 and 17). The PPI members drew my attention to a series of templates developed by the NIHR Clinical Research Network for Stroke (see NIHR, no date), which I used in my information sheets. I also produced a digital video recording of me reading the information sheet. Consent forms were available in a ‘regular’ and an ‘easy-read’ format (Appendices 10, 11, 14, 15, 18, 19). All potential respondents had a minimum of 24 hours to consider the participant information sheet prior to taking part, and in most cases individuals had the information for a considerably longer period. I aimed to speak to each participant on the phone, or meet them in person before the data collection activity; if this was not possible I contacted them via email. The pre-meeting offered an opportunity for the participant to discuss with me any queries they had about taking part. After the data collection activity, I debriefed participants, providing information about additional sources of support, if they found they then needed this.

5.6.1 Strand 1: Interviews (n=20)

I chose a semi-structured interview technique because I already knew enough about the topic to discern what was and was not relevant to answering the research questions, but could not yet know the range and breadth of themes that my participants would discuss (Morse, 2012). The semi-structured interview would allow me to generate context-specific knowledge about the lived experience of rehabilitation (Mason, 2018), because the technique would permit me to be flexible and responsive to the direction taken by the interviewee, sometimes asking follow-up questions to obtain more information about a particular episode, and sometimes excluding questions if they had already been covered elsewhere. I began by asking the participant to talk to me a bit about their impairment, and if they felt comfortable to do so, the circumstances in which they acquired it. Then I moved on to eliciting information about their rehabilitation experience, including the aspects of it that went well and less well and the extent to which they had felt in control and involved in decision-making processes. The interview schedule is available at Appendix 7 and a transcript excerpt at Appendix 25. I conducted the interviews in a mutually convenient quiet place. This was usually either a booked room at UEA or at the participant's home.

At a later date, participants were sent their transcripts and asked to check that they accurately represented what had been said. I came to feel that this part of my protocol was not always a helpful addition to the process and that sometimes it was oppressive and burdensome for participants to be asked to 'sign off' their interview transcript. Because I took a year's maternity leave immediately after the fieldwork, by the time I was able to send transcripts to participants, much time had passed. In most cases participants responded quickly and affirmatively when I sent out transcripts, but occasionally they wanted to specify sections of text that I should remove, and in a few cases I had difficulty getting hold of participants or they seemed too busy to engage with the process. Ultimately, all participants did engage with the process. As I grew in experience as a researcher, I began to feel that this section of my protocol was ambiguous in terms of what it sets up and potentially burdensome for participants. This was certainly a stage of the research process that I would think carefully about using again in future projects.

As previously noted, recruitment was relatively straightforward, and all 20 interviews took place in quick succession during the winter and spring months of 2017. I was able to recruit interviewees of various ages (from mid-20s to 80s), with a range of different impairment experiences. Eight participants were female and 12 were male. Although I did not ask participants their ages, I was able to judge, from references they made during the interviews about life events, that approximately five were older people (late 60s+), 12 were middle-aged (late 40s-early 60s) and three were young (20s-early 40s). The participants had a range of different conditions: two had MS, two had congenital conditions that affected their mobility, four had sensory impairments including one individual whose blindness was part of a complex condition. Two participants were stroke survivors (one of whom was elderly, the other was middle-aged). Two individuals had a range of related long-term acquired conditions, while two others had rare genetic physical conditions. There were two individuals who had an acquired brain injury, two with spinal cord injuries, one amputee and one polio survivor. A large minority of individuals identified strongly with aims and objectives of the disability rights movement, but a small majority did not, or at least they did not make this part of their identity explicit to me during the interview. In terms of ethnicity, all of the interviewees were white. I was not approached by any potential interviewees from other ethnic backgrounds, which is perhaps a reflection of the fact that Norfolk is a relatively mono-ethnic county, compared with other parts of the UK.

5.6.2 Strand 2: Focus group x 5 groups (n = 6 per group)

I designed the focus groups to help me understand how meaning about rehabilitation is negotiated and produced through the interactions of a small group of people who share a similar impairment (Mason, 2018). I hypothesised that the group setting would give me insights into the attitudes and opinions of people who had lived experiences of rehabilitation (Hennink, 2007), although

I analysed these views as the product of a particular set of interactions that took place in a given group context (Barbour, 2008). The focus groups took place in booked rooms at UEA, and were run by me, with support from a co-facilitator (a fellow student or colleague). As the overwhelming majority of rehabilitation research (including both the qualitative and the quantitative), has focused on a single impairment type, it made sense to group participants according to impairment or, where this was not possible, according to the timing of onset of the impairment. This was intended to make it easier to draw out connections with the existing research, and to see whether specific trends emerged in relation to particular experiences, policies and practices. The focus groups were therefore organised as follows:

- Group 1: acquired impairment: individuals with spinal cord injury
- Group 2: acquired impairment: individuals who have had a stroke or brain injury
- Group 3: individuals who have a degenerative neurological condition such as MS
- Group 4: impairment from childhood: individuals who have cerebral palsy, spina bifida, or another condition that has affected them since childhood
- Group 5: individuals who have a paediatric or acquired sensory impairment (e.g. blindness or deafness).

I undertook some training on supported communication within the UEA School of Health Sciences prior to starting recruitment; this equipped me with the skills I needed to facilitate the inclusion of aphasic participants within interviews and focus groups.

I organised the focus group discussions around a series of topics, as follows (see Appendix 7):

- what went well, what went less well
- decision-making and control
- goal-setting
- communication among staff
- relationships
- access to relevant support, information, funding, equipment

- transitions

In practice, as people discussed, a lot of the resulting talk was linked to more than one of these themes. I recruited for the focus groups in spring 2017 and held them in May of that year. Four groups went ahead and were well attended, with the exception of the group for people who had been disabled since childhood, which ultimately only had two attendees, due to participants withdrawing at very short notice. The three well-attended focus groups resulted in lively discussions. Once again, most groups had a good balance of ages and genders represented, but there were no participants from ethnic minorities. The group for people with sensory impairments was all women.

I was unable to recruit sufficient participants for Group 1 (respondents with spinal cord injury), and I tried again at a later point in my project, but to no avail. However, by that stage I had collected a large amount of data, and many of the same themes were arising repeatedly across the data. I had been able to involve participants with experience of spinal cord injury in the interviews. Therefore, because my data indicated theoretical saturation (Bloor and Wood, 2006), and because my time was very constrained by this point, I ultimately decided not to attempt to run a focus group with this impairment group.

5.6.3 Strand 3: Creative writing group (n = 10)

Drawing on the aforementioned theories of the role of creative writing in yielding qualitative insights (Greenhalgh, 2016; Barone and Eisner, 2012; Leavy 2009), I sought to design a structured fieldwork session that would be both stimulating and widely accessible. I discussed my protocol with colleagues with experience of using arts-based methods in research, as well as with a professor of creative writing at UEA, to seek tips on how to facilitate the session and how to elicit creative thinking. These colleagues highlighted the importance of creating trust within the groups and among participants, so I placed emphasis in the research design on having time for participants to get to know each other, as well as on simple tasks early on in the session to explore the words we associated with our rehabilitation experiences. I designed the creative writing element of the study to ensure that individuals could take part in the writing workshop as a purely exploratory activity, without anyone being required to share their work either with the group or with the project as data. I planned for this by holding two separate meetings of the same group, that is, the same people attended both groups. I also wanted to make this element of the project as accessible as possible, so that if someone was interested and enthusiastic about taking part, but, for example, struggled with the physical act of writing, there would be a way for that individual to be included. During the course of my planning I set up a project advisory group to discuss the implementation of the creative writing group, which led to the submission of an amendment to my protocol creating options to promote access to the groups (see approval letter at Appendix 2). So, for example, participants could choose to dictate their writing to a facilitator, use voice recorders, or work in pairs, and they could request that their writing be read out by another reader, anonymously, during the sharing group. My protocol (Appendix 3) also enabled me to share the planned writing exercises with people in advance, to give people a flavour of what to expect and to make participation less daunting. The meetings I ran were as follows:

1) a writing meeting, in which there were exercises to inspire people to write about rehabilitation using prose fiction and poetry (see Appendix 23); the meeting was not recorded and no data was collected. I held this group to encourage free writing, as stated above.

2) a sharing meeting, approximately two or three weeks later. Individuals who attended the first group were invited to attend, but were be under no obligation to do so. Individuals were encouraged to share their writing with the group if they felt comfortable to do so, and this was used as a prompt for discussion about the lived experience of rehabilitation. These discussions were recorded and used as data, with permission from attendees. If participants did not wish to share their own writing, they were free to read a poem or extract of published writing by an author they admire, that they saw as relevant to the theme.

I recruited six people (out of a possible maximum of ten) to take part in the creative writing group. Recruitment was more challenging than for the other strands of the fieldwork, and after a certain period I invited previous participants to take part, in order to boost the numbers. Those who did take part were very committed to the process and all participants returned for the second group.

A participant was permitted to take part in more than one strand of my data collection. However, priority was given to research participants who had not taken part in another strand of the research, in order to maximise the range of experiences captured by the research.

5.7 Remuneration

All participants were offered a £10 shopping voucher (One4All Post Office voucher) for each interview and focus group they took part in, and they were offered one voucher for taking part in both meetings of the creative writing group. Reasonable travel expenses could be refunded for the focus groups and creative writing groups. The ethics of offering remuneration for involvement in research are not clear cut, as this is always bound up with power (Hollway & Jefferson, 2012), however, this level of remuneration was seen as unlikely to act as a significant inducement, and was an important way of recognising what participants contributed to the research, and thanking them for their involvement.

5.8 Ethical considerations

I gave consideration to ethical issues throughout the duration of my project. Rather than associating research ethics only with the procedure of applying to a regulatory body, I conceptualised ethics as integral to my practice as a researcher, and sought to continuously evaluate my processes and practices, acknowledging that there might not always be a clear ‘right’ answer (Mason, 2018). I recognised that engaging with ethical issues from an academic perspective entailed exploring the conventions, as well as the scholarly and disciplinary emphases, that have given the field of ethics its contemporary form, but that it was also necessary to go beyond this in my approach to my research (Bowman, 2015). I knew that I would learn about ethics by doing my research and workshopping the dilemmas I faced with my research team, drawing on each instance as an opportunity to deepen my reflexivity and sharpen my judgement. Therefore, with regard to ethical practice, I was developing my approach iteratively and reflexively during the course of the research project, allowing opportunities to take stock and to learn from experience.

5.8.1 Risks to participants associated with taking part

As a qualitative study, my research posed minimal risk to participants. However, I sought to identify those that might arise. I planned to take the following steps in order to manage and minimise risk:

1) I was aware that participants might recall aspects of their rehabilitation experience which were distressing. I informed all participants that they did not have to answer all questions, and that they could take a break from the activity at any time should they need to do this for any reason. I also let them know that they were free to opt out of the study at any stage. I involved a co-facilitator in all of the group activities, so that there was a colleague on hand to help me in the event of someone needing to leave or take a break. Throughout the data collection activities I remained sensitive to the state of mind and behaviour of each participant, and offered them opportunities to take breaks whenever this seemed appropriate. I planned that if a participant should become distressed I would respond by pausing the interview and exploring whether or not it was appropriate to continue. I noted that I would not leave a participant in the event that they were distressed, but would explore how best to support them; for example, checking whether they had a friend or relative who could be contacted to support them. With inpatient participants I had planned to explore whether a nurse could support the individual; ultimately I did not interview any inpatients. I debriefed all participants at the end of each data collection activity,

asking them how they found it and addressing any immediate concerns or queries they had. If appropriate, I offered them a list of sources of support (see Appendix 24). Although no participant became obviously distressed during a data collection activity, I was aware that in some cases the experience of discussing their rehabilitation did awaken strong emotions. In these cases, I took extra care with the debriefing process, spending a little longer with participants at the end, to talk about how they had felt about taking part, to ask whether they had any concerns, and to point them in the direction of sources of support.

2) Safeguarding: I planned that if, during the data collection activities, I became aware of actions which posed a significant risk of physical or mental harm to the participant or other people, I would take action to minimise this risk. This included informing relevant authorities. I planned that if necessary, I would discuss any issues that arose with one of my supervisors or with Bridget Penhale, an academic expert on safeguarding at UEA, to determine what was appropriate for any external referral (for example, the NHS Trust or Adult Social Care). Participants were informed during the consenting process that I might need to discuss safeguarding issues with authorities, but that I would talk to them about this first. In the case of a small number of participants, I did seek advice from my supervisors and from Dr Penhale, when I had concerns about an individual's mental health. In each case, after talking matters through carefully, being careful to anonymise participants at all times, I decided that there was no further need for an external referral.
3) Burden of time: I aimed to keep this to a minimum. In most cases, participants were asked for a one-off involvement in a single data collection activity, although they were informed about and free to take part in other activities when these were under-subscribed.

5.8.2 Risks to me as a researcher

1) Lone working: It was necessary for me to go to participants homes on my own, as some participants had disabilities that made it difficult to meet at the university or on another site. This did create a low risk for me as a researcher. When undertaking interviews, I let one of my supervisors know the address where I would be. I told my supervisor the start time for the interview and what the anticipated timescale was. I notified them when the interview had been successfully completed. Another colleague at UEA, Andrea Stöckl, offered to be a contact person within this process if my supervisors were away or busy. I carried out all interviews during daylight hours as far as possible.
2) Hearing patients' stories required emotional resilience on my part. I had the opportunity to debrief with one of my academic supervisors whenever necessary, and if I needed to, I was able to discuss any potential duty of care issues arising with the UEA safeguarding leads. I also made sure not to schedule more than one fieldwork activity per day, in order to allow me time to process each encounter. Although I did have to exercise considerable resilience in the course of the fieldwork, I found that the provisions I had made were adequate and I felt well-supported by my research team.

5.8.3 Confidentiality, anonymity and data protection

All data that was gathered was anonymised/pseudonymised and no one other than myself, the co-facilitators and the transcriber had access to non-anonymised data. These people signed non-disclosure agreements that were created by the UEA research office, and they were people with integrity, whom I trusted. The only situation in which I would have passed on non-anonymised data would have been if I had become aware of the urgent need to safeguard an individual, in which case it would have been necessary to share non-anonymised data with a member of a relevant authority, for example the NHS Trust.

Personal data, including interview and focus group recordings, were stored within my secure folders on the password-protected University of East Anglia computer system. Recordings were deleted from recording devices themselves as soon as they had been transferred to university computers. Recordings were kept on computers only for as long as necessary while transcription and member-checking of interviews could take place. I will delete all non-anonymised data at the end of the study but will retain anonymised data for up to 10 years after it is generated to enable me to complete work on any related publications. I may need to keep this anonymised data on a password-protected personal computer in the event that I am no longer working at UEA. Paperwork that includes personal data, including consent forms, is stored in a locked cupboard within a locked office at UEA, and will be retained only as long as necessary and shredded as soon as it is no longer needed.

5.9 Data analysis

My data analysis procedure was informed by my pragmatic approach to the research problem, which led me to adopt an abductive reasoning strategy (Mason, 2018; Blaikie, 2007), whereby I moved back and forth between the transcripts, the research problem and my own thinking about emergent themes and thematic connections with existing work in the literature from disability studies, rehabilitation science and user involvement. In the upcoming sub-sections, I describe the stages of the process that led to my producing the three analysis chapters that follow this one.

5.9.1 Experiencing fieldwork and creating transcripts

The process of analysis began in the interviews, focus groups and creative writing groups themselves, which were often powerful and moving experiences for me, requiring me to draw on my own emotional resources. In the interviews, in particular, I was very aware of how painful the adjustment to life as a disabled person had felt to many of the participants, and I quickly became aware of the centrality of ‘adjustment’ as a key theme that participants highlighted in relation to their rehabilitation experience. There were also plenty of moments when experiences of exclusion, stigma and (internalised) oppression felt very raw in my encounters with participants. I spent time after each interview making fieldnotes on what the experience of the interview had been like for me, on what I felt the participant had highlighted about their experience, and on what a rights-based version of rehabilitation might look like for that person. I was able to draw on these notes as additional evidence of emerging themes during the analysis process.

As planned in my research protocol, I audio-recorded the interviews, focus groups and the creative writing sharing group on a portable voice recorder. My recordings were transcribed by a trusted third party who had a lot of experience in transcribing qualitative interviews. I instructed that the tapes should be transcribed verbatim as far as possible but that the transcriber could exclude fillers such as ‘um’ and ‘ah’, and that highly repetitious utterances could be paraphrased (see example transcripts at Appendices 25, 26 and 27). This is conventional in qualitative health research that uses a thematic approach to data analysis. In fact, as Lapadat and Lindsay (1999) observe, it is actually quite rare for qualitative researchers to discuss transcription as a practice that has implications for the results of their research; instead, transcripts are often seen as a transparent window giving unmediated access to the ‘reality’ of the interview. Lapadat and Lindsay argue that ‘researchers make choices about transcription that enact the theories that they hold’ (p. 66). Throughout data analysis, I sought to remain aware of the fact that decisions about transcribing might therefore affect how I was interpreting the data, and to think carefully about the status of my interpretations with this in mind. I found that listening to the tape recording tended to draw my attention to way in which an account of rehabilitation was being produced in the course of a dialogue with me, whereas focusing on a section of a transcript in which the participant was speaking at length made it easier to reify the participant’s account as a piece of ‘information’. Each medium thus afforded specific insights, and gave me one set of reasons for starting the analysis process by listening to every tape alongside its transcript. The process helped me to keep track of key concerns that were communicated via aspects of the interview process which could be less easily discerned through transcripts, such as tone of voice. Nevertheless, the transcripts were the main components of my data that I worked with.

I made notes in the margin of each transcript, drawing attention to what I thought were the key terms, ideas and themes (see Appendices 28, 29 and 30). I used colour-coding to highlight words and phrases. I re-read transcripts several times. Sometimes, once I had recognised a dominant theme, I undertook word searches on the transcripts, looking for the occurrence of words that were connected with the theme. Once I became familiar with an individual transcript I would create a mind-map of key themes for it, seeking to hierarchise, spatially, the significance of particular ideas within the transcript, as well as their interconnection. Later I was able to make mind-maps depicting a proportion of the data set, and then the whole data-set, but this was achieved gradually via 'trial runs' (Mason, 2018, p. 204) of making notes on themes, and even writing up sections of data analysis, before returning to the data to consider how far particular themes were indeed dominant. I include an example mind map at Appendix 32.

5.9.2 'Literal', 'interpretive' and 'reflexive' readings of the data

I used Mason's (2018, p. 134) schema of 'literal', 'interpretive' and 'reflexive' readings of interview data when reading and re-reading transcripts. I deployed all three modes of reading, and I display a few examples of how I used this schema in Appendices 28 and 29. Sometimes I was working with the texts very literally, for example, if an interviewee expressed a view about an aspect of rehabilitation services, framing it expressly as a view they held. The interviewee might emphasise the point or reiterate it later in the interview. Sometimes a literal approach could be used when analysing data from focus groups too, especially when participants expressed agreement, although in such instances it was nevertheless important to be able to interpret the group dynamics and the extent to which a person might be agreeing because a view or opinion appeared to them to be socially acceptable in this context.

Other excerpts of data might not directly express a view about rehabilitation, but could be interpreted as saying something about social norms and how these affect the lived experience of rehabilitation (interpretive reading). For example, participants' references to their sense of their time being seen differently since becoming disabled could be understood to comment on how disabled people's lives are valued, and also on how the time-consuming work of rehabilitation itself was being valued. It was also necessary to place utterances in their interactional context, to think about how the interview context or the group context might have structured what emerged (reflexive reading). Due to the fact that I had amassed a large amount of data, and to the fact that my time was limited as a doctoral researcher, I decided that it would not be possible to work reflexively with all of my data, even though I was very aware that each research encounter was a product of a particular set of interactional dynamics. Nevertheless, this mode of working with the data proved important in relation to the creative writing groups, where I elicited comments from participants about the experience of writing about the lived experience of rehabilitation as part of the group, and I sought to focus on participants' experiences of the creative and interactive process of participating in the group, in and of itself. In my analysis of that data (see Chapter Seven), I sought to place the excerpts within a wider context of their elicitation, and to acknowledge that simply deciding to run a creative writing group would have valorised writing.

5.9.3 Taking time; working iteratively

Analysing data is time-consuming (Mason, 2018). I found that time was an essential ingredient in this analytic process. Sometimes, the first time I read a transcript, I overlooked a phrase or disregarded it as inconsequential. But then it would come back to me later, when I was doing something else and allowing my day's work to percolate in my mind. Sometimes I would be reminded of that phrase when reading another transcript, or it would jump out at me when I revisited the transcript and I would wonder why I had not highlighted it before; and perhaps this happened because, as I was learning about the data and thinking about it, I started to see different things in it. Thus, the passage of time played a role in creating the conditions for iterative and reflexive thinking about the data.

On what basis did I decide that a particular theme was a ‘key’ one? The process of deciding on key themes was not always about what was apparently self-evidently ‘there’ in the data, but involved critical thinking and iterative work, back and forth between different transcripts, my processing work and my own academic knowledge. I acknowledge that my judgement played an important role in the iterative work of reading transcripts, creating mind-maps, selecting themes and then ultimately writing the analysis chapters. I had a lot of relevant data and I could not write about all of the themes in it. Throughout my analysis process I was thinking about my research questions, and asking myself how a particular excerpt of data helped me to address these, and hierarchising emergent themes accordingly. I tried to ensure that my selection of themes was simultaneously a fair reflection of themes that were dominant across the data, and themes that spoke to the concept I was seeking to understand, ‘rights-based rehabilitation’. I achieved this by doing a ‘trial run’ with a particular theme (Mason 2018, p. 204), and writing up a section of analysis on this theme, and then returning to the data to cross-check my thinking. The writing of my analysis chapters was itself also an iterative process, because after writing each chapter I would go back to the transcripts to see how well my interpretations fitted with what I found. For these reasons, I describe my analytical process as ‘abductive’ rather than ‘inductive’, because whilst it was necessary to close-read the data whilst keeping an open mind about the kinds of theories that might help me interpret it, in practice the work of analysis always involved weaving between close-reading, reflexive interpretation, thinking about the research problem and drawing on my knowledge of the academic fields within which my study fits.

5.9.4 PPI involvement in analysis; reflexivity

The latter stages of my iterative analysis process involved a shared data analysis event with PPI members. I wanted to understand from this process what my project advisory group regarded as the salient themes and issues in certain key data extracts, and to explore their thoughts and feelings about these extracts through discussion. This activity was intended to enrich my analysis process by a) exploring whether my own readings of data excerpts were shared by others and b) highlighting to me my own biases about rehabilitation, especially if different themes emerged in this discussion from those that I had originally seen in the data. Like all of my PPI, the function of the activity was also to take steps towards democratising the research process.

The data analysis group data did not represent formal ‘triangulation’, because that term implies that there is 'one objective and knowable social reality’ which can be measured and corroborated (Mason, 2018, p. 239); instead, as this chapter has shown, my method involved recognising this data as constructed in and through the research encounters themselves, and my analysis of it as a situated activity, which would always reflect my own understanding of the research problem and my own interpretation of what was significant in the data I collected. This is not to say that I approached data analysis with a pessimism about the possibility of reaching any consensus about what it meant, nor to say that my interpretivist stance means that I was not interested in trying to convey ‘what disabled people felt and thought about rehabilitation’. Interpretivist practitioners are sometimes depicted as not being interested in seeking the ‘hard’ research findings which will lead to social change. But Mason (2018) offers another way of looking at it, which is that the interpretivist emphasises rigorous analysis and self-analysis in the research process, always providing a reasoned explanation for conclusions that s/he draws, and always seeking to be critical and reflexive about the factors that might have influenced certain conclusions. From this perspective, the interpretivist can be understood as someone who can be thoroughly committed to seeking to convey ‘what disabled people felt and thought’ and whose thinking can be more rather than less dedicated towards such ends by attempting always to reflect on the role of factors and processes such as context, bias, interaction and mediation.

I selected four excerpts from my interview and focus group data (see Appendix 31) to send to the three attendees, who had been involved with the project since the beginning, and who each have a different experience of long-term disability and of rehabilitation. The extracts were selected for use on the basis that, firstly, they demonstrated one (or more) of the themes which emerged in data analysis, which later became the basis of the proposed analysis chapters. My analysis had suggested that these were rich extracts. Secondly, as far as I knew, the members of the group did not know the individuals whose data I was using in these extracts. I anonymised the data to a very high level, removing specific details of types of impairment where necessary. I sent the extracts to the group members approximately a month in advance of the meeting, inviting them to consider:

a) how each extract characterises rehabilitation,
b) what key themes and ideas it raises,
c) whether they see any connections with their own experience of rehabilitation.

I explained that there were no ‘right answers’ but that I was interested in how they read the materials. We spent a little over an hour in the meeting discussing each passage in turn.

As the PPI members examined only a tiny proportion of the data, selected by me, their role was not to systematically corroborate my readings of the data, but to support my own critical-reflexive work, by showing me aspects of my own positionality of which I had been less aware before I had met with them. I drew on the comments of my attendees as I finalised the data analysis and discussion chapters; the process was much more helpful than I had expected in showing me how a different lived experience of rehabilitation could lead to subtly different ways of reading the data.

5.9.5 Analysis of the creative writing data

As a pragmatist, I did not approach the creative writing data with a pre-given framework for analysing it or a sense that it would necessarily and specifically require a different set of tools from those used elsewhere in the research. Rather, I sought to remain open to what might emerge in and through it, both about rehabilitation, and about creativity, about research design, about epistemology and about inclusion. I did read widely on using arts-based methods in research while planning and implementing the creative writing group. Due to time constraints in my own schedule, and to the effect of the Covid-19 lockdown on my access to my data, I had relatively limited time to analyse all of the data which emerged in the creative writing discussion group and decided to focus closely on one short section of the data in the analysis and discussion presented here. The creative writing groups took place much later than my other data collection activities and much of my analysis of the other data also took place before the creative writing group had happened. Because I had a large amount of rich data on the lived experience of rehabilitation from my interviews and focus groups, and because it was therefore already necessary to be highly selective in terms of what to ultimately present in this thesis, I made the pragmatic decision that this thesis should focus mainly on the analysis of the interview and focus group data. The limited work I was able to do on the creative writing group data before the Covid-19 lockdowns led me to think that I would need to write a separate chapter focusing on that data in order to do it justice; this then proved impossible to do during the lockdown. Appendix 30 provides an indication of the kind of work I would seek to undertake when I am able to return to analysis of the creative writing data. I have nevertheless been able to analyse and present some data which illuminates the agentic process of writing itself, and to reflect on some of the epistemological issues which were thrown up by the process of deploying a fieldwork activity that was perceived (both by me and by my participants) as unconventional (see Chapter Seven).

5.10 Explaining the processes that led to the foci of the analysis chapters

The following three chapters offer analyses of the qualitative data collected in this project, exploring the lived experience of rehabilitation through three thematic lenses: ‘involvement’, ‘agency’ and ‘temporality’. I developed these themes through my abductive process (see 5.9.3). The strategy I adopted was cyclical, involving data selection, analysis, writing and then returning to the data. I made decisions iteratively about what to classify as a superordinate theme and what to present as a subordinate theme, drawing on both the knowledge I was gaining from participants’ accounts and on my growing understanding of how this knowledge intersected with, and could be purposed and made legible within, significant lines of inquiry in the fields of disability studies, rehabilitation science, and patient and public involvement.

I could have chosen a different set of concepts to organise the findings seen here in the analysis chapters. For example, I could have used the theme of ‘rehabilitation relationships’ as a chapter heading, and indeed an early version of the chapter on involvement had this title. Ultimately, I judged that, by focusing my interpretation through the conceptual lens of ‘involvement’ instead of ‘relationships’, I would be better able to elucidate the evidence produced by this project in terms of the rationale I had set out, in which I highlighted the lack of involvement of disabled people in designing their rehabilitation (WHO, 2011). By organising sub-themes about relationships, such as ‘consultation’, ‘partnership’, and ‘support over time’, as categories that elucidate ‘involvement’, I was creating an analytical frame that articulated the ways in which disabled people’s accounts of rehabilitation were relevant to inclusive policy-making and practice.

In iteratively moving towards the concept of agency, I was guided to focus my analysis through this lens by study participants’ emphases on the significance of being actors in their own lives, as well as by my knowledge of the relevance of similar concepts within the disability movement and the independent living movement, such as empowerment and asserting control over decisions (Evans, 2002). The decision to deploy the term ‘agency’ to organise the analysis, over related terms such as ‘control’, came down to the specificity of the experiences I was seeking to interpret, where ‘control’ and ‘empowerment’ did not always seem substantial enough: ‘agency’ implies something more active and enduring than control. Another factor that influenced the decision was the use of the term ‘agency’ by other rehabilitation researchers (see the qualitative synthesis in Chapter Three), and the use of the term ‘patient agency’ by medical sociologists and historians of medicine (e.g. Hunter et al., 2015; Armstrong, 2014).

The decision to focus on the temporality of rehabilitation was taken in response to the amount, and type, of data that referenced this theme; it had not been a theme that I had anticipated in particular, or that I sought to elicit in the structure of the fieldwork topic schedules. However, it became clear that participants’ emphases on markers of time, and on time’s perceived value in their lives, were signalling connections between lived time and control over rehabilitation, which also chimed with evidence from the qualitative synthesis.

5.11 Summary of methodology

I used a pragmatic, problem-solving approach to design my study, which entailed diagnosing my ‘experiential’ and ‘mechanical’ puzzle (Mason, 2018, p. 12) and being guided by this analysis to choose methods which would enable me to explore participants’ views and experiences of rehabilitation. To develop a methodology that would yield insights into ‘rights-based rehabilitation’, I also worked iteratively, reflexively and collaboratively, drawing on learning from previous research and study I had undertaken, on data from the literature reviews I had performed, and on insights from conversations with other researchers and PPI representatives. For example, I used my review of the PPI literature to plan the involvement of members of the public who had lived experiences of rehabilitation in designing the study. Furthermore, I deployed my knowledge of the humanities to consider how creative writing might be used to yield insights about rehabilitation experience. I understood rehabilitation as a culturally, historically and psychosocially situated experience, and structured the fieldwork so as to yield insights into rehabilitation in a particular place and time, conscious that the interactions I had would themselves generate a situated perspective.

My diagnostic analysis of the research problem led me to choose three complementary modes of data collection: semi-structured interviews, focus groups and a creative writing group in order to gather qualitative, context-specific and (in some cases) fictionalised data about rights-based rehabilitation. I anticipated that the interviews would provide insight into biographical experiences, the focus groups would create knowledge about people's views and opinions, and the creative writing group would help me to explore the emotional truths of rehabilitation, and to find out what kind of data emerged when people were more focused on engaging their creativity and less focused on providing an accurate account of 'what happened' (Leavy 2009; Barone and Eisner, 2012). In Chapter Nine, I explain how the different strands of data collection complemented each other in practice.

In the course of collaborating with PPI members to design the project so as to make it useful and relevant to disabled people with lived experience of rehabilitation, I diagnosed accessibility and inclusion as key components of the research problem that would need to be solved. The handling of these issues would affect the diversity of my sample and the acceptability of the research within the disability community. With the help of my project advisory group, I found practical solutions which would make participant information more accessible. My collaboration with PPI representatives enabled me to problem-solve inclusively. Over time, this collaborative and consultative way of working taught me that the ethical and methodological aspects of the project were inseparable; this was a concept that had emerged in the PPI review and which I discuss further in Chapter Nine. Thus, relatedly, I came to conceptualise ethics as an ongoing set of questions to ask myself throughout the project's lifetime, which were a facet of my reflexive, problem-solving approach to the research, rather than being a discrete set of tasks that would result in ethical approval.

Having collected the data, I used an abductive reasoning strategy for analysis, which involved an iterative movement back and forth between the data, the research problem, my own academic knowledge and the expertise by experience of the project advisory group. I judged that abduction would best serve my interpretive activity, because it enabled me to make the most of the knowledge I was accumulating over time about rehabilitation experience and theory. Over the next three chapters, I present three significant overarching themes that emerged through the analysis process.

Chapter Six
Conceptualising involvement in rehabilitation

6.1 Introduction: Aims of this chapter

This is the first of three data analysis chapters, each of which is structured around a theme that I identified, during analysis, as having the potential to play a key role in responding to my research questions. This chapter focuses on the notion of ‘involvement’ in the data, and aims to elucidate participants’ conceptualisation of ‘involvement’ in their rehabilitation through discussion of six sub-themes.

In the initial sub-section, I explain how I came to focus on ‘involvement’ in my analysis, including a brief discussion of how I understood the concept of ‘involvement’, how it related to the objectives of this research, and how it connected with a notion of ‘rights-based rehabilitation’. This section develops the practical discussion of my abductive process begun in section 5.10 of the previous chapter. I will then go on to examine how the idea of ‘involvement’ in rehabilitation was conceptualised and represented to me by participants in the research. In the chapter sub-sections which follow, I begin with accounts of difficulty accessing full involvement, then move through discussions of the way in which the *notion* of patient involvement may be mobilised in the absence of a thoroughgoing *practice* of involving patients in their care, and on to explore the qualities that participants associated with their full involvement in rehabilitation relationships. Through these thematic discussions, I aim to demonstrate that, for participants in this research, their involvement in their rehabilitation was not something that they could count on, but when it was facilitated well, it could be transformative, and could be a facet of what we might call ‘rights-based rehabilitation’.

6.2 Why ‘involvement’?

The question of what it means to be involved in one’s rehabilitation is central to the rationale for this project. If we frame rehabilitation as a disability equality issue (Shakespeare et al., 2018), and indeed if disabled people are to be more fully engaged in processes of designing rehabilitation services (WHO, 2011), then we need to understand what it feels like to be involved in decision-making, as well as what it is like to be excluded from such processes. To this end, I sought to elicit accounts of ‘decision-making and control’ in rehabilitation in my fieldwork.

The theme of involvement might be said to have been amenable to a ‘literal’ reading of the data (Mason, 2018, p. 134) in the sense that it appeared to be very clearly ‘there’ in my reading of the data. This could have been partly because I was directly eliciting material about involvement from participants: through my interview and focus group schedules, I was indicating that I thought this was an important theme in rehabilitation research, and that I was interested in hearing participants’ take on it. Nevertheless, whilst I was eliciting material about involvement, decision-making and control, I was inviting participants to give their own accounts of what these concepts meant to them in the context of their rehabilitation. As a result, a range of themes emerged, and the six themes I have chosen to discuss here represent those themes that either recurred in a number of transcripts across the data, or that emerged as major, sustained themes in one or more individual transcripts.

As the discussion of each theme shows, participants described encountering various barriers to full involvement, as well as frustrations when their participation seemed superficial, but when they did recount experiences of feeling fully involved in rehabilitation, these were often transformative experiences. The sub-sections I use are as follows:

1. **‘I really had to fight to go there’: The ‘battle’ to be involved;**
2. **‘We are the disabled people who are able to vocalise’: The need for vocal resources;**
3. **‘You get all the fancy words that they’ve come up with’: Paying lip-service to involvement;**

4. **'"We can't have any of that"': Being told what to do versus being consulted;**

5. **'A world full of opportunities': Involvement as a supported discovery of agency;**

6. **'It's a bit of a pupil / teacher relationship': Involvement as partnership.**

6.3 'I really had to fight to go there': The 'battle' to be involved

Participants often cast their rehabilitation narratives in adversarial terms, as a battle to be heard, or to be allocated resources. In this first section, I examine this view of rehabilitation, which was very common across the data, with most participants making some reference to such difficulties. The emphasis differed from one participant to the next, but some participants experienced the system as shutting them out. The terms 'fight', 'battle' and/or 'struggle' feature in many of the transcripts. Participant #10, a woman who had lived with MS for many years, used the following words to describe an experience of not being fully involved in decision-making:

> …later on, to me rehabilitation wasn't actually responding to me, it was, it had put me in a category, a person with MS…who therefore would have…set treatments. […] And everything turned into a battle because, it wasn't actually what I was wanting […] or what I needed. (Participant #10)

This participant uses the image of a battle when rehabilitation is perceived to be out of tune with her own needs as a disabled person. Here, the participant's language gives agency to rehabilitation, as a thing that has 'put [her] in a category, a person with MS' while, she, it is implied, is a passive recipient of 'set treatments', without a voice in the process. The idea of 'set treatments' suggests that the services in question had a rigid structure, while the reference to being ‘put […] in a category’ implies that the system taxonomises people according to their impairment label. The participant here seeks a form of engagement that is more responsive (‘responding to me’), taking into account individual circumstances and needs. This individual’s use of such language occurred in the context of her account of trying to obtain a treatment which she had been denied on the basis of a decision that had categorised her as unlikely to benefit from it. She explained during the interview that, by fighting, she did overturn this decision. It is notable that the experience is perceived to have ‘turned into’ a battle, rather than just *being* a battle. When something ‘turns into’ a battle, there is the implication that the participant’s energy could have been saved if the battle were not necessary. The phrase implies that it was up to the participant to ‘turn it into’ a battle, and that, had she not done so, she would simply have been denied the treatment she felt she needed. This implicitly characterises services as reactive, and as responding mainly to the persistence of the individual, rather than being open to involving participants in their rehabilitation decisions. At various points in the interview, Participant #10 alluded to a perceived need to fight to the scarcity of NHS resources, noting that ‘there is an ever-shrinking availability’. This account demonstrates the energy and resources that may be required to make rehabilitation into a practice that ‘involves’ its subject: this is a theme that will recur throughout the data analysis; I will demonstrate how it contributes to a notion of ‘rights-based rehabilitation’.

Participant #8 also referred to having to ‘fight’ to access rehabilitation services. This participant, a woman in middle age, had lived with cerebral palsy all her life. A few years before we met for the interview, she had suffered a fall which left her needing inpatient rehabilitation in order to re-learn to walk. She explained that, prior to her fall, she had been able to live independently with minimal support, although she had mobility difficulties. She told me that she had to push in order to get a place in a rehabilitation hospital:

> I really had to fight to go there [rehab hospital]. Had I not said anything I think I would have been in [mainstream hospital] a lot longer. (Participant #8)

Here this participant invokes the metaphor of ‘fighting’ for rehabilitation (as she does frequently throughout the interview), and indicates that she thinks she would have received different treatment if she had not fought. Participant #8 also spoke about her experience of involvement in the following terms:

> My expectation was that they would ask me what I could do before the accident. (Participant #8)

As this excerpt suggests, her expectations did not match the reality of the treatment she received. This experience might perhaps be contextualised with reference to a reported mismatch between service provision for children with cerebral palsy and adults with the condition in the UK (Thornton, 2018). The participant felt it was reasonable to expect to be asked about the level of physical function she had enjoyed before her accident, but this did not happen. She used the following phrases to describe the way she was treated: ‘they didn’t listen’ and ‘they wrote me off straightaway’. These short excerpts suggest that the participant did not feel that her voice was heard during rehabilitation; the choice of the term ‘didn’t listen’ suggests that she feels that her perspective was actively ignored, as does the term ‘wrote me off’, which suggests that assumptions were made about this participant’s impairment and her normal level of function without checking with her. She explained that she ‘felt very isolated’; this phrase conjures a sense of an unsupported individual who has to reach out for what she needs rather than being included in the process. Participant #8 cited communication difficulties as one of the reasons, in her experience, for her exclusion from decision-making; as someone with a speech impediment she relied on good Wifi to be able to communicate with family and friends who usually supported her, yet this was not available to her during her hospital stay.

The data explored in this section has highlighted the work that participants did, or felt compelled to do, in order to maximise their opportunities to be involved in, or consulted about, rehabilitation decisions and activities. Participants were at risk of being excluded from having a say in the process. These are key issues to consider in re-imagining services that could work with and for disabled people.

6.4 ‘We are the disabled people who are able to vocalise’: The need for vocal resources

The two case studies discussed in the previous section reveal the significance of vocal resources in decision-making about rehabilitation, which is a theme I consider in more detail here. Both participants discussed in the last section indicated that aspects of their rehabilitation might not have happened if they had not ‘pushed’. In the case of Participant #8 in particular, an experience of not being consulted arose in the context of a participant displaying a long-term speech impediment, which raises questions about the role of vocal resources in opening doors to involvement, especially in an under-resourced NHS. This theme was also apparent in the focus group I held for stroke survivors, several of whom had experienced aphasia, and one of whom had severe aphasia. The issue was dramatised during the focus group itself, in which I sought to adapt communication modes and styles in order to include participants and to ensure that their voices were heard. We used closed questions, had paper and pens for illustrating the conversation, and allowed extra time for the conversation to unfold, but even so there were moments of tension and of ambiguity, and one individual’s narrative usually took the form of qualifying the others’ responses. I had met each individual beforehand in different contexts, which helped me to prepare to support their communication. The participants, who already knew each other, seemed to know how to support each other to tell their stories, and were comfortable with the setting: as a result, it was a very productive group in the sense that a great deal of data about the lived experience of rehabilitation emerged. But it was easy to see how, in a pressurised environment, these were the kinds of voices that might get excluded (see Parr, 2007). One participant from this focus group made the following comment about what was needed from healthcare professionals, in order for people with aphasia to be fully involved in their rehabilitation:

> They need to understand just how difficult it is to not be able to express yourself, and therefore they need to take the time and use different techniques for getting the information across. […] If I felt that somebody actually out there really understood it and was prepared to take the time, I would feel much more at ease with the world. (Stroke FG participant)

This quotation highlights twice a need for interlocutors to ‘take time’ over communication. Involvement, in these circumstances, is something that cannot be done in a hurry; this is a theme that will re-emerge again in discussion of other data, and which points to the need for ‘rights-based rehabilitation’ to take place within a temporality that suits its users. Furthermore, the reference to wanting to ‘feel at ease’ here suggests that it may not be time alone that is in short supply: the phrase draws attention to potential discomfort. It is possible that all parties may feel uncomfortable when the norms of vocal communication are breached.

The social connotations of not speaking were illustrated by another participant in the group, who stated that:

> A lot of medical staff think that because people can’t say ‘yes’ or ‘no’ they haven’t got the [mental] capacity. (Stroke FG participant)

This statement suggests that in the experience of the speaker, this individual found a lack of understanding about aphasia within the NHS, leading to encounters in which participants are treated as though they are not capable of being fully involved in decision-making. There was a general consensus in the group that having a speech impediment often leads to being patronised, or treated like a child. Another participant described how he addressed a new member of the stroke survivors support group to which he belonged:

> We said to her, ‘It doesn’t matter how you talk, how you walk, what you think of, you are always welcome here.’ (Stroke FG participant)

The phrase ‘it doesn’t matter’ reveals a sense that in other contexts it ‘does matter’ and that there is ongoing social stigma, and internalised stigma, experienced around aphasia.

Meanwhile, Interview Participant #6, who had also experienced aphasia, gave the following account of an encounter in which he wished he had had vocal resources:

> You don’t have a label across here [indicating forehead] that says anything […]. I can remember in the early years somebody [*inaudible – noise*] and it stuck with me forever, and because of the aphasia and not knowing words… I can remember a receptionist once telling me to come back when I was sober, and that bloody… I was a bit too upset to say anything at the time. I now wish I’d given her a mouthful, but that’s neither here nor there. Those sort of things happen and so you learn to strategise around it. (Participant #6)

This experience of having been perceived to be drunk rather than aphasic had ‘stuck’ in the participant’s memory; it had clearly been a defining incident in the early part of his rehabilitation. In his account, ‘not knowing words’ had led to being profoundly and painfully misunderstood and stigmatised. The connotations of ‘giv[ing] her a mouthful’ are of weaponising the contents of one’s mouth, one’s words, in order to right a perceived wrong. Participant #6 contrasted this exchange with the much more productive, and consultative, relationships he had built with his OTs, who had taught him the very ‘strategies’ he refers to having needed in this moment of difficulty. Thus his account of rehabilitation did include positive reflections on certain interpersonal encounters, as well as instances of learning ways to manage communication difficulties. Indeed, it seemed that one of the most profound and important aspects of Participant #6's rehabilitation had been 'learning to strategise' in response to a new cognitive and physical reality. This type of learning undoubtedly played a necessary role in supporting him to adjust, however the emphasis on strategising, and the phrase 'those sorts of things happen' might indicate that this person had internalised stigma about disability to a degree. One could say that the need to 'strategise' in order to cope with a lack of vocal resources does not change social stigma; rather it seems to naturalise stigma. How would involvement look if it could reshape 'strategising'? This might be a question for 'rights-based rehabilitation' to pose.

The need to 'speak up' about being disabled was a demand which some participants experienced during their rehabilitation. Participants who had rare conditions found that they sometimes had to act as their own advocates in relation to doctors' actions. As Participant #3 said:

> You go up the hospital and you see people and, that's 'Right, explain what you're actually going through or what you've been through.' You think, 'Well, you've got my medical notes there. Surely, two add two equals four. Just, sort of, research before you get the patient.' (Participant #3)

Here she refers to being asked to 'explain' her medical history, and suggests that it would be easier if the doctor did some 'research' before seeing her. Similarly, Participant #18 spoke of the work of having to explain:

> …oh, yes, every appointment I see a new doctor and I have to explain a lot. I've got booklets and notes and lots of medical journal stuff that I take with me.
>
> […]
>
> My condition is very difficult and multi-disciplinary and it's very difficult when you come up against doctors who don't believe in the condition […]. […] We could be seen to be painkiller seekers, drug seekers, but that's simply because it's a quiet condition. There's not a bit of your body that doesn't hurt. (Participant #18)

The reference here to ‘booklets’, ‘notes and […] medical journal stuff’ suggests that the participant has done a lot of her own research into her condition. The statement that she ‘takes [the material] with [her]’ implies that she has learnt that she will often need to be the one guiding the doctors. Yet, the suggestion in the second excerpt that she might be a ‘drug seeker’ jeopardises her status as a patient and implies that she may have to work harder than others to retain it, and to maintain credibility, because her condition is contested. This participant was very positive about her GP (‘very understanding’) and her physiotherapist (‘who understands’), but the participant’s affirmation of particular individuals here reveals that the experience of being understood is not something she can take for granted in her engagement with rehabilitation. These excerpts underline the importance of feeling enabled to speak, and of feeling that one’s attempt to communicate experience will be rewarded with careful attention, in clinical rehabilitation encounters.

Elsewhere in the data, most prominently in the focus group for people with a sensory impairment, participants displayed ambivalence about their ability to pass as non-disabled, and about dilemmas around deciding whether and when to ‘speak up’. One individual in this focus group, who had a hearing impairment, explained that people she had met did not always know that the severity of hearing loss or sight loss can vary from one person to the next. This led to other people making assumptions about her ability to hear on the basis of her ability to use the phone, even though she was using a phone loop at the time. She said:

> I think it’s really useful when people do understand the effect and are able to make those adjustments but without making a big song and dance about it. (Sensory FG participant)

Here, as above, it is the ‘understanding’ of others, in the absence of her having to explain, that she desires. Another participant from the same group spoke of ‘hating’ using a long cane. She felt that its very connotations, as a clinical object, were stigmatising. But as the following remark she made shows, the use of a cane signifies disability so that she does not need to ‘speak up’:

> I’d use it if I thought I really had to, but that was more to show to other people that I was disabled, rather than to actually help me, because people would think I was drunk or stupid because there was no obvious sign that I was disabled. (Sensory FG participant)

In this context, she presents the white cane as standing in for the need to explain oneself (‘to show other people that I was disabled’). Its presence de-stigmatises a self-presentation that will otherwise attract abjection and exclusion, according to this participant. This recalls Participant #6’s desire for a ‘label’ on his forehead highlighting his invisible disability, to help him avoid being mistaken for being drunk. The assumption of drunkenness also came up in the focus group for stroke survivors, suggesting that the labour of having to explain oneself and one’s impairment may be a fairly common aspect of disability experience.

The data I have discussed in this section have highlighted the role of speech in involvement. The analysis aimed to demonstrate that where participants had difficulty with speaking in rehabilitation settings, they often reported experiences of being misunderstood, isolated, or stigmatised. In other situations, being able to speak articulately about one’s condition to medical professionals was experienced as a prerequisite for being taken seriously, especially with contested diagnoses. The experience of passing as non-disabled was a mixed blessing, as it sometimes led to professionals failing to recognise the severity of a condition, or to being further misunderstood in public space. The data upon which my analysis relies is mostly transcribed speech, and I recognise that this often means that highly articulate participants are over-represented in the extracts selected for discussion. One interview participant (#11) had severe aphasia and I decided, in consultation with him, not to record our conversation. I made notes instead. Although I used these notes when creating thematic mind-maps, I am aware that the participant does not appear as the speaker of any extracts. One of the focus group participants observed: ‘We are the disabled people who are able to vocalise because we’re able to actually get here; we speak on behalf of those who can’t’. This statement raises important questions about who gets included and how – both in decisions about rehabilitation, and in the research process. The ability to ‘vocalise’, as the participant put it, plays a significant role here, and this means both being able to speak and being able to get into the room in the first place, as she says. In these instances, rehabilitation works well when participants are enabled to vocalise, and given the resources they need for this to happen; this may be an important finding for the development of a rights-based rehabilitation policy.

Being able to ‘fight’ and to ‘vocalise’ had an impact on many of my participants’ experiences of being involved in their rehabilitation. But how did they conceptualise their ‘involvement’ (or lack of involvement) in rehabilitation? Did they feel that their involvement was being built into rehabilitation encounters, or was it something that was added on as an afterthought? What did they think it was like? It is to these questions that I turn for the remainder of the chapter.

6.5 ‘You get all the fancy words that they’ve come up with’: Paying lip-service to involvement

In this section I aim to explore how participants conveyed involvement that felt superficial. The jargon of patient involvement was a theme that arose frequently. 11 out of 20 interview participants used or referred to such terminology: they used or talked about terms like ‘patient-centred care’, ‘experts-by-experience’, ‘experts on tap, not on top’, and ‘the expert patient’. Participants who used such terms tended to have knowledge of either the disability rights movement or of working in the health or social care professions. For example, Participant #5, who had previously worked as a healthcare professional, spoke of the need for ‘person-centred medicine’. Participant #9, who had experience in the caring professions and in the disability movement, spoke of the need to involve disabled people in rehabilitation decisions. Such language was also common in the focus groups.

It often seemed that participants used this kind of language to refer to *notional* involvement: to talk ‘in theory’ about what they would have expected to find, or what should be the case, in rehabilitation experience. Some participants compared and contrasted their own experiences of being involved in rehabilitation decisions with a notional, or imagined, version of what they felt involvement should be. Others were more comfortable talking about involvement in theory, but they were reluctant to give concrete examples.

The term ‘lip-service’ was used by two participants to describe involving patients in their rehabilitation. For Participant #9, who lived with a range of long-term conditions:

> … the interests of the organisation have always come first so if there’s any clash, then finance is the main thing. Local authority finance is the main question, as you’ve just seen with the budgets that have been set […] for further cuts. They pay lip-service to the needs of the individual but it doesn’t work like that. That’s a cynical point of view. (Participant #9)

Here, organisations are perceived to be ‘paying lip-service’ to what individual patients need, but ‘it doesn’t work like that’; with this phrase, the participant positions himself as able to see something other than what the organisation in question wants him to see. The participant connects a superficial practice of involvement (‘lip-service’) with financial constraints suffered by the organisation. He highlights a belief that the organisation will always prioritise its own interests, which, in his experience, translates into a loss of practices of patient involvement. The participant is aware that his view is a ‘cynical’ one, but it is perhaps not a surprising one, when taken in context. This participant had spent many years engaging with health and rehabilitation services, in order to manage several long-term conditions, and had encountered a good deal of difficulty along the way. He was a vocal disability rights activist and was involved in protesting the UK government’s austerity programme, which had affected the budgets of health and social services during the period when I undertook the interviews.

Another participant framed ‘lip-service’ slightly differently:

> Again, with the NHS it is so important they must work with disabled people and not just the lip-service of it, because you have that a lot within social care. I do a lot of work with social care and they say they are ‘person-centred, personalisation,’ and you get all the fancy words that they’ve come up with. ‘What do you actually do to be person-centred and what’s that person’s opinion of this, that and the other?’ ‘Well, I’m the expert.’ ‘Well, you’ve just told me you’re person-centred’. (Participant #4)

There is a different emphasis here: whereas Participant #9 suggested that deficiencies are due to budgetary constraints, Participant #4 argues that healthcare professionals themselves are resistant to the very idea of reconceiving the notion of the expert. In Participant #4’s experience, ‘person-centredness’ is one of the ‘fancy words’ that is used to dress up business as usual. This participant recounts a generic experience of trying to find out what is actually meant by a ‘person-centred’ model of service delivery. Instead of finding a professional who is open to working collaboratively with the patient, he finds that the professional claims the status of ‘expert’, implicitly relegating the patient to the position of passive recipient of services. Although both Participant #9’s and Participant #4’s explanation for the problem of lip-service resonate with other participants’ accounts of this issue, most participants attributed superficial experiences of involvement to budgetary constraints hampering individual professionals who were genuinely very committed to involving patients in their rehabilitation.

These participants allude to the need for rehabilitation services to enact the involvement that they claim to undertake. They suggest that a real shift in the balance of power towards patients and patients’ perspectives has not always happened, even though a language of ‘involvement’ is commonplace within rehabilitation contexts. Relatedly, as we will see in the next section, participants also experienced didacticism from services, rather than consultative engagement with patients.

6.6 'We can't have any of that': Being 'told' what to do versus being consulted

The theme of being 'told' what to do, or doing as one is told, emerged across several transcripts. The opposite experience of being consulted, was also present in the data. This section explores both of these themes as an aspect of (non)involvement. Here Participant #10, who lived with a severe impairment that was getting worse over time, discusses how she feels she is perceived in her interactions with services:

> I love people, and fascinating problems, and because I look a bit odd, well, and I'm battling with all these things that cause bother, they've sidelined me – but they're not me – so I need people to continue treating me as a human being. It's like …. you've had – you've had your character deconstructed – you're no longer at the moment – you lose your right to be the person you were because you're taking resources, and therefore you will do as you're told… (Participant #10)

The participant speaks eloquently here, both of those aspects of her impairment that 'sideline' her and of the stigmatising impact of living with these 'things that cause bother'. She refers to the effects of her impairment as 'not me', asking others to see beyond these and to see her for herself. The statement 'I need people to continue treating me as a human being' gestures powerfully to a hinterland of dehumanising experiences. This is intensified by the participant's sense that others' perceptions of one's impairments act to 'deconstruct' one's 'character'. Although in this image there is some ambiguity as to whether it is the impairments, or other people's perception of what the impairments mean, that cause the deconstruction of her character, this phrase nevertheless suggests that the participant feels she is rarely seen as 'whole', as a person, but more often feels regarded as a collection of needs. The participant explicitly connects this experience of being metaphorically taken apart with a loss of personhood and of rights. A nebulous fear that she must be 'taking resources' is felt to be driving the loss of rights she experiences. This extract highlights the lived impact of a cultural discourse that frames the wider society's shared resources as both finite and vulnerable to being plundered by disabled people who are seen as 'takers'. When it comes to conceptualising involvement, the question of whether and how disabled people are imagined (and imagine themselves) to have a right to rehabilitation plays a role in their interactions with others, including rehabilitation professionals. This extract draws our attention to this important psychosocial dimension of rehabilitation experience. If rehabilitation professionals and services are experienced as 'deconstructing' their users, so that users feel as though they are not 'human beings' but instead represent a set of problems, or a collection of body parts, or a financial burden, involvement will not take place on the basis of person-to-person relating. A prerequisite of involvement is thus 'treating me as a human being', as Participant #10 says.

In the focus group for people living with MS, participants discussed their sense that rigid protocols were making it difficult for rehabilitation professionals to really tune into the needs and wishes of the disabled people with whom they were working. One of the participants told the group about the frustrations she experienced when she first moved into the area, and was trying to have equipment installed. She reports a conversation with the OT, who said:

> 'Oh, we can't have any of that. We can't have your computer desk in.' My husband said, 'Where is she going to work?' – because I was doing the magazine then and some other writing stuff. 'She's got to be able to work,' […]. They said, 'She can't have it there,' and there wasn't any room, because I couldn't access any other rooms except the kitchen. (MS FG participant)

The focus here is placed on the professional telling the service user that a certain arrangement of furniture 'can't' be done. In the reported conversation, we do not have any sense of the framework that determines why a certain arrangement is impossible. The participant conveys an experience of the service as intransigent and unable to be responsive to her need to work. She does not feel involved in the decision-making: when someone does speak about her needs, it is her husband, rather than she, who voices concern. Another participant in the group responded to this account as follows:

> It’s an interesting thing you’re saying, which is that people will tell you what you can and can’t do, what you can and can’t have, telling you what you can have in your living room. But I’m afraid I’m the sort of person who will say, ‘Sorry, that’s my living room,’ and nobody can actually *tell* you. You can just say no to all of it, if you want, because it’s *your* condition. (MS FG participant)

This second participant begins by reflecting back what she has heard: that people ‘tell you what you can and can’t do’; she shows that she has listened to the earlier speaker. She invites the other participant to reject this experience of ‘being told what to do’ by modelling the self-assertion that she herself invokes in such situations. Yet, she rightly identifies that she is the ‘sort of person’ who feels comfortable making her position clear, but not everyone would necessarily feel confident to do this. She here connects involvement with an individual’s pre-existing sense of her ability to speak up. Interestingly, it is the active ownership of the ‘condition’ that is seen as being at the root of feeling empowered to speak out. This could be compared with other participants’ accounts, for example, that of Participant #10, where the emphasis is very different: being identified *with* the condition leads to a loss of personhood (‘you lose the right to be the person you were’). I interpret the focus group participant as drawing a distinction between two possible modes of engagement with this scenario. On the one hand, in her view, disabled people may identify with their conditions and internalise others’ understanding of what their conditions mean (i.e. the idea that ‘you ARE the condition’). On the other hand, they could take active ownership of the condition and seek to shape others’ understanding of what it means (i.e. the idea that ‘I am the one WITH this condition, you have to consult me’).

Another participant within this group spoke passionately of his difficulties with NHS Wheelchair Services, which was a service which was noted as a lowlight whenever it was discussed in the data. This individual had experienced great difficulty in obtaining the right kind of wheelchair for his impairment, and his account displayed his sense that he had not been properly consulted:

> After many, many months of arguing about it, they eventually said they'd give me the next one up, but that it wouldn't be made for me but would come off the shelf. I was willing to try anything. But they didn't look at me from an MS point of view. They looked at me as somebody who needed to use a wheelchair, so they gave me one that was built for somebody with a spinal injury, which was terrible. It was light in its way that it tilted and lifted, but it was slow in its pushing. So, I was given an inappropriate piece of equipment, which I kept falling out the back of. (MS FG participant)

Here, the participant gives active verbs to the teams who were making decisions; he is often the object of these verbs, rather than their subject ('they eventually said', 'they didn't look at me', 'they gave me'). These language choices suggest that he feels unable to influence decision-making himself, but rather that he is being told what to do and feeling that he has to accept these circumstances. The phrase 'I was willing to try anything' implies that he feels desperate for the equipment he needs, after the long wait he mentions, and that this renders him passive. He lacks the energy to argue. He relates the consequences of decision-making that did not fully involve him: he received a wheelchair designed for someone with a different type of impairment, which was 'inappropriate' and which was not secure for him.

This was one of the extracts I discussed with my project advisory group. Certain members of the group had experience of using wheelchairs and they were able to provide helpful context for interpreting the extract. There was some discussion of the question of whether NHS wheelchair services might be oriented towards SCI patients. This was inconclusive, although as one group member explained, a standard procedure does exist for assessing SCI patients for wheelchairs. There seemed to be agreement that NHS wheelchair services was not always able to tailor its strategies to meet the needs of the individual in question. It was observed that patients' needs may change over time, but that the service is not always flexible enough to cope with this, and that this might be a particular issue for MS patients, whose condition might fluctuate. One group member noted that in her experience of engaging with wheelchair services, there had been a lack of explanation as to the trade-offs involved in choosing one kind of chair over another; there had also been long waits, gaps in contact or periods of being taken off their books, and difficulty repairing wheelchairs, for example when a company would go out of business. The third member of the group confirmed that he had been given wheelchairs that were very difficult for him to use. The group's interpretation of the passage was similar to my own, but their experience of engaging with wheelchair services provided context for some of the remarks made by the research participant that might otherwise have remained opaque to me. In particular, the comments about the need for a more personalised strategy helped to illuminate the participant's experience of having been given a wheelchair for a person with a different kind of condition.

By contrast with these focus group participants, who found themselves being told what to do, there were a small number of examples of more consultative experiences in the data. Here is Interview Participant #4, recounting the interactive working relationship he had had with a rehabilitation worker:

> I went to the GP and was referred to [rehabilitation type]. I worked with them for a while. They were really good at explaining what was going on, what may have caused [the issue] and what to do and just checking with me, all the time, as to how things were going…. giving me things to practice every week, and even though I was frustrated that I couldn't fix it straightaway there were little things I could do to improve, improve stuff, which is good. Now […] I have ways of managing it […]. But as I say, [this person] was really helpful and worked with me, with it, which I thought was really good.

> […] it was really nice to see something different, in terms of [the person] would work with me and ask lots of questions and how I was doing and kinda, would track progress, and that kind of thing which wasn't always the case with the [other rehabilitation] stuff that I'd had. (Participant #4)

The participant highlights the fact that the rehabilitation professional 'explain[ed] what was going on': this contrasts with the previous participant's experience of being told that he will be 'given' a certain piece of equipment on the basis of its availability rather than in response to his needs. As this excerpt highlights, explaining possible causes of an issue, as well as possible techniques for working with it, is seen as an important part of a consultative process, because it enables the patient to understand the rationale for using a particular intervention or treatment, and the clinician's decision for using that technique. The patient experiences the professional as involving the patient fully in every step of the treatment programme; this is underscored by phrases such as 'just checking with me' and 'ask me lots of questions and how I was doing'. Here, it is the rehabilitation worker's consultative and question-based manner which appeals to Participant #4, and which contrasts with his prior rehabilitation experiences. He describes having felt 'like a cog in a machine' with some other rehabilitation professionals, who focused on 'repairing' him, whereas this experience 'seemed a little bit more human, to me'. The image of the 'cog in a machine' suggests a conceptualisation of the body, and of the person, as something which could be expected to meet uniform standards; as if the rehabilitation professional will only be performing his/her job if s/he brings this imagined template into her consultations and seeks a machinic uniformity. By contrast, the participant's description of this rehabilitation worker suggests a more open, adaptable manner, in which the patient is fully involved in the process of rehabilitation.

The excerpts discussed in this section draw attention to participants' sense of the importance of being consulted, in order to ensure that rehabilitation worked for them, and offered them the kinds of outcomes they needed to be able to maintain their quality of life. The data also highlights the issue of power in rehabilitation relationships: participants did not always feel able to speak up about what they needed, but in some cases felt that their identity as a service user meant being a ‘rule taker’. This section has highlighted the varying status of the patient’s own lived knowledge in rehabilitation encounters. The extent to which rehabilitation professionals drew on, or appeared to disregard this knowledge, varied greatly in the accounts I analysed. Where patients’ own knowledge was overlooked in favour of the need to follow protocols, or because of resourcing issues, this situation had the potential to create epistemic injustice (Fricker, 2007): that is, the neglect or de-prioritisation of certain kinds of knowledge or modes of knowing. This neglect of certain modes of knowing may come about because they are seen to be attached to people of low social status.

6.7 ‘A world full of opportunities’: Involvement as a supported discovery of agency

Thus far, the data discussed in this chapter mainly illustrate difficulty in relation to involvement in rehabilitation experiences: the battle to be involved, the sense that involvement was being undertaken superficially, or that one’s very right to rehabilitation was being undermined. But there were also a range of accounts of rehabilitation in which a participant had felt fully involved in the process, or had become fully involved via the skill of a rehabilitation worker or peer supporter. These were narratives in which working with someone else had had a significant impact on a participant’s rehabilitation journey, and were often recounted in terms of discovery. In this section I aim to elucidate the contribution that these stories make to our understanding of involvement as a social aspect of rehabilitation.

6.7.1 Discovering reciprocal expertise

Participant #18, a young woman with a rare condition requiring attention from a range of medical specialties, reported very varied experiences of the rehabilitation services she had used. Yet she spoke enthusiastically about what it had been like to discover a physiotherapist who had a similar impairment and therefore experiential links to her own:

> P18 Currently I'm under a lady physiotherapist who has [a related condition] and has given a lecture to her fellow physiotherapists on the condition […]. She's a very good physiotherapist to talk to about [my condition].
>
> HC How do you find working with a physio who's got a similar condition?
>
> P18 It's been amazing because it's not traditional physiotherapy of get you well after you've been sick. It's trying to help you when there's no recovery in sight so it's not as goal-led as 'in eight weeks' time we'll have you jogging again'. This has got to be slow, considered, and what we do is Pilates. We do beginner level Pilates with some adjustments. […] So even some of the Pilates stuff is difficult to get on with. So, she has worked with me for a while now but instead of getting my NHS six appointments and you do it over six weeks, we've been meeting once every two or three months, so I've [been] given a set of physiotherapy Pilates to go and do and then I come back to her and we see what my progress is like. (Participant #18)

Here, the interweaving of the pronouns 'I' and the 'we' suggests that the participant's individual agency is retained throughout, but that it is occasionally augmented by a supportive other, so that it becomes a 'we', working for common outcomes (but not 'goals'). The programme requires the participant to do her exercises by herself between sessions, and in this sense her rehabilitation is self-directed, but she appears motivated by the idea that she is going back to the same professional, whom, she feels, has a real interest in her progress ('we see what my progress is like'). What works in this partnership is the recognition of the particularity of the patient's needs: a programme that acknowledges that it is maintenance, rather than cure, that is the focus, and a set of sessions that are spread out, accordingly, over time. It appears that the participant has been involved in designing a programme that really works for her, and feels invested in following it as a result. Furthermore, the fact that her physiotherapist has lived experience of a similar condition is described as ‘amazing’ by the participant and she directly links this to her sense of being heard in her need for a way of working that maintains her health rather than seeking to fix her. Involvement here seems to be about something quite simple: it does not require any ‘fancy words’ (to use Participant #4’s term), but it does require a human connection that arises, it seems, because the therapist is able to listen to what is needed and to implement it.

The fact that Participant #18’s physiotherapist has also given lectures on their shared condition is also an important detail, because this individual told me that she regularly encountered healthcare professionals who were much less well-informed about her condition than she herself was, and whom she experienced as treating just one part of her anatomy without regard for the whole. Thus, this participant wanted and needed her therapist to be an expert in the science of physiotherapy and its application to her condition, but she also wanted her own expertise-by-experience to be used in their partnership. Their relationship thrived because both forms of expertise could be recognised for what they were and deployed appropriately. This is a rare example in the data of a patient-centred rehabilitation experience in which the participant retains control but is supported by a partnership that enhances outcomes.

6.7.2 Being challenged to re-examine disability and take up agency

In a range of instances, participants highlighted the ways in which sustaining relationships enabled them to become fully involved in, and take control of, the rehabilitation process. A striking account was given during the focus group for people with an experience of sensory impairment. A middle-aged woman who had been living with blindness for a number of years told the group that when she first became blind she felt as though her life as she knew it was ‘over’, but that a change of rehabilitation worker made a huge impact on her feelings. The participant explained:

> I just decided that my life, as it was, had been over and just her [i.e. the rehabilitation worker] having this ‘can do’ attitude and challenging me to change my perception of myself and the world around me, just seemed to open that world up again as a world full of opportunities that I then wanted to do everything ‘today’ because it was like, ‘Yay, it’s all there,’ and I was like a child at Christmas with all the Christmas presents. I could go out there and do things. I suppose that really set me on the way back to feeling much [more] confident about myself, getting out and about, eventually getting back into employment so, in my mind the biggest thing about […] my rehabilitation was the attitude of my rehabilitation worker. If she’d’ve had a different attitude, it may have been a very different outcome, really.
>
> […]
>
> Basically, her taking me and showing me that there was an alternative way to do things really made a big difference to my life, because once I realised I could do that in a different way, I just thought, well I must be able to do everything in my mind in a different way, and it was just about finding that way to do it. Then I just got over-excited, I suppose, and wanted to do everything at once… (Sensory FG participant)

In these extracts, the participant describes how she went from feeling despondent to hopeful about her life with blindness, accounting for the shift wholly in terms of the ‘attitude’ of the rehabilitation worker who ‘challenge[d] her’ to ‘change [her] perception of [her]self’. Here it is the rehabilitation worker’s ‘“can-do” attitude’ which facilitates a perspectival shift in the participant. The participant was able to re-engage with her own life (‘I could go out there and do more things’) as a result of the encouragement she received in this rehabilitation relationship. But the rehabilitation worker also supported her by showing her that there were practical alternatives she could use, in the place of sight, to do the things she wanted to do in her life, and this ‘made a really big difference’ because it enabled the participant to reframe her acquired disability as something she could work with, rather than being the barrier it had previously been ‘in [her] mind’. The participant reports her sense of excitement at realising that ‘it was just about finding that way to do it’: everything about her account in these two excerpts is centred on the effects of the discovery.

Implicit in this account of this participant’s newfound buoyant mood is the sense that her discoveries might not have happened by chance, but rather that they are the result of the input of the skilled rehabilitation worker, who manages to achieve exactly the right blend of emotional support and practical advice as she builds a rapport with her client. Here the participant’s emotional involvement in the process is conceptualised as the bedrock of a successful rehabilitation experience, yet it is not an ingredient that can be taken for granted, but is, rather, something that has to be cultivated over time. Furthermore, her emotional involvement was the result of a relationship in which the rehabilitation worker not only took the time to really hear how the participant felt about her disability, but also *challenged her* on this, and *showed her*, in practical terms, that she could help herself to change her outlook by rethinking her assumptions. She seems to have felt this ‘challenge’ as a deeply caring act, because it was, in some ways, the opposite of pity and sympathy. It did not entail glossing over difficulty, but, rather, it demanded that she re-examine the difficulties. She framed this as a way of taking hold of difficulty, de-stigmatising it, and seeing it for what it really was without the layers of stigma attached. The ‘taking and showing’ was also an empowering experience for the participant because it allowed her to see something for herself, rather than just feeling that she was being told what to do. Indeed, this participant explained, referring to experiences of low mood about acquired impairment, and their effect on one’s ability to be proactive in rehabilitation, that ‘you kind of just accept almost what you’re being told there is, because you’re not really expecting any more yourself’. This phrase shows both that the participant’s mood profoundly affected her capacity to take up agency in the rehabilitation process, and that being ‘told’ rather than being ‘shown’ had been part of her lived experience of that process. Thus, both being ‘challenged’ and being ‘taken and shown’ supported this participant to be fully involved in her rehabilitation, because they were acts which enabled her to see her impairment through a different lens, and in this way to take control of it.

6.7.3 Discovering someone similar: Involvement through identification

Some of the most positive rehabilitation experiences recounted in the transcripts occur when participants describe how a relationship enables someone to think differently about disability. Participant #1 referred to an enabling peer-support relationship in the following terms:

> A visitor came in a wheelchair, one day, another chap, and for a minute I thought he'd come from a different ward and was a bit lost, but after he introduced himself and he explained to me in great detail what his life was like in the wheelchair, which was an enormous help… erm, it wasn't straightaway that it sort of dawned on me. It took him at least, I think, he must have visited me 10 times. Erm, I was in a bad place to begin with, but I would suppose halfway through those visits, I started to understand, come to terms within a much better, positive way, that maybe I could, maybe I could deal with this. Maybe I could. (Participant #1)

In this instance, a meeting someone with the same impairment makes a difference to Participant #1's sense that he 'could deal with this'. As the interviewee explained, the man in the wheelchair was visiting on behalf of a voluntary organisation supporting people with spinal cord injuries. The sense that this visitation feels unexpected is highlighted by the participant's reference to his confusion about who the man was ('I thought he […] was a bit lost'). He recounts how he struggled to grasp the purpose of the meeting initially. Rather than feeling involved, the participant seems to have felt disorientated, but the perception of the other man as a 'lost patient' gradually gave way, over a series of meetings, to a realisation that life with a disability goes on beyond patienthood. Like the participant whose life was changed by her rehabilitation worker's capacity to involve her in her rehabilitation, this participant reports this supportive encounter in terms of discovery ('it […] dawned on me'; 'I started to understand'). Importantly, Participant #1 went on to emphasise that he was only able to believe in the idea of life after spinal cord injury because 'somebody had wheeled into my room, and not walked into my room'. The encounter would not have had the same impact if the person he had met was not a wheelchair user, so identification plays a powerful role here. Furthermore, the vulnerability of the participant, and his uncertainty about whether he could face the future, is highlighted in the repetition of 'maybe I could', which implies that the unspoken opposite term, 'maybe I couldn't', might have dominated his thinking up until this transformative relationship developed. The phrase 'maybe I could' suggests a turning point in terms of the taking up of agency in the rehabilitation process. Peer support was often cited as a playing a transformative role in rehabilitation in the data I collected, and although I looked for counter-examples, I did not find any.

In these examples, participants' experiences of being fully involved in a rehabilitation relationship are depicted as profoundly transformative. The representation of such experiences as pivotal led me to focus devote more of my analytic attention to accounts of being enabled to take up agency in one's rehabilitation, and to explore some of the factors that participants emphasised as facilitating this enablement. This is the focus of the next chapter. For now, I turn to a linked sub-theme, which again underscores the role of relationships in rehabilitation: involvement as partnership.

6.8 'It's a bit of a pupil / teacher relationship': Involvement as partnership

In some of the narratives in my data, especially those from individuals with sight loss, I noticed that rehabilitation was configured as a joint project with a rehabilitation worker. In this section I look at the texture of these accounts of partnership, in order to understand what they elucidate about how involvement might look within rights-based rehabilitation.

Participant #16, an older man with a degenerative sight loss condition referred to 'working as a team' with his rehab worker, and having a 'close working relationship' with the hospital. Participant #15, who had been partially sighted all his life, and was now blind, described long cane training, albeit with some ambivalence, as a 'teacher-pupil relationship':

> There have been times when I've thought, 'Why are they telling me that? I'm a grown adult. I don't need that!' – a little bit, I have resented it, but then I've thought about it and I've realised that although I'm in control of referring myself for more help to learn a new route, I've had to accept that it's a bit of a pupil/teacher relationship where you do have to accept that sometimes you have to accept constructive criticism… (Participant #15)

This description suggests that it has not been easy for the participant to accept that another adult knows more than him, and that at times he feels that this undermines his status as a 'grown adult'. But the quotation also emphasises what is to be gained by recognising one's limitations, by understanding which aspects of the process one has 'control' over and by accepting that rehabilitation may involve learning. The distinctive reference to the 'pupil/teacher relationship' stood out during my work of reading and re-reading the transcripts, because it told me something about rehabilitation as a partnership. The term 'pupil/teacher relationship' suggested to me that the speaker identified an inevitable inequality in this partnership, but did not necessarily denigrate this particular manifestation of inequality. Many other transcripts framed rehabilitation as relational, and yet, nobody else used quite these terms. I saw it as broadly positive that the participant's representation of rehabilitation in this way was, according to his account, something he came to after a period of reflection. I read the statement as saying that even if there is an explicit inequity between the pupil and the teacher, there is an unavoidable reason for tolerating that inequality, which is that the pupil is learning something from the teacher, and so is benefitting. My discussion of this excerpt with the project advisory group was illuminating. Certain participants emphasised the need for rehabilitation workers to recognise and validate disabled people's expertise-by-experience in their interactions. A colleague felt that it seemed that the disabled person was seeing himself as inferior to the rehabilitation worker. This project advisory group member commented that it is very easy for disabled people to start to see themselves as a 'nuisance' in the context of scarcity of resources. My colleague read the phrase as a rationalisation of the need to 'accept' the pupil role, which could suggest that the participant was accepting oppression. I think that the passage could be said to contain both something of my own reading, and something of my colleague's reading: ambivalent feelings towards rehabilitation relationships are on display here. Indeed, our readings were ultimately not so very divergent: my colleague went on to explain that this interaction appeared to be a success because the participant's trust had been won by the rehabilitation worker sufficiently for the participant to learn well.

When I tried to sum up what I thought Participant #15 was saying about rehabilitation in this context, I used the word 'negotiation', and asked him whether he thought this was a useful word. He agreed, and said, 'that's right, absolutely'. The term 'negotiation' suggests reciprocity. It chimes with the remarks made by one of the participants from the focus group for people with experiences of sensory impairment, whose narrative was discussed in the previous section. For her, the biggest obstacles to rehabilitation were, as she described it, her own negative mind-set about the cultural meanings of blindness, and the fact that she felt 'very low' initially about going blind. In this context, the idea of expertise-by-experience has limitations if the person's emotional experience of disability is making it very difficult for that person to draw actively on, and put to use, the expertise s/he is gaining from life. For the individual who was struggling with the meaning of blindness, the rehabilitation worker helped her to challenge the stereotypes she had internalised about how her life would be (as did encounters with peers), and ultimately she was able to get the most out of rehabilitation. This participant was making an important point about how rehabilitation can only work if the patient is *in a position to receive something from it*; sometimes a dialogic experience of partnership with a rehabilitation worker is what is needed to trigger this. The participant felt that choice and control in rehabilitation were highly dependent on her feelings about her impairment, and the emotional support she received to come to terms with it was pivotal. In these cases, involvement in rehabilitation is not experienced as something that can be expected to happen simply by paying lip-service to it, but rather it is negotiated over time. The patient has to be ready to accept her limitations and be open to what rehabilitation can offer, and the rehabilitation worker has to facilitate that openness.

In Participant #17's narrative of residential guide dog training, a key part of the process is about bonding with the dog:

> P17 What I felt when I was there […], the provision was amazing. I was given a hotel room which… part of the reason you have to go away from home is so you can bond with your dog, because the dog stays with you in your hotel room and it is extremely intense. It's basically like learning to drive a car because the dog doesn't just lead you, you are driving the dog, and it's so subtle that people can't tell. There's a series of voice commands, foot positions, body language that's communicated between you and the dog.
>
> HC Foot positions to show the dog which…
>
> P17… yeah. It's a huge myth that people look at guide dogs and think it's basically a teddy bear with GPS that knows exactly where it's going. But it is a dog the same as anything else. If you ride a horse you've got to tell it where to go – exactly the same thing with a guide dog. You are riding a horse, effectively. If you say to a horse, 'Take me to the Post Office,' it's not going to take you to the Post Office unless you tell it woah, left, right – and it's the same thing. So they learn routes. We walk into town, to my office, a lot, so she does know that route, but she still needs direction. She still needs to be told to slow down or to speed up or to stop sniffing… (Participant #17)

This account emphasises the interdependence of guide dog and owner, and the way in which getting from A to B involves working as a partnership, requiring both the 'subtle' and skilful input of the owner, and the dog's responsiveness, capacity to bond with a particular individual and ability to learn new routes. As the participant explains, the role of the owner is much more active than many people assume, noting that the dog is not a 'teddy bear with GPS', but needs to be given directions. The training is residential and 'intense', in this participant's account, because of the need to build up a relationship of trust with the dog, so that the dog will follow the commands that are given, and also so that the learner can get to grips with the 'foot positions' and 'body language' that are required for communication. In the interview, the participant described feeling apprehensive about having to be away from home for so long in order to do the training, but in the event she came to understand that in this instance immersion was a necessary part of the 'bonding' process (for both dog and human), and she described the training as 'amazing'. Thus, in this example, rehabilitation is only possible with the participant's full involvement in the process, because it is predicated on the formation of a new partnership that then becomes central to the participant's life.

The examples in this section, and in the previous section, have demonstrated how, in some instances, an enduring, two-way, reciprocal involvement in rehabilitation can create a strong bond between patient and rehabilitation worker. This can lead to a profoundly positive outcome for the patient.

6.9 Chapter summary

In this chapter, I have analysed how the research participants represented their involvement, or lack of involvement, in their rehabilitation. I aimed to demonstrate the main ways in which 'involvement in rehabilitation' was conceptualised by participants in my study. This included elucidating participants' experiences of not having been included in decision-making, as well as those of more thoroughgoing involvement, to demonstrate both the range of experiences, as well as the transformative nature of more reciprocal and enduring forms of involvement. In this conclusion I briefly review the themes that have been covered in the chapter.

Involvement was not necessarily a ‘given’ in participants’ rehabilitation experiences, but was instead **an element of rehabilitation that might have to be fought for**. Involvement was closely **connected with having a voice**, in some cases literally: participants with impairments that affected their speech sometimes felt excluded from consultation processes, or felt that people working in health services did not always have (or allow) enough time for disabled people to express their wishes. Being able to ‘speak up’ about one’s rehabilitation experience played an important role in getting access to services, especially for participants with rare or contested conditions. Yet not everyone was able to ‘speak up’.

Participants discussed ‘involvement’ as being an aspect of contemporary discourses of patient-centredness, but this did not always translate into positive experiences of being involved. Some participants felt that **lip-service was being paid to ‘involvement’** in services that did not have enough resources to implement this in practice. Others recounted experiences of services being enacted rigidly, and of practitioners whose protocols made them unable to respond flexibly to patients’ specific needs.

When participants saw involvement as working well, it usually involved the **forming of a partnership** between the patient and the clinician, rehabilitation worker, or assistance dog. A partnership did not necessarily mean equality between each party, as the example of the successful ‘pupil/teacher relationship’ showed. But it usually required some kind of acknowledgement of the **different types of expertise** brought to the relationship by each party; such working relationships were characterised by negotiation, by listening, and in the most positive cases, by reciprocating. Successful involvement was sometimes characterised by participants in terms of **revelation or discovery**; when they had felt fully involved and supported in the process, they had been able to reconceive of what it meant to have an acquired impairment, and this could give them the courage they needed to embrace the practical aspects of rehabilitation.

Chapter Seven

Narrating agency in rehabilitation: Re-skilling, reciprocity, writing

7.1 Introduction: Aims of this chapter

In this second of three data analysis chapters, I explore how participants represented their experiences of being an actor in the rehabilitation process. I aim to demonstrate the significance of 'agency' to participants in this research, and thus also to a notion of rights-based rehabilitation. I will achieve this via analysis of participants' representations of varying scenes and practices of agency, as well as via a discussion of what I learnt about agency by doing the creative writing fieldwork activity.

In the first sub-section of the chapter, I aim to explain what brought me to this theme, and how I conceptualised 'agency' in my abductive work on the data, developing the discussion begun in section 5.10 of the 'Methodology'. This is an extended explanation, because of the ways in which I came to understand 'agency' as a connecting thread in the data, drawing together moments from different fieldwork activities. I then proceed with my analysis of participants' representations of scenes and practices of agency, starting with a focus on the sub-theme of skills and re-skilling in rehabilitation, and moving on to examine reciprocity and the relationality of agency in rehabilitation relationships. In the second half of the chapter, I discuss the creative writing fieldwork I undertook as a site in which it became possible to explore the relationship between agency and narrative. My overall aim in the chapter is to weave together these different instances and stories of agency, and to demonstrate how they make a case for considering 'agency' as a pillar of rights-based rehabilitation.

7.2 Deciding to focus on agency

Article 26 of the *UN Convention on the rights of persons with disabilities* (United Nations, 2008) focuses on the *enablement* of disabled people, via rehabilitation, to achieve ‘maximum independence’ and to participate fully in ‘all aspects of life’ (my italics). Thus, the framework which underpins this research is invested in promoting infrastructure that offers disabled people agency in their lives. In the previous chapter, a key theme of my analysis was how participants represented themselves as battling to be more involved in rehabilitation decisions that they felt excluded from. These participants resented feeling that they were not being given responsibility, or opportunities to act, and that they used up all their energy on actions to get access to a service, rather than on rehabilitation decisions *per se*. Building on the analyses begun in the last chapter, in this chapter I focus more closely on participants’ representations of what it was like when they *were* enabled to take up agency in their rehabilitation.

During data analysis, I was struck by moments in participants’ accounts when something that I might have easily overlooked because the content seemed mundane, or even off-topic, was represented to me as being a pivotal aspect of a participant’s lived experience of rehabilitation. Such anecdotes drew my attention to a range of experiences across different settings, but a key, connecting thread tended to be the participant’s sense of being enabled to act in that moment, and, in some sense to take ownership of their rehabilitation, or indeed ownership of the narrative of their rehabilitation. Participants placed emphasis on how motivating, and valuable, such moments of agency were, and, as the phrasing ‘being enabled to take up agency’ suggests, they often conceptualised agency as something that was predicated on intersubjective encounters or exchanges.

The term ‘agency’ is an analytic category that I have used to interpret data pertaining to participants’ accounts of feeling themselves to be in charge of the process, however it was not (usually) a term that participants invoked themselves. The terms ‘agency’ and ‘patient agency’ are generally reserved for academic discussion, and have particular resonances in the history of sociology (the agency-social structure debate) and health sociology (the concept of patient agency), as discussed in my review of the history and theory of patient and public involvement in research (Chapter Four). Yet, even if the term ‘agency’ can be understood as an academic one, the genealogy of agency discussed in the PPI review has significant implications for how people imagine the role of the patient in their everyday experiences of healthcare. As discussed in that chapter, the idea of the patient as an active figure in health decision-making can be understood as a relatively contemporary development (Armstrong, 2014). Etymologically and historically speaking, a patient is not a doer at all but rather is expected to be passive as something is ‘done to’ him or her: a patient is ‘a person who *undergoes an action*’ (Oxford English Dictionary, 2005, my italics). But today, the notion of the patient-as-actor is a significant feature of certain contemporary healthcare discourses, notably the discourse of patient-centred care. Given the contemporary prominence of the idea of redistributing agency in the clinical encounter in contemporary discourses of patient-centred care, it is perhaps not surprising that this theme should have come to the fore at various moments in this research.

Given the focus of the UNCRPD (United Nations, 2008) on the *enablement* of disabled people, via rehabilitation, to achieve ‘maximum independence’, and the role of this policy document in shaping this project, my questions to participants on the subject of choice and control in decision-making can themselves be read as implicitly reinforcing the value of individual agency in healthcare, and of a patient-centred paradigm. My choice to elicit material on these themes is not a coincidence, but instead reveals the ways in which my own thinking about my research problem took place within a particular sociocultural context, and was informed by a particular model of the rights of the cohort of people I involved in the project. This acknowledgement offers a social and intersubjective context for the thematic discussions that follow, recognising that this data is specific to the research encounters that I constructed.

A further reason for the decision to explore agency came via the process of reflecting on the experience of embedding creative writing into a fieldwork activity. One of the core ideals of the project was that of redistributing agency, not just in the clinical encounter, but also in the research encounter itself. This ideal, and its potential implementation, was visible in the protocols I used to maximise inclusion in the creative writing group and follow-on group. The fieldwork experience also highlighted novel ways of thinking about this ideal, as I shall describe. Running the creative writing group and the follow-on focus group led me to think about the ways we may habitually conceptualise knowledge production in social research, which often situate the university researcher as the one who is seeking to ‘know’ what participants have to ‘share’. My lived experience of doing this part of the fieldwork, as well as my fieldnotes and reflections, led me to think that introducing creative writing might have the potential to disrupt this conventional model by seeking opportunities to enable each participant to engage in the process of discovering their own rehabilitation narrative, and that each participant could author that story. I had not gone into the process expecting these outcomes, but it did seem that this process had created a some space for research participants to become agents of their own rehabilitation narratives, with the group acting as witnesses of these stories. I draw on data from the follow-on discussion group later in this chapter to explore this aspect of agency in this research.

Drawing on the experience of running the creative writing groups, I have called this chapter ‘Narrating agency’. Narrative constructs the need for a witness or an audience, whether that is another person, or an internal interlocutor – a space inside the self for reflection. As well as being connected via the over-arching theme of agency, the sub-themes in this chapter are linked by a common emphasis on the figure of the Other in accounts of agency in rehabilitation. Becoming an actor in one’s rehabilitation is often contingent upon the enabling role of an ‘Other’, be it another person, or a service, or a researcher, or indeed an ‘Other inside the self’. The chapter begins by focusing on narratives of becoming re-skilled, where participants’ sense of agency is connected with be able to do something useful, or make something beautiful, that may be appreciated by an Other, or by a newly-appreciating self. In the accounts which follow, participants became animated in these moments of narrating agency; they also connect agency with creativity. The next section examines a theme introduced in the previous chapter, and considers accounts of the role of the Other’s demand in invoking agency, in helping the individual to be, or to remain, an actor in their rehabilitation. This theme is then developed through a discussion of what it meant to participants to be able to share their experiences of rehabilitation: opportunities for reciprocity during or after rehabilitation supported participants to connect with a sense of empowerment. Finally, the last two sections of the chapter explore the theme of ‘narrating’ more fully, drawing on participants’ accounts of what it was like to write about rehabilitation in the creative writing group. The chapter’s sub-sections are as follows:

1. **‘It taught me something […] far beyond that’: Being re-skilled produces agency**

2. **‘Come on, you’ve got to do it’: Demands that invoke agency**

3. **‘If I could help a health professional…’: Reciprocity as a source of agency**

4. **Narrating rehabilitation 1: Writing as processing**

5. **Narrating rehabilitation 2: Redistributing agency in the research process?**

7.3 ‘It taught me something […] far beyond that’: Being re-skilled produces agency

Certain interview participants highlighted the transformative role of becoming re-skilled in the course of their rehabilitation. Sometimes, the activities that participants described were associated with creativity rather than being seen as traditional rehabilitation practices. The number of participants who drew my attention to such activities was small, but the enthusiasm with which they described these activities (Participant #1 in particular) caused these accounts to become a focal point for analysis, especially latterly as I reflected on the new data from the creative writing groups. These agency-inducing experiences seemed in part to be significant because of an external demand to make a specific item as part of one's rehabilitation. Participant #1 gave an account of making his own transfer board, through which he learnt new skills. As an inpatient, following spinal cord injury, he was instructed by the OT department to make his own transfer board, to use when moving in and out of his wheelchair:

> P1 You make the board. You're given the specifications of the board, then you're given the wood, you cut the board out…
> HC … using a saw and everything? …
> P1… using a saw…
> HC… Wow! Why is that?
> P1 You have an occupational therapist, an instructor with you, who does most of the work for you. So once that's cut out, it's put onto a table and then you proceed to sandpaper the board [*talking over each other*]…
> HC… wow!...
> P1… and then lacquer it…
> HC… but why do they feel like that's, that's an important part of the process [*talking over each other*]…
> P1… it's your board, it belongs to you.
> HC So, there's a kind of sense [*talking over each other…*
> P1 … so you have a relationship with the board, if you like. (Participant #1)

In this extract, the participant describes the various stages of making the board, including cutting, sanding and lacquering it. It was clear from the participant's description that what had been valuable was, in part, the *process* of making the board, which enabled him to take ownership of it ('it's your board, it belongs to you'). The participant conceptualised this episode in terms of developing a 'relationship' with the board, a piece of equipment he would need to carry with him for a long time, and so needed to 'know' really well. The creative activity supported the transition to becoming a wheelchair user because it allowed Participant #1 to build familiarity with his equipment, as well as enabling him to shape it for his needs. The process of learning how to 'relate to' an assistive device such as a transfer board is, it seems, enabled by the creative, skill-endowing process of making the board, which allows time and space for adjustment to the idea of needing it. The making process offers the participant some agency over an aspect of his rehabilitation which is otherwise associated with hard work and difficulty (this participant spoke about how hard it was learning to transfer).

Participant #3 connected an experience of being re-skilled with starting to re-frame her view of her impairment. This participant had suffered a stroke in adulthood, and here she spoke about the experience of being encouraged to take up knitting during her rehabilitation, in the context of a question about setting goals:

> P3 …when I had my stroke I went to the community hospital for some physio and to get my left hand going, they suggested I tried knitting […].
>
> HC So that really worked for you.
>
> P3 Yeah, and I went back every week and they wanted to see how much I'd done – 'Haven't done much today,' but to them, 'Done a lot there,' but to me it was just like, 'Not achieved nothing here.' But like they said, again, take it down to bite-sized pieces. You think you've done nothing but, for argument's sake, you've knitted half a scarf, or whatever. So that was really, really helpful, that was really positive [*talking over each other*]…
>
> HC… so that was a really helpful task, and was that helpful because it was structured around having a goal?

> P3 I guess so and it was also… […] it was a positive in that they were then helping me to do something productive… (Participant #3)

Here it is the encouragement of the physiotherapists which the participant depicts as leading her to try knitting, which then proves successful in helping her to regain use of her left hand. But, according to the participant, this intersubjective experience also helped her to reframe her own sense of not achieving much in the rehabilitation process. She is convinced that she has done ‘nothing’ or ‘not much’, but, with support from the therapists, she is enabled to see her progress in terms of ‘bite-sized pieces’. This term suggests that something that felt overwhelming and unmanageable has started to be seen differently, broken down into parts or stages. The participant describes this experience as ‘really, really helpful’ and ‘really positive’, emphasising what a significant and empowering episode it was for her. Moreover, in response to my question, the participant highlights not so much the fact that this task was goal-oriented as that it was, in her words, helping her to ‘do something productive’: it helped her to feel that she is using her time in a worthwhile way. Indeed, the notion of using one’s time productively and usefully was a widespread theme in the data, and one that is discussed in detail in the next chapter. The participant has regained a skill that she thought she had lost, and thus knitting represents the process of becoming re-oriented in herself. For a person whose interview transcript is laden with examples of her sense of reliance on others, the brief focus on knitting is an interlude in which the participant’s autonomous activity is foregrounded. Thus we might say that this part of the participant’s rehabilitation involves discovering agency by regaining a sense of herself as having a particular skill, and being able to use this skill creatively.

To give another example from the dataset, Participant #1 spoke movingly of the moment when, as an inpatient, he discovered a creative activity that involved using his hands, and which was key to his re-finding the motivation, purpose and enjoyment of life he needed in order to keep going with the more tedious aspects of rehabilitation:

> I must have spent three hours doing it. I was completely and utterly entranced. I was totally immersed in making…
> […]
> And if there was a rehabilitative process that gave you a skill, gave you time to learn something and time to produce something, the end product is usually a lift, your mood, your spirits, your morale and it duly did that. There's no question. […] Every time I went in there I smiled. It was a big, big lift, because it didn't teach me to transfer, it didn't teach me to pass a catheter, it didn't teach me bowel care, didn't teach me how to wash, how to sit up straight, how to put my shirt on. What it taught me was something far beyond that and I got to know my instructor and everybody used to come round, and [describes the messiness of this creative activity, and how this is part of the joy of it], but I loved it […] but I absolutely loved… if that was a rehabilitative process, it worked for me! (Participant #1)

In this passage Participant #1 celebrates creative immersion and absorption, as well as the mess of the process. Time has passed without the participant noticing because he is so 'completely and utterly entranced' by what he is doing. The intensity of the language here highlights what an important moment it is for him. This account of creative absorption is embedded within an interview that highlights the difficult feelings associated with coming to grips with a radically changed embodiment. The way he describes time's easy passage under these conditions suggests that the experience is partly transformative because of the reprieve it gives him from the arduousness of other rehabilitation activities. The participant's repetition of 'it didn't teach me' has a rhetorical power: it relegates traditional rehabilitation activities, framing them as comparatively insignificant when contrasted with the need to re-ignite the desire for life, which is achieved via this creative activity.

The participant focuses on becoming skilled as an important attribute of rehabilitation. The activity itself is portrayed as giving ('gave you a skill, gave you time'): what is being given here is not only the satisfaction of 'produc[ing] something' but also the 'lift' in his 'spirits'. The re-skilling process enabled this participant to make contact with positive feelings that, according to his narrative, he had not been able to access since becoming disabled, and it seems that what the experience ‘taught’ him was to reconnect with an agentic part of his old self. There is a direct benefit in terms of his wellbeing, and it is in this sense that the participant designates the activity a ‘rehabilitative process’. The skills he learned enabled him to make beautiful things for his family, he told me. This excerpt stood out within this participant’s transcript as a transformative moment in which he was able to take up agency within his rehabilitation, because of the fulfilling experience of creative absorption and the empowerment associated with learning a new skill.

Accounts of rehabilitation as a site of skilled creativity and flow were relatively rare in the data: opportunities to take up agency, such as the ones described above, were often represented as precarious, or fleeting, or dependent on the encouragement of another, or even on an external demand. Participants’ status as actors was not secure, but as the accounts discussed in this section suggest, the experience of being an actor in rehabilitation was valued all the more because of the way that this rare moment of creative flow, or animation, stood out in contrast with the rest of rehabilitation experience (see also Sennett, 2008). Rights-based rehabilitation therefore could and should emphasise the transformative potential associated with creativity and the learning of a new skill.

7.4 ‘Come on, you’ve got to do it’: Demands that invoke agency

In the previous section, some of the activities that participants tried were undertaken because of an external demand, or in response to encouragement from a rehabilitation professional. In this section, I look more closely at the role of the external demand in producing agency. At various points in the data, participants referred to the significance of a demand from an external figure (for example, a healthcare professional, rehabilitation worker, or carer). These were demands to take up responsibility for the trajectory of one’s rehabilitation, or to take up agency over one’s life. The experience of being challenged to reconsider one's view of disability was emphasised in particular by one of the women in the Sensory Impairment Focus Group. As discussed in the Chapter Six analysis of involvement, this individual felt that her whole attitude towards rehabilitation had changed in response to being pushed to think differently about the meaning of blindness by her rehabilitation worker. Here, I explore an account in which similar feelings are displayed about the effect of a demand. This is from the transcript of Participant #10, who has a severe neurological condition, which was getting worse over time. We were discussing a phase of her life during which her cognition had been poor, and she explained how her personal assistants, who had known her over a long period, responded to this:

> It was the carers, who were familiar with me, who said 'come on, you're usually bossing us about, come on, come on, you've got to do it', and insisted. Um, and one of the carers [...] could tolerate [my] sort of – absences – and - and still prod me to make – to try and get me to do things – she was still sensitive to leaving time for me and trying to get it to be me rather than her who took over – so yes, I think there is quite a lot of specialism in there, in among the social side of it, and *that* was hugely beneficial to my physical health because then I was able to fight back, but then you know, does anyone care? This is the point [laughs with sadness in voice]. (Participant #10)

In this quotation, Participant #10 values the work of her PA to prompt her, as the employer, to take decisions, and yet also to allow her the time she needs to do this. The participant observes that this intersubjective work is difficult and skilful ('I think there is quite a lot of specialism in there'), and recognises that the PA's ability to wait, and to leave time for her employer to do things in *her own* time, has been 'hugely beneficial' to the physical side of her rehabilitation. Yet the participant also values the fact that the PA continues to 'prod' her, always making sure that the agent of the task is the employer. Here, interestingly, care is characterised in terms making a *demand on* the disabled person – telling her to 'come on'. In this instance it is this act of *making a* *demand* or *issuing a challenge* in a relationship with a disabled person, which is powerful. It seems to be powerful because of the way in which this act encourages a disabled person to take up her own agency ('trying to get it to be me […] who took over'). Whilst it is important to note that this is a relationship with a personal assistant (PA) that is being discussed here, rather than a relationship with a healthcare professional, there are nevertheless significant implications here for rehabilitation relationships. Firstly, as the participant notes, it was this caring PA relationship which gave her the emotional support to 'fight back' and to get what she needed in terms of physical rehabilitation. But secondly, this example of the interlocutor who makes a demand on her employer models a possible mode of relating in rehabilitation that supports the patient to become an agent over the process. Indeed, Shakespeare et al. (2017) have evidenced the relational dynamics in PA relationships and their role in empowering disabled people. The example here reveals a form of engagement on the part of the interlocutor that involves noticing the patient's capacities and strengths, and which respects the patient's full humanity by making a demand which invites the patient to take up agency. This is something that the participant seems to value deeply in a climate in which real care, which involves the recognition of personhood in the Other, is in short supply.

Without the interlocutor's recognition of the patient's agency, the latter's role in the relationship can become quite one-dimensional. The following quotation – which is important for rights-based thinking – is also from Participant #10's interview:

> It's like …. you've had – you've had your character deconstructed – you're no longer at the moment – you lose your right to be the person you were because you're taking resources, and therefore you will do as you're told… and I am awfully grateful when I looked at the huge number of things that we've done, and the way I've adapted through a huge number of things, and assistance, little bits of help here and there, and bits of equipment – I mean there's a

> whole army of people who have helped me over the years. I am very, very, very grateful. (Participant #10)

Part of this quotation has been analysed in Chapter Six, where I highlighted the type of connection that is being made here between *using up resources*, on the one hand, *and the withdrawal of rights*, on the other. The loss of rights is also linked with a loss of agency, and the requirement to become a rule-taker ('therefore you will do as you're told'). 'Doing as you're told' is very different from being the recipient of a demand that makes one into the agent of one's life. Although both concepts appear to invoke imposition, 'doing as you're told' infantilises the disabled person, shutting down choice, whereas the demand to participate is a recognition of, and a conferral of, personhood.

As the utterance continues, the participant can be seen to move into a register of gratitude for all the help she has received. In the wider context of the interview, in which the shrinking availability of services was invoked so many times, the emphasis on gratitude is worthy of analysis. As I analysed this excerpt, I found myself thinking about the stereotype of the disabled person as an ungrateful 'taker' of resources, or even as a scrounger, which pervaded the mass media during the austerity years in the UK (see Crow, 2014), and which was sometimes implicit or even explicit in the interview transcripts (in this one, as well as in that of Participant #18). Such a stereotype implicitly relies on a notion of the disabled person as unequal, because it posits the idea of a disabled person's access to the services she needs as something for which she should be thankful, rather than something to which she has a right. The recourse to gratitude reinforces a sense of the dominance of this logic of charity over rights (see Fleischer & Zames, 2011), and of the inescapability of the stereotype of the 'demanding disabled person', in this participant's encounters with rehabilitation services. This participant's transcript was filled with stories of having to make demands on others in order to get access to rehabilitation. Yet the idea that someone else might demand something of *her, the disabled person,* offers a powerful counterpoint to this *modus operandi*, and it points to the potential significance of conceptualising patient agency in rehabilitation as something that emerges when a humanising expectation or demand is placed on the patient. The example discussed in this section points to the relationality of agency in rehabilitation. An individual can be enabled to become an actor within his or her rehabilitation via the careful, thoughtful facilitation of an Other. As this example shows, this is a mode of relating that requires mutual trust, and takes time, in order for agency to flourish. This may be an important aspect of the rehabilitation process for a rights-based policy to reflect. In the next section, I examine another form of relational agency.

7.5 'If I could help a health professional…': Reciprocity as a source of agency

Building on the discussion in the previous sections in which expectations were seen to produce agency, here I take a closer look at a similar theme: instances of the desire for reciprocity. This emerged as a significant sub-theme. Specifically, participants often framed their keenness to take part in this project in terms of a wish to 'give something back' to a health service that had offered them a great deal at a time of need, or to have their voices and views heard, in order to contribute to education and training. This was perceived as a way of exercising agency over the future shape of rehabilitation services. Whilst not every participant made reference to this idea as a source of motivation, it was very common, and as a theme it often emerged in the conversations that were peripheral to the interview or focus group, at the point when a participant first enquired about the research, and so the issue is not always evident in the transcripts themselves. Equally, the issue sometimes arose in the interview itself: here Participant #14, an older male with an impairment acquired in his youth, speaks during his interview about his involvement in healthcare education and how this made him feel:

> But I like helping other people, either newly disabled people on day one of their journey or health professionals in their training, because my experiences, if I could help a health professional in their training they will then be able to help somebody else in reality […]. That helps me. That takes the pain of my condition away, because I get paid for doing that, as well, so that's even better. […] Money doesn't

> bring happiness but money will take the ouch away from the discomfort of the loneliness that disability brings upon me. (Participant #14)

He expresses how the act of helping others ‘takes the pain’ of disability away, both by reducing loneliness and by enabling the participant to play an active role in the future rehabilitation of others. ‘Being paid’ plays an important role in removing the ‘discomfort of loneliness’, suggesting that the isolation experienced by this participant relates to a sense of lacking a useful social role; payment is experienced as recognition of a contribution. The reference to being paid also draws attention to the importance of an experience of reciprocal relations in this situation. The participant raised this point voluntarily in the context of a discussion of the availability of resources to help manage the psychological impact of disability, and so he was indicating this work as an example of what helps him to feel better. Later, this participant described an aspect of this work with health professionals as a ‘specialism’ to which he is uniquely suited, as a disabled person. The concept of having a ‘specialism’ and of being useful are of particular importance to this participant, suggesting that what may be hardest to tolerate is a loss of status and of a clearly defined relationship with the social world. As a ‘specialist’, the participant’s useful knowledge is recognised, and he experiences himself as having agency and dignity in the world. He is seen as an expert-by-experience. The participant also used the term ‘compensation’ to describe this form of participation: he was referring, I think, to the ongoing sense of loss he associates with disability, even many years after he became disabled.

The theme of wanting to ‘make a difference’ to other people’s experiences of rehabilitation featured elsewhere in the data too. Participant #4, a young man with cerebral palsy, spoke passionately about the need for education around disability equality within the NHS, as well as on the subject of involving young people, including teenagers, in NHS decision-making processes around service provision. He referred directly to the potential of this research to support such work (‘I hope that’s what this research kicks off’), implying that these ambitions played a large part to motivate him to take part in an interview.

Similarly, Participant #8, a woman in middle age, who had lived with cerebral palsy all her life, closed the interview by telling me:

> I'm pleased to share my experiences. I think it's very important that these experiences should be shared. (Participant #8)

Here, sharing offers a type of agency: the sharing of experiences is seen to contribute to a body of knowledge about rehabilitation. Participants from all strands of the research voiced a desire for the research to feed into improving services. This is a key point, especially given that a significant proportion of the voices heard in this data are ones that are socially marginal; they belong to people who are marginalised in one or more ways, whose social experiences may have led them to experience a loss of status and to feel that from now on they are a more dependent 'service *user*' rather than someone who has something to *give* to society. This sense of loss of agentic status comes across in a number of transcripts in different ways: for example, Participant #5 told me that he no longer felt valued because he could not be an economically productive member of society, and Participant #4 spoke of his anger in relation to encounters in which he felt he was being treated according to a stereotype of disabled people as unable to work. Participant #6 frequently interrupted his own narrative with queries about whether what he was saying was relevant to this research activity – perhaps characterising me as the busy professional and himself as somebody of low status by comparison. Thus, the relationships which developed in the course of the interviews sometimes echoed the dynamics of giving and receiving that had been in play in rehabilitative relationships, or alternatively the participant showed awareness of the need to create something different, in which the participant could be actively helpful to another person undergoing rehabilitation, by taking part in this project and then sharing experiences of the rehabilitation process.

As the excerpts discussed in this section suggest, these forms of social participation and reciprocity were felt to activate agency. The development of a rights-based rehabilitation could develop these moments of agency by seeking to institutionalise the involvement of disabled people in the delivery of the health sciences curriculum and in health research. This point will be taken up in Chapter Nine.

Thus far, I have explored the ways in which participants were activated as agents through enabling relational structures and through the (re)discovery of skills. I now turn to a discussion of ‘narrating’ as another kind of enabling structure.

7.6 Narrating rehabilitation 1: Writing as processing

If sharing their stories with a researcher gave participants a sense of agency over their rehabilitation, so too did writing, for certain individuals who took part in the creative writing group I convened as the third strand of my fieldwork. For the remainder of this chapter, I focus on both my experience of running the creative writing group and on some of the data that arose from it in the subsequent discussion group, which highlighted the role of writing in narrating and processing rehabilitation experience.

In the discussion group, which took place approximately two weeks after the creative writing workshop, I began by asking people to introduce themselves, and I also invited them to briefly share any observations they wanted about the experience of writing about their rehabilitation, either in the writing session or subsequently. This introduction process was intended as a to help people reconnect with each other and to build rapport within the group, because I thought people would need time to warm up to the idea of sharing their writing. I was surprised by how much certain individuals wanted to share about the writing process, and by how animated they were during these early discussions. These initial exchanges set the tone for a discussion group in which participants were frequently thematising the relationship between rehabilitation events and their representation in writing. One of the common themes in the upcoming quotations is the idea that the process of writing is itself bound up with the process of making meaning. Here is one of the participants, an older woman who was adjusting to an acquired impairment:

> When I am writing, my mind is freewheeling, if you like, and I've written things down on paper that I *never* would have arrived at if I was discussing anything with another person. Um, you know, the paper doesn't judge you, you just scribble out what you want to say, and I found that very helpful… Um, it's not always helpful to read it back, but sometimes it is because you can then realise you've moved on… or abandoned that idea. […] I'm not naturally a writer; I'm more of a talker, but I'm more guarded when I talk so it has been good for me. (Creative writing group participant 1)

Here, this participant is connecting writing with letting one's guard down and free associating ('my mind is freewheeling'). She also characterises writing as an activity that allows feelings, thoughts and ideas to emerge because the page is seen as non-judgemental. The participant feels she can 'scribble out what [she] want[s] to say' and this is 'helpful': the writing process is associated with expressing herself freely, and it is contrasted with talking, which is a mode of expression in which she tends to be 'more guarded'. This author may thus imply that writing enables the creation of an authentic intersubjectivity with an internal self, which allows free thinking in a way that cannot necessarily be replicated with an interlocutor who is an Other. One of the remarks here suggests that the participant can be quite surprised by the products of her writing: her assertion that it has enabled her to 'arrive' at things that she would never have reached in conversation. Writing facilitates processing an idea because it can create space for an internal dialogue with an Other-inside-the-self, which can be the former self that held an idea that the contemporary self recognises herself to have 'abandoned'. The activity of writing therefore can allow the writer to gain some distance from her feelings and then return to them, realising that she has moved on.

Another participant made the following observations:

> [The writing process] made me…try to be more reasonable, because I start out very angry about things, and then when I put it

> down, I think, ‘oooh, is that really true?’, and gradually I break it down into what’s causing the anger, and I get to the nub of it. (Creative writing participant 2)

For this participant, writing helped her to be (in her words) ‘reasonable’: it enabled her to gain some perspective on the events she was reflecting on. The process helped her to give shape and order to her rage about feeling that she had become a ‘case’ instead of a person within rehabilitation services. As the extract shows, writing permits dialogic thought to emerge, whereby the author questions her own framing of events (‘ooh, is that really true?’). Like the first participant, this individual benefits from the gap which emerges between herself and her feelings by ‘put[ting] [them] down’ on the page; writing facilitates processing by setting up a the possibility of interlocution with an Other-inside-the-self which becomes more visible when written out onto the page. Writing allows her to ‘break’ an experience ‘down’ into its constituent elements, and to get to the ‘nub’ of what is causing her anger. Through writing, the participant can really work something out with precision. The idea of ‘breaking’ something down is reminiscent of the participant who benefited from trying out knitting, and found that this helped her to see both the knitting process (and, by implication, rehabilitation) as a series of ‘bite-sized pieces’.

Writing was associated by a third participant with helping her to take care of herself. She referred to the difference between ‘life before disability and life afterwards…’ and talked about how she found herself ‘trying to be the person [she] was before’. As she went on to say: ‘being able to write some stuff down has helped me to accept who I am…’. Again, in this instance, the speaker sets up a duality between two versions of the self: writing helps her to examine the relationship between them. Alluding to the difficulty of integrating a newly acquired disabled identity, the speaker highlights the role of writing in achieving self-acceptance. She links acceptance with being able to get ‘stuff down’ on the page, as if the process of externalising helps with the difficult feelings of wanting to be the person that she was before becoming disabled.

In all of these cases, phrasal verbs associated with self-expression ('scribble it out') and with the capture of feeling in writing are used ('put it down' 'write it down' 'break it down'). The 'down' in each phrase emphasises the process of capturing and taking control of an experience; it gives agency to the writer. Writing is also associated in these extracts with a shift or a change. Participant 2 characterises writing as crafting, as a dialogic process within the self, through which new, more precise concepts emerge. Participant 1 refers to going back to writing and finding you have 'abandoned an idea' and moved on, suggesting that writing has helped with the process of reflecting on rehabilitation experiences with a degree of distance. Participant 3 finds that writing helps her to accept who she is now that she has a disability. In these participants' utterances, there is a sense that getting words down on the page is associated with achieving new understanding or new mental states – particularly precision, clarity, reason, or acceptance, or perhaps the ability to maintain anger or momentum by invoking angry feelings in a reader whilst having found greater calm for oneself. Writing supports agency for these participants, because it helps them to get to know what they think and feel in a space that is outside the immediacy of spoken conversation, and because it creates a space for dialogue between different parts of themselves. The experience of adjusting to impairment and undergoing rehabilitation provokes strong emotions, as many of the data extracts across the analysis chapters show. For these participants, writing supported the difficult work of managing these emotions linked to adjustment work.

Some researchers argue that the opportunity to write (instead of, for example, responding orally to interview questions) liberates participants from anxiously focusing on producing a 'truthful' account, allowing the *meaning* of an experience to emerge (see Barone & Eisner, 2012; Leavy 2009). The examples here show some participants invoking writing as liberatory, and therefore as freeing their capacity for action, but they suggest that it can also be much more than this: they suggest that the act of writing itself is an act of processing and of making meaning. Indeed, these utterances reveal a series of sites of knowledge creation: of participants using the writing experience to discover what they themselves think or thought about rehabilitation, of participants changing how they feel about rehabilitation through writing. In this section, we have seen how participants were authoring knowledge of the rehabilitation experience both in the act of writing, and in relaying their experience of the process to me.

The discussion group also saw a conversation develop in which participants responded with feeling to each other’s writing, and there was a developing sense of the group as making a space of community and solidarity, signalled by comments made to me outside of the taped parts of the session, about enjoying the process, about the way it had helped a participant to feel belonging instead of loneliness, about feelings of gratitude towards me for organising it. The discussion group had 100% attendance: everyone who attended the creative writing group returned to discuss their work, which surprised me, as I assumed that people might feel shy about sharing their writing. It seemed that the element of creativity altered the dynamics of the research encounter: the university researcher was no longer the person who was finding out from them, because everyone was finding out about themselves; knowledge was no longer reified as a ‘thing’ that participants ‘have’ but was instead conceptualised as something that was more contingent upon the words that might be given to it and the constellation of people in the room who might or might not actively encourage a particular interpretation. The university researcher was no longer the person with sole curatorial power to decide what to foreground in a transcript; the creative work of foregrounding was being undertaken by participants themselves. This data ‘collection’ activity could be seen to disrupt the tidy image of knowledge-about-rehabilitation flowing towards me, the researcher, and instead, highlighted ways in which participants were authors of knowledge themselves. Conventional qualitative methods such as interviews are also caught up in these processes of co-production. However, because the interview has become almost synonymous with qualitative sociology, it is sometimes more difficult to see its qualities as a staged interactional encounter, and may be easier to think of it as an exercise in which information flows in one direction from interviewee to interviewer. In the next section I examine these questions further, exploring the qualities of the creative writing fieldwork activity which helped to disrupt methodological certainty. I ask whether this activity was able to redistribute agency in the research process.

7.7 Narrating rehabilitation 2: Redistributing agency in the research process?

My experience of embedding creative writing within a broader data collection activity helped me to see more clearly how conventional methods and practices can be routinely configured so as to prioritise *certain voices* and *certain forms of knowledge over others*. This is not to say that using creative writing in the way I did is *inherently* emancipatory or democratising, nor indeed that everyone will share in the experience of creative writing as an activity that helps with processing, but rather that this process in this study drew my attention to a methodological and epistemological question that I had not come to my attention when using interviews and focus groups as data collection methods. This question was : “if this research activity produces new insights, *for whom* are these new insights?”. By which I mean, both: ‘does creative writing produce new insights for writers themselves?’ *and* ‘for whom are insights being produced in research?’ Whose knowledge is this?’

This question arose as I was reflecting on what was *distinctive* about the data that emerged from the data-collection discussion group which followed the creative writing group. I was anxious that, in terms of ‘content’ towards answering my research question, I had not yet gained many new insights that I could not have gleaned from the interviews and the focus groups. Yet, listening again to their transcript, it became clear to me that, as far as certain participants were concerned, creative writing had enabled a *very distinctive mode of engagement with their experiential knowledge*, which had triggered particular emotions and thought processes. It seemed to contribute to a more agentic process of narrative-building about rehabilitation. These realisations did, in fact, help me to respond to an aspect of the overall research questions for the project, because they allowed me to understand, through experience, how the decisions I made about how to conduct the research had a direct impact on who I was empowering as a ‘knower’.

In my doctoral work, I sought to be guided by my research questions in the planning of the fieldwork. Even so, by contrasting the process of designing and doing the creative writing groups with the process I used for the semi-structured interviews and focus groups, I realised that for the latter activities I had been investing in the idea that tried-and-tested, off-the-shelf sociological practices such as interviews which would yield ‘good’ data if I just did the methods ‘right’ (see Law, 2004). This meant that, during my work with those practices, I did not always question a conventional positivist model of research that says, ‘I, the researcher, am finding something out’. By contrast, when I asked myself fundamental questions about what it is that this method is doing and what it will achieve for the research, I had to be able to make a case for what and how a method will ‘find out’. Creative writing disrupts a notion of research as ‘finding out’ and relies on an altogether different metaphor for how knowledge comes about, and how it ‘gets to be’ in a place (such as a conversation, a transcript, a PhD thesis); it is altogether more compatible with a constructivist stance, which sees data as something that is built, and co-created, in the research encounter. Furthermore, the creative writing participants quoted here reveal that writing was a process of discovery for them as much as it was for me, and that it was *through the very process of creating writing* that they made meaning about rehabilitation. Meaning was not a ‘thing’ that participants ‘had’ and which they could give researchers access to; instead it was something we were exploring together, and which the tasks given to the group might or might not facilitate. The process of authoring rehabilitation knowledge conferred agency: the agency of making a narrative out of the lived experience of rehabilitation. We think of a piece of prose or poetry as something that a person has created, as an object with an author, but we do not tend to think of an interview transcript in the same terms. Writing offers an altogether different, and more fluid and uncertain, way of conceptualising the knowledge-making process in sociology, for me as well as for participants, because in going into this process without knowing what would come out of it, I was taking a step back and inviting the participants to take up greater authority – as authors – within the study, even as our roles also continued to be constrained and demarcated by the norms of the research process and by the relevant protocol. I was questioning what kind of agent I should be to facilitate participants' narratives of finding agency. For the remainder of this section, I shall briefly reflect on the strengths, limitations, and specificity of the claims I have made about the creative writing data, before I summarise the findings I have discussed in this chapter in a concluding section.

7.7.1 Strengths, limitations and specificity of the claims for this research

The data I have analysed in this part of the chapter have taken me into a meta-analytical mode, because the excerpts illuminate aspects of the research process itself that gave (or withheld) agency from participants. The decision to present this data within an analysis chapter, rather than as part of the discussion chapter at the end of the thesis, relates to my focus on the idea of redistributing agency, both in this chapter and in the thesis as a whole. In a project that is about how disabled people are involved in shaping agendas for research and service provision, the separation of this material about the enabling aspects of the research process from a thematic analysis of agency could perpetuate a mode of thinking about agency in which this term is always contained and demarcated by the researcher. The data presented here may show how using an innovative fieldwork activity to question certain norms of the research process can be enabling. It may help both the researcher and the participants to rethink agency in the research process. For disabled people, whose voices are not always amplified either in policy-making processes or in research, the fact that this fieldwork activity had an element of 'exploring together' can be seen as a clear strength.

It is important to note that, in the creative writing groups, participants were commenting specifically on the experience of doing writing as part of this research, or on how they had used writing in general, in their lives, to manage the feelings associated with rehabilitation. They were not discussing writing as an activity that had been given to them in a rehabilitation setting. I should be clear that my writing groups were not set up to provide therapeutic benefits for participants, but were purely for my research. Any benefit to participants was entirely incidental. Participants' utterances about the role of writing in helping them process rehabilitation should always seen in the context of a discussion group led by me, reflecting on writing tasks devised by me. Perhaps the fact that I was the source of an external demand – to write, in a particular format – was itself an agency-giving experience. Perhaps some participants' responses were structured by a desire to compliment me on the process, even if their comments were simultaneously very genuine. The hierarchical structures governing the research process – and my apparently powerful role as a university researcher – were not undone by the writing group. To the extent that I can make a claim about writing as an activity that might support the development of agency in a rehabilitative process, it must be qualified by an acknowledgement of the possible constraining role of these psychosocial dynamics.

Participants' utterances reflect the specificity of *their* experience of writing, which may not be shared by others, especially because not everyone finds writing easy; indeed, not everyone in the group itself spoke about finding writing transformative. I do not seek to make a generalised claim here about what writing can or cannot do for disabled people who are undergoing rehabilitation, but rather to draw out some specific ideas in participants' comments which connect with key themes that recurred throughout my analysis, about practices and processes that helped participants to adjust, re-orient themselves and find ways of being in control of rehabilitation.

It seemed that I had created a some space for research participants to become agents of their rehabilitation narratives, although I do not want to overstate the 'participatory' or 'co-created' credentials of this element of the project. I was, and remain, the university researcher who gets to curate the data which emerged from the creative writing activities, and who gets to accrue academic capital by presenting at conferences about the process and publishing in academic journals. Furthermore, creative writing is not equally accessible to everyone, as one member of my project advisory group made clear. Participants were self-selecting in their decisions to make enquiries and to request to take part in the writing groups. Drawing on advice from PPI members, I adapted my process to accommodate people with impairments which made writing difficult, and indeed one of my participants had aphasia, and I supported that individual with writing. Nonetheless, it is still highly likely that some people may have been dissuaded from taking part if they did not enjoy writing, or perhaps were unable to write. Not everyone experiences writing as discovery. Those who took part in my group were likely to have chosen to take part knowing they felt comfortable with the kinds of writing tasks I presented to them.

In this sub-section, I have sought to explore some of the psychosocial dynamics of knowledge production that may have been in play in the lead up to, and the running of, the creative writing group and discussion group. I have sought to consider both the ways in which the creative writing group may have re-distributed narrative-making agency in the research process, and the ways in which any re-distribution of agency was necessarily constrained by pre-existing hierarchies. I now seek to conclude the chapter by explaining how I have met the aims set out in the introduction, and what the key findings are for rights-based rehabilitation.

7.8 Chapter summary

This chapter aimed to demonstrate how participants drew my attention to the central importance of being an actor in their own rehabilitation, and what this might mean for the design of a rights-based rehabilitation policy. To meet these aims, I have discussed how participants conceptualised agency as something that emerged in relation to re-skilling, in relation to being able to reciprocate, and in relation to being given space to tell their stories. The analysis has sought to show how these thematically diverse data converge on the transformative significance of being enabled to act within one’s own rehabilitation experience, whether this be through re-building skills and thus confidence, finding ways to impart one’s valuable lived knowledge to others who can make good use of it, or making meaning through narrative. I shall briefly rehearse the chapter’s main themes in the summary that follows.

In the latter part of the chapter, I demonstrated that participants' utterances about the act of writing creatively on the topic of rehabilitation thematised the role of **writing-as-processing**: participants felt that writing supported the work of coming to terms with life as a disabled person, and the emotional labour associated with rehabilitation. While noting that these utterances had a different status to others examined in the analysis chapters, because they offered a metatheoretical commentary on writing and on the research process, I nevertheless suggest that this data helps us to understand how participants conceptualised agency in this project. This can be seen to be the case when placing this data alongside analyses of excerpts in which participants explained how they felt when they mastered a skill such as knitting, making a transfer board, or doing a creative activity with one's hands. In all of these instances, participants highlighted the ways in which a 'process', such as a creative process, or **a re-skilling process**, was instrumental in helping them to shift their perspective. That shift may have meant moving towards accepting disabled embodiment. Alternatively the shift may have entailed abandoning a long-held view that might have been hindering their engagement with rehabilitation, gaining clarity on what they felt or thought about a service, or finding a source of motivation for rehabilitation in and through the creative act. In these senses, their creativity helped people move on with their rehabilitation; **the creative act was linked with becoming an agent in/of one's rehabilitation**.

This chapter also highlighted the **empowering role of reciprocity**, and **of receiving external demands to take up agency**, on participants' sense of being in charge of their own lives and their rehabilitation. In a parallel with the previous chapter on involvement, here agency was felt to be mobilised in the context of supportive relationships. It often seemed that participants were referring to the diminution of personhood which could be associated with the experience of internalising a stigmatised identity and of the profound difference it can make when an external source expects something of you, or wants something from you, as opposed to framing you as the person who is always in receipt of services (or 'taking resources'). When someone expects something of you, and you find yourself being required to take on the responsibility of acting, this confers the dignity of personhood and is a source of agency, in these accounts. This experience seems to be linked, in study participants' accounts, with a perception that disabled identity has downgraded their social status: the demand to take up agency went some way towards re-building a sense of self-worth.

During the process of running the creative writing group and then analysing data that emerged, I realised that one of the reasons I had chosen to use a creative writing activity was because I wanted to problematise received ideas about who has agency in research. When I asked myself what 'finding out' means, and who we think of as being the agent of discovery in research, I was also able open up a space in which **research participants could narrate their stories and become authors of their own experience, as well as interpreters of others' experiences**. Although this could happen in any qualitative research encounter, I have argued that, in de-familiarising aspects of the research process, creative writing can have a distinctive role to play in helping both the academic community and participants to interrogate the metaphors we rely on to conceptualise knowledge (as 'gathered' or 'created', for example). By challenging such metaphors, we can critically evaluate how different qualitative methods curate the relationship between voice, authorship and agency, both in rehabilitation and in research.

Chapter Eight
The temporality of rehabilitation experience

8.1 Introduction: Aims of the chapter

While the relationship between narrative-building and agency emerged prominently in the analysis undertaken in Chapter Seven, in this third of three analysis chapters, I examine ways in which participants drew my attention to the temporal dimensions of their rehabilitation narratives. I aim to explore what participants' emphases on time and temporality may signify for rights-based rehabilitation, via discussion of a series of linked sub-themes. I open the chapter with a section which describes how I came to focus on temporality in the data, and how I came to understand this term via my abductive work; this section expands on the discussion in 5.10 of the Methodology. Then my analysis of participants' representations the temporality of rehabilitation proceeds through five sub-sections, which explore sub-themes relating to: adjustment over time; time as a resource; and the ongoing nature of rehabilitation time. I aim to highlight how central the temporality of rehabilitation was to participants' accounts of the process, and the ways in which temporality was seen to mediate a sense of control over rehabilitation.

8.2 Why 'time'?

Early on in the data analysis process, I noticed that themes highlighting the temporality of rehabilitation, such as waiting, administrative time and adjustment over time, recurred frequently in relation to rehabilitation experience. Participants seemed to emphasise their experiences of time's (elongated or rapid) passage during rehabilitation itself, as well as the role of time's passage in the way they retrospectively attributed meaning to rehabilitation in their lives, and evaluated successes and areas for improvement. Many participants also contrasted the perceived value of their time with that of other figures, such as healthcare professionals, who featured in their rehabilitation narratives. They often linked their own sense of being in charge of rehabilitation, or of being overlooked or peripheral to decision-making, to the temporal dimension of rehabilitation. These early observations suggested to me that it would be crucial to explore in more detail how markers of time were being marshalled in disabled people's accounts, in order to explore how the lived temporalities of rehabilitation were involved in creating (dis)empowering processes and practices. From the qualitative synthesis presented in Chapter Three, I knew that experiences of temporality (including temporal disruption) had emerged in other researchers' studies exploring the lived experience of rehabilitation (Papadimitriou & Stone, 2011; Bourke et al., 2015). Working abductively with the data in this study, I sought to inquire into the specificity of the sense of time's importance to the participants who generated it, in order to understand the key issues that might pertain to rights-based rehabilitation.

To evaluatively examine the emerging time-related sub-themes more thoroughly, and to explore their inflection of 'rights-based rehabilitation', I reread the transcripts, paying particular attention to references to time. I also undertook a word search (electronically) on the transcripts, on the following words: time / wait / fast / quick / slow / long / short / minute / hour / day / week / month / year. The latter process was not always as revealing as the former, because very often references to time's passage were made by participants in terms of the way they marked their speech, via terms such as 'before', 'after', or even through the use of different verb tenses to draw a contrast. Attending more closely to phrasing was therefore more useful to my interpretation than word searches.

This analytical process suggested to me that the relevance of time was connected with participants' creation of a biographical narrative (see Plummer, 1995). The more I returned to the data, the more it struck me that the use of language signalling the experience of change, rupture and discovery, or indeed of stasis and the need for persistence to precipitate change, seemed to be a fundamental part of the lived experience of rehabilitation, and that these themes were deeply connected with participants' sense of their own biographies, with their sense of agency and even with their access to rights in the rehabilitation process. Later, thinking again about this data as I reflected on the creative writing workshops I had run, I began to think that narrative-making played a vital role in rehabilitation; this was discussed in Chapter Seven, and I draw on my insights into the importance of narrative-building in my analysis of the temporality of rehabilitation here. Here, the focus is placed on three main thematic areas (discussed over five sub-sections), which emerged prominently in my abductive work on the data. Firstly, I look at the idea, narrated by a number of participants, that rehabilitation can be understood as an individual's work of **adjusting** to life with a disability, in the case of acquired impairment in particular, and that the elements of rehabilitation may or may not be experienced as happening in a timely fashion, when a person is 'ready'. Secondly, I explore time as a **limited resource**, which may be valued or seen as expendable; in this context I consider how participants' experiences of waiting, or of structuring their own time, or having to organise rehabilitation, are narrated by them using the language of value and investment. Thirdly, I consider the way in which rehabilitation time is described by participants as **ongoing and enduring**, and as linked to the work that they do to maintain fitness and functioning on a long-term basis: this often contrasts with the finite temporalities of treatment regimes they encounter within services. The analysis of these themes is presented under the following sub-headings:

1. **'I think I was ready then': Adjustment, the future and timeliness**

2. **'I was just going through the motions': The experience of waiting in rehabilitation**

3. **'Right, what have I got planned today?': Time, value and investment**

4. **'It takes up so much of my time': Organising rehabilitation**

5. **‘We’re dealing with it every day’: Rehabilitation time as ongoing maintenance time**

8.3 ‘I think I was ready then’: Adjustment, the future and timeliness

The work of adjusting to life with an acquired impairment, and the time this took, was highlighted by a number of participants in this research. As this section will indicate, the timing of rehabilitation interventions played a crucial role in how well participants were able to receive and benefit from services. Disabled people’s experience of the efficacy and acceptability of aspects of rehabilitation may be deeply connected with timing, and as such, timing can be understood as a rights issue.

Five out of seven participants who had acquired their impairment suddenly (#1, #2, #6, #7, #19) referred to having to adjust their expectations for the future as they became accustomed to their disability, while another (#14) seemed to have been struggling to adjust over a number of years. The theme of needing to adjust one’s expectations about the time it would take to recover, or to adapt to a different embodiment, emerged strongly in a number of the transcripts of people with acquired impairments. Participants #6, #7 and #19 all told me that they had made the assumption at the outset that they would be going back to work in a matter of months, and that they had gradually become disillusioned:

> Everything is a battle to get up, to get dressed, to play tennis, have a workout, go to [support organisation], to see you, to shave and so here we go again. I’m still adjusting to a life with a brain injury. […] My quality of life is totally different now, so I’m still adjusting. (Participant #7)

Here Participant #7 makes two explicit references to adjusting over time. The qualifier ‘still’ in both occurrences of the term highlights the time this process is taking him. He refers to a range of activities that are now a ‘battle’, suggesting both that these were straightforward for him before he had his acquired impairment, and that they require huge amounts of energy now. He compares his quality of life before and after the injury with the term ‘different’.

Some participants (#7, #19) had been supported through their transition by occupational therapists, who were helping them to identify alternative vocational pathways or goals for the future. Yet even if this was helpful, sometimes the sense of loss associated with adjustment was hard to contain, as Participant #7 revealed:

> Because it’s only up to me to adjust [to] it and all these health professionals who are absolutely fantastic and mean well, they don’t really grasp the fact that because they are all working people, they get up and go to work, da, da, da, - fine. (Participant #7)

Here he speaks of the difference between being a healthcare professional and *knowing* about how to treat his impairment, and actually *living* with it *day-to-day*. This comparison highlights his own sense of being isolated with the burden of having to do the work of adjusting, even if the health professionals ‘mean well’. The tone of his ‘fine’ at the end of the excerpt is quite sharp, in the sense of, ‘it’s fine for them’. Here, the relentless quality of the *lived time of adjustment* is contrasted with the finite *lived time of doing one’s job* and going home afterwards. In this example, adjustment takes work, and yet it is not explicitly conceptualised as work: instead, work is associated with the health professionals. This excerpt suggests that part of what the participant is adjusting to is life without his vocational identity.

Participant #2 spoke of the importance of *not* adjusting her expectations when she recounted a lack of attention given to ‘the future’ during her inpatient rehabilitation for a spinal cord injury, which took place in the late 1960s. The future was especially important to her because she was an ambitious young woman:

> The expectation was that I would go home and [*pause*], yeah. But I don’t remember anything about talking about the future. As it was, the college kept a place for me open and I did eventually get back there. (Participant #2)

Here, the pause followed by the ‘yeah’ suggests that there were few expectations for her as a disabled woman when her rehabilitation ended. She notes that she cannot recall the future having been discussed. Elsewhere she talks about the limited expectations ascribed to her future by staff at her inpatient rehabilitation setting:

> So, I was thinking what can I do when I go – that was on my mind a lot. And I remember talking to the occupational therapist about it, because after a while I thought, ‘This is a good job, this OT. I could do this.’ But when I mentioned it they said, ‘Oh, no, you couldn’t possibly do that in a wheelchair.’ I think about that, now, because later on, when I went back for check-ups – which I did for a long time, I don’t do that now – one of the doctors was a wheelchair user… (Participant #2).

In this excerpt, the participant highlights again how much her future is in her thoughts while she is an inpatient: ‘that was on my mind a lot’. Yet, rather than opening up a conversation about what the future might hold, in this reported exchange, the OT closes down options by arguing that they would be impossible for someone who uses a wheelchair. The participant contrasts this position with her experience of having encountered a disabled doctor subsequently; she later remarked that the view of the OT was ‘of its time’. Here the participant was being expected to adjust not only to her disability but also to a disabling view of herself and her future. Participant #2 explained to me that her determination to go on to take up her college place played an important role in her motivation to re-learn to walk, against expectations. Her account of the episode with the OT, with the participant’s sense of ‘I could’ being turned into a negative ‘couldn’t’ contrasts with the imagery of light and discovery she used when discussing her encounter with the disability rights movement, which she described using the term '"light-bulb" moment'. In the following excerpt she reflects further on the significance of coming into contact with the disabled people's movement:

> This was an important part of my rehabilitation, I think, so I only grew up as a disabled person after I'd connected with other disabled people and accepted that I was, yes, a disabled person, but that wasn't a bad thing, and that I had rights, as well. (Participant #2)

Here, the marker of time 'after' is associated with the qualifier 'only', suggesting that her discovery of disability rights played a unique and irreplaceable role in this participant's altered self-image. Again, she connects this experience with rehabilitation, emphasising how broad this category is, and how important the social elements of it are (she stresses the significance of 'connecting' with others who share her experience). Furthermore, this participant links her discovery of disability rights with 'growing up as a disabled person': this image counters the infantilising imagery sometimes associated with disability by suggesting that growing up entails *embodying disability*. This process of coming to embody the body one has over time is also linked in this passage with self-acceptance and de-stigmatisation, as well as with reclaiming of personhood and associated rights ('I had rights, as well'). Thus, the adjustment to her identity which accompanied her inauguration as a disability rights activist was, for Participant #2, truly an 'important part of her rehabilitation'. Yet, it took many years for her to have the encounters which enabled this adjustment. Based on this narrative, rights-based rehabilitation could be said to be a project which recognises that an individual's existence in time can be disrupted by an acquired impairment, and which seeks to better understand the idiosyncrasies of this disruption, so that 'adjustment' can be supported as part of a holistic programme of rehabilitation work. Once again, here, adjustment involves identity work, but this is not work that accrues social status as such, and it does take time.

Similarly, Participant #1 emphasised that adjusting takes time, and that therapy needs to come at the right time in order to be helpful:

> I was pleased I saw a psychologist because I think I was ready then, I was ready for the catharsis and all the talking about what happened to me and all the distress. I was ready to let that go and that must have been the right time – it felt the right time. (Participant #1)

The repetition of ‘ready’ three times in this short excerpt, combined with the two references to ‘the right time’, emphasise this participant’s sense of how rehabilitation is a process, and that its elements have to be available within a timeframe that works for the individual. The term ‘catharsis’ and the phrase about ‘let[ting] that go’ depict a therapeutic process that involves a sequence of release, reconciliation and acceptance. This participant was referring to an experience that came some years after his inpatient rehabilitation, and was quite clear that he did not think he could have experienced the benefits of psychological therapy any sooner. He went on to refer to rehabilitation as ‘a narrative process’, which is a phrase that highlights not only the role of the passage of time but also the active work undertaken by an individual or a partnership to construct meaning over time. The participant’s optimism in this excerpt is drawn from the connection he draws between meaning-making and timeliness: the ‘narrative process’ has happened because of *when* it happened. Agency is linked with having the tools to make sense of one’s new identity, but it is also necessarily linked with timing.

By contrast with Participant #1, Participant #14 seemed trapped in his narrative, living it but struggling to move forward from it. This was not for lack of time, since he had acquired his impairment suddenly, many years previously. To quote at length:

> In harsh reality, I am a prisoner of my disability, but I’m allowed, on day-release, now and again, to go out and do things. At the end of the day I come back to my disability. Whatever I’ve done in the

> daytime I have to come back to… that's how I feel. I'll never be released from it. [When I acquired my impairment], I just couldn't see [many] years ahead of me, even 10 years ahead of me, still being… I thought that I would wake up one day and I'd be normal again. I think it's because I couldn't… because I became disabled overnight I could not adjust to that sudden, enormous change as quick as that. Even now, [many] years down the road, it's still… part of me still won't accept it. I still have that, 'No, this isn't happening.' It's still a – won't say a nightmare, but it's not a very pleasant dream and then one day I'll wake up and I'll be normal again. That's been difficult, that's been hard to accept, that is. (Participant #14)

This individual provides a vivid evocation of what it means to *live* the time of adjustment, or in this case of struggling to adjust. The prison metaphor suggests stasis, in which his experience cannot be transformed, even if there can be temporary moments of reprieve ('day release'). He calls up a moment in the past when he imagined a future that he 'couldn't see…. ahead of [him]': this difficulty of 'seeing' the future ahead of him seemed to make it impossible to live that future, even though time has passed. Time itself has taken on an oppressive quality for this man: he describes being unable to imagine 'get[ing] old' and still being disabled, which leads to dreams about 'waking up' being 'normal again'. The reference to being 'normal' gives a powerful sense of the internal stigma he continues to carry about disabled embodiment. This participant explicitly attributes his difficulties to the problem of having to adjust too quickly to an impairment that was acquired dramatically and suddenly. He appears to be haunted by a life that could-have-been (the 'nightmare' that he won't call a nightmare); it is as if the suddenness of his accident was traumatic rupture that he could never quite accommodate into the fabric of his existence. Although I asked him about his experiences of physical rehabilitation, his narrative kept drifting back to his current lived experience of being a 'prisoner'. This idea seemed to dominate his lived experience, suggesting that if adjustment work is hampered, it might make it much harder for an individual to attain a position to benefit from the other aspects of their rehabilitation.

The examples discussed in this section highlight the ways in which adjustment may be experienced as a form of time-consuming work for the individual, but the fact that it is not recognised, culturally, as ‘work’ can redouble an individual’s sense of being isolated and burdened by disability experience. Yet adjustment is crucial if a participant is to be ‘ready’ for particular kinds of intervention, as Participant #1’s excerpt shows. The data discussed in this section build a case for the need for timely rehabilitation as a facet of rights-based rehabilitation. This would entail attending to the specificity of an individual’s trajectory in adjusting to acquired impairment, as well as recognising and valuing the work the individual undertakes to adjust. I now turn to a related theme: that of waiting, or being made to wait for rehabilitation services, which, as we will see, is often closely connected with the work of adjustment.

8.4 ‘I was just going through the motions’: the experience of waiting in rehabilitation

The experience of waiting in relation to rehabilitation appeared commonly in the fieldwork. All but four of the interviewees made reference to the concept of waiting, and whilst many participants voiced frustration about such experiences, this was not always associated simply with disempowerment; a great deal depended on the rationale for waiting, or how the need to wait was communicated. As the accounts in this section suggest, waiting might be easier to tolerate if it can be planned for, and if the individual receives honest guidance about why they may need to wait.

In most cases, waiting was connected, in the interviewees’ accounts, with the NHS, or with other rehabilitation services delivered by the state. Two interviewees highlighted positive experiences in this context: Participant #13 mentioned *not* having to wait for physiotherapy and Participant #15 spoke of having an acceptable waiting time (of ‘a month or two’) for input from the sensory support team. A number of participants readily made allowances for the fact that, as Participant #18 put it, ‘the NHS is stressed’, and took this into account in terms of how they spoke of waiting times. Yet the majority of those who discussed waiting in relation to NHS rehabilitation experiences nevertheless voiced feelings of frustration about it. Once again, this was a theme that brought questions of empowerment and agency into play.

Waiting for an appointment, for treatment, or for a wheelchair, was a key theme in the data. For Participant #4, accessing the physiotherapy he needed to maintain his health had involved a wait of almost 6 months. In contrast to his experience as a child, of receiving frequent (and often unwanted) physiotherapy for his cerebral palsy, as an adult he found he ‘had to keep pushing for it’ (see Thornton, 2018). The term ‘pushing’ suggests that this is not a service he can access unless he is very proactive. This participant explained to me that the process of referral itself was slow, and then that the time spent waiting for an appointment was further prolonged, by two separate postponements, both at short notice. This individual had also experienced an unacceptably long wait for his wheelchair to be mended by Wheelchair Services. He described to me how his flat became a prison for the duration of this period of his life:

> I couldn’t work, I couldn’t do anything. I was in the house for four months, waiting for this chair to come through. I was phoning them every week asking what’s happening with the chair. In the end I said, ‘What do I have to do to get this chair? This is ridiculous. I can’t apply for a job, I can’t go out.’ I think in a four-month period I’d gone out three times. (Participant #4)

Here, Participant #4 experiences being made to wait for his wheelchair as having a significant impact on his agency, highlighted by the repetition of ‘couldn’t’ and ‘can’t’. Waiting, according to his account, has a major impact on his professional life, because he can neither work nor apply for a job. Perhaps, in these Covid-19 times, we read the inability to go out or to work differently, but this account relates to a previous era in which home working was not established as the norm, even though it might have benefited many disabled people if it had been. In this excerpt, waiting is connected very explicitly with disempowerment. Yet the reference to ‘phoning them every week’ to seek information suggests that the disempowerment stems from feeling oneself to be kept out of the loop about how long the wait might be, and what is causing it. The phrase ‘what do I have to do?’ is a rhetorical invocation of the participant’s sense of lack of personal agency in the process.

In another account of waiting, Participant #8 had hoped that, on discharge from inpatient rehabilitation, she could expect a home visit from a physiotherapist the following week, but her wait turned out to be three weeks. She opted for private treatment so as not to miss out on any mobility gains she should be making in the meantime: in this case, she was afraid that waiting might lead to a (preventable) permanent loss of function. Participant #7 recounted his story of waiting for brain surgery, and the psychological difficulties of managing uncertainty: on at least two occasions he was preparing for his operation only to have it cancelled at short notice due to the prioritising of urgent cases. On one such occasion he even spent hours in the hospital waiting room, only to be told that his operation would not take place that day after all. He told me how this felt, and what kind of impact it was having:

> This was on the Friday and I’d also been told that as well as losing my driving licence I can’t do any form of work because while the tumour was in there, there was also a risk of having a stroke. So, at that point I can’t work, I can’t drive, my depression had - had flared back up again, because I also suffer with that as well, and it felt as if I was just going through the motions, waiting, waiting, waiting; not in control, have no purpose and every day was get up and very much a case of hurry up and wait. (Participant #7)

The participant emphasises the centrality of ‘waiting’ to his experience by repeating the term, as if to elongate its place in this narrative. This repetition evokes the renewed round of waiting that has just been precipitated by the decision to postpone his operation yet again; waiting seems long and slow in this case because the participant does not have a clear sense of when it will end. Waiting is connected both with a ‘flare up’ of depression, and with a disempowering inability to work. Like Participant #4, this individual links work with agency, and waiting is experienced as a deprivation of the agency associated with his vocation. The term ‘just going through the motions’ suggests an experience of living that has been deprived of meaning. Waiting is explicitly linked with a lack of ‘control’ and ‘purpose’, which are themes which recur throughout this interview transcript. Being made to wait in the NHS seemed to be an expression, in microcosm, of a wider sense of no longer being in charge of his life, associated first with the discovery of the brain tumour, and later with the adjustment to being a brain injury survivor.

For participants with rare conditions, there were sometimes waiting times associated with diagnosis or the lack of a clear rehabilitation pathway. Participant #3, whose rare condition caused several impairments, framed these difficulties in a positive light, noting that:

> It is nice to know that there are people out there if you’re pointed in the right direction and the right time. (Participant #3)

This quotation hints at the fact, referenced elsewhere in her account, that she has had experiences of struggling to get the right treatment when she needed it. It also touches on the previously mentioned theme of timeliness; the success of rehabilitation may depend on receiving a service or intervention at ‘the right time’.

In her discussion of getting a guide dog, Participant #17 spoke about her sense that in this case, waiting time was connected with the time-consuming work that a service was doing for her. She explained:

> […] at that point I think I was registered for a guide dog and I had to wait for two years for the appropriate match. With guide dogs they have to match you with the right dog. […] it can be ten minutes’

> wait or it can be two years. It depends on your circumstances. They look at your lifestyle… (Participant #17)

The participant understands the wait time to be connected to the fact that guide dog matching is a bespoke service that looks at and your 'circumstances' and your 'lifestyle'. This can be a long process, or occasionally a short process, because dogs are matched very carefully with owners according to their needs, and this is built into the dog-training process. So, as the participant went on to say, a person who jets around the world for work needs a dog who is trained differently from someone whose life is mainly home-based. In the excerpt above, the focus is not on the frustration or inconvenience of waiting but rather on the recognition of the specialist nature of the service on offer. This episode was part of a larger narrative in which emphasis was placed on the labour and time of the disabled person who has to arrange and undergo rehabilitation, and the frustrations which may accompany this. In this context, the excerpt here suggests that the participant's understanding of why she had to wait ('they have to match you'), and her respect for the specificity of that process, helped her to manage the waiting time. This account of tolerable waiting seems to pivot on the availability of information explaining what to expect and why, and in this sense it contrasts with some of the more painful experiences seen elsewhere in this section.

The data I have discussed here suggest that participants often recognised the inevitability of waiting as part of their rehabilitation experience. What distinguished best practice was when a service gave an honest and real account of what patients should expect, and tried, as far as possible to stick to this. Participants' accounts also suggested that it was helpful to be made aware of the reasons for the need to wait. Without these features, waiting could contribute to the difficulty of adjusting to life with a disability, making the rehabilitation journey harder to navigate. Thus, being able to make sense of waiting mediated a sense of control over rehabilitation.

8.5 'Right, what have I got planned today?': Time, value and investment

As the evidence presented in the last section demonstrates, the characterisation of waiting time that participants gave seemed to be linked to the issue of being involved in rehabilitation decisions, as well as to the quality of the information that the participant had about the reasons for a wait. This reveals a connection between being involved in rehabilitation, being informed, and feeling that one's time is valued. In this section I look more closely at these linked themes. 'Being valued' was a theme which came up in the majority of the interviews, and in a number of cases such valuing was associated with time, including the investment of time in rehabilitative processes. More connections emerge here between time and agency.

One participant (#14) was worried about 'wasting' the time of the rehabilitation professionals. This topic arose when Participant #14 spoke about the anxiety he continued to experience as he adjusted to being disabled. But he said that he would 'feel like a bit of a fraud' going to see his GP about this, and stated that he would be 'wasting their time' if he raised this issue. These comments suggest a sense that NHS staff time is scarce and valuable, combined with a feeling of disentitlement to access this time and these resources. Here he discusses these feelings in more detail:

> A lot of people invested their experience and time in me to get where I am now, whereas if I'd said I'd give up and do nothing, all those people […] all their time and effort would have been wasted. They might as well not [have] done anything. (Participant #14)

The participant thematises NHS staff's time as an investment in him, and gives this as a justification for making an effort to overcome anxiety and re-engage with life following his traumatic accident. Experiencing the NHS's investment in him motivates this individual not to 'give up and do nothing'. A little later, this individual spoke of mixed feelings about using a prosthetic arm and leg, but seemed persuaded of the value of wearing them because 'society has invested in me to enable me to participate in society, where if I decided not to use that, the resources would have been wasted'. This participant thus appears to feel a social obligation to engage with the devices of rehabilitation, because of the time and resources that the NHS has invested in him.

Another participant (#6) projected his fear of wasting time and of keeping ‘on topic’ into the interview encounter itself, with frequent interjections to apologise for, as he perceived it, being irrelevant (in his words, ‘off-subject’ or ‘not informative’), as though he were wasting my time. I had not said anything to elicit such apologies, nor had his narrative had not gone off-topic at the points when he mentioned it. In this case, I felt I was being interpellated as a ‘professional’ who had no time to spare, in implicit contrast with the way the interviewee referred to his own time: the fact that he could no longer work, and had to plan out his days with frequent rest-breaks because of the fatigue associated with his brain injury. This theme, of one’s time no longer having the same value placed on it, because there was suddenly so much of it, was common among other middle-aged men in the study who were adjusting to acquired impairment. For example, Participant #5, who had MS, gestured to the difficulty of filling his time when he said:

> I suppose when you can’t do the things that you were used to doing, you maybe spend much more time just sitting thinking about things, which may be good or may be not so good. (Participant #5)

This excerpt suggests that time has an altered quality for this participant now, since becoming disabled: the reference to ‘just sitting thinking about things’ implies that he has too much time. The ‘just’ is interesting, since it appears to undermine the value of the activity it describes, as if it were unimportant. This participant spoke with sadness about feeling that he was now an ‘unproductive’ member of society.

Meanwhile, in a similar vein, Participant #7, who had an acquired brain injury, described how his changed circumstances as follows:

> Who the hell is going to employ me and that’s why all the experts say: ‘[Name], you’re doing far too much and you’ve just got to rest,

> rest, rest and literally take each day as it comes'. And that's what I'm trying to do, but everything is a battle. To get up in the morning, because of tiredness, […] my partner gets up, goes to work, that's it, job done. Right, what have I got planned today? Oh, is that it? (Participant #7)

For this participant, adjusting to life as a disabled person involves a loss of status that he associates with being employed, indicated by his sense that when his partner goes off to work that is 'job done' in terms of filling her time, whereas he always has to ask himself what he has got 'planned' for the day. There is labour associated with managing this loss of structured time ('everything is a battle'), and yet, even though he has to put work into this project, it does not feel valuable to him: he asks himself 'is that it?' as though his plans for the use of his time do not amount to anything he can value. For this individual, an important aspect of rehabilitation was learning how to cope with this excess time. A little earlier in the interview he had told me that 'the job of the OT is to give me ways to plan my day and coping ways to actually get the most from this life', yet even with this support, this facet of rehabilitation appeared to be a struggle, as the longer quotation suggests. The participant contrasted life before his operation, when he could 'be impulsive' with the fact that his day was now 'planned' and 'structured'; although the latter seemed to help him manage, he was aware that he was grieving for his previous existence, posing questions to himself during the interview about his 'identity' and his 'purpose'. His experience of time which *had* to be 'structured' seemed painfully connected with a required identity shift that this participant was struggling to incorporate, as though previously time had just passed easily, without him noticing.

In these examples, it is not that the participants lack time, but that their time has lost a crucial quality: it is no longer perceived (by themselves or, they believe, by others) as valuable. This is linked with a sense of losing of agency and control; in these cases, it also seems to be connected to a loss of the ability to do particular kinds of work. These participants often attribute value to the time of others, particularly that of individuals who are perceived to have higher social status than them, such as the medics and rehabilitation professionals who treat them. The examples suggest that being disabled, or becoming disabled, can mean feeling that society does not value one's time in the same way. Time spent doing rehabilitation, for example, is not understood or valued as work, but for many individuals it was the work they needed to do in order to be able to make the most of their lives.

A minority of participants told me about the experience of speaking up for the value of their time in relation to accessing services. Participant #4, a young man with cerebral palsy, recounted to me a phone conversation with a staff member at a rehabilitation service, who was calling him on the day of his appointment to postpone it. He recounted the conversation:

> And he turned round and went, [*clears throat*] 'Well, why can't you just rearrange for tomorrow? We can offer you an appointment for tomorrow. That's what I've been trying to offer you.' I said, 'I can't do tomorrow.' 'Why can't you?' And I said, 'Not that it's any of your business, but I'm a – I work. I'm not a disabled person in *your* mind, who sits at home counting his tablets and fixing his wheelchair. I actually have a job. (Participant #4)

> I pay for a PA to help me and they're all organised and this is what I tried to explain to this guy on the phone. 'Why can't you do tomorrow?' 'I can't do tomorrow and I can't cancel the PA I've got now. So, I've got to pay for a morning's wage of the PA that if I wasn't going to an […] appointment I wouldn't have called them in today.' (Participant #4)

In the account he gives here, Participant #4 feels he has to challenge an implicit assumption that his time is disposable, and that he is able to change his plans at short notice. He uses a negative trope of the disabled person as someone who does not work, whose time is not valued, whilst drawing attention to the fact that he himself has a job. Again, work time is used by this participant to signify valued time and social status. When the participant recounts having said, ‘not that it’s any of your business’, he it seems to indicate that he felt that he was being asked to account for his use of his time in a way that felt intrusive. In the second excerpt, the participant points out the knock-on effects of this sudden cancellation of an appointment: he has to rearrange his PA, and pay his PA’s wages at a time when he does not otherwise need help. The experience of having his appointment changed thus appears to have direct financial implications for him, and leads to time-consuming administrative work re-organising his PA’s work pattern. Thus, this excerpt leads me on to another theme that occurred across much of the data: the time invested by participants in organising their rehabilitation, to which I turn in the next section.

The data discussed in this section highlight participants’ sense that the time they invest in their own rehabilitation may not always be being valued by services. This may affect disabled people’s motivation within the rehabilitation process. The excerpts also reveal that disabled people may internalise a view of their time that devalues it; for some disabled people, this may affect their own self-perception and their sense of purpose. Some, but not all, individuals are able to fight this sense of being perceived to have disposable time. In the next section, I shall be exploring a related theme that Participant #4 alludes to in discussing the difficulty of managing appointments that are changed at the eleventh hour: this is the time-consuming nature of both rehabilitation and organising rehabilitation.

8.6 ‘It takes up so much of my time’: Organising rehabilitation

Approximately half of the interviewees talked about their energy spent arranging or trying to arrange their rehabilitation. Administrative time is an important issue for rights-based rehabilitation because again, it brings into focus the unequal valuing of disabled people’s time: the study data suggests that some disabled people are having to spend a lot of time on this, sometimes experienced as wasted time, leaving them less time than their non-disabled peers to do other activities, for example, to focus on their careers. Time spent organising rehabilitation was a key theme for Participants #4, #9 and #10, a significant theme for Participants #7, #8, #17 and #18, and a minor theme for Participants #3, #12, #15. It also emerged strongly in the focus group for people living with a long-term neurological condition.

As we saw in the previous section, Participant #4 highlighted the fact that he felt his time was being wasted or under-valued when he tried to engage with rehabilitation services. He felt that his time was treated as expendable. He also told me about the difficulty he experienced in trying to get a part for his wheelchair fixed:

> So I phoned up to get it repaired and they said, ‘Oh, um, you know, what chair have you got?’. I told them the make and they said, [*taking on tone of weary/patronising interlocutor*] ‘That’s a specialist chair.’ I said, ‘No, it’s not. It’s a [brand name] everyday chair. […] ‘Oh, yeah. We like the [other brand name] chairs.’ I said, ‘You might do but they are no good for someone who’s a manual wheelchair user who propels themselves’ I said that that’s the chair I’ve got. ‘Right okay’; I said ‘how long’s it going to take?’ ‘Um, four weeks, because we don’t hold the parts on order so we have to order them in’. ‘Right, okay’. Four weeks came and went and nothing happened. I asked what was happening and was told it was a specialist chair, it was a nightmare to get parts for it. (Participant #4)

In this excerpt the participant relays his sense of being made to feel as though he is being singled out as a difficult and *time-consuming* patient, simply by virtue of having a particular sort of wheelchair, which the service is at pains to designate as ‘specialist’. The participant seems to feel that he has to justify his need for a manual chair that he can propel himself: his account suggests that the tone of his interlocutor put him on the defensive immediately, even though he has what appears to be a relatively straightforward query. The derogatory term ‘nightmare’ is associated with his chair, as though the participant is creating unnecessary difficulty for the service. Participant #4 explained to me that, exasperated by the long wait, he eventually contacted the manufacturer directly, only to find that spare parts could be ordered to arrive in a matter of days. This cumulative experience of chasing up equipment and appointments had had the following effect:

> It’s made me into a person, now, when it comes to [the] NHS, when it comes to any equipment, when it comes to any service, I don’t trust that they will do it properly, so I then think, ‘Right, who have I got to speak to?’ […] I’ve got a repair I need done on the chair now, so I’m just sort of mustering up the energy to do that phone call […] (Participant #4)

Here, the participant gives voice to his internalisation of a sense that nothing will be straightforward, and that every interaction to maintain his health will require difficult conversations. His experiences of trying to engage have, he says, transformed him into a person who cannot ‘trust’ services to do their job; instead he is immediately thinking about whom he will have to ‘speak to’ in order to check what is happening, suggesting that the whole process takes up much more time and mental labour than he feels it would if he *could* trust the service. The phrase ‘mustering up the energy’ implies that even imagining the process uses up mental resources, and that it requires a level of perseverance from him that seems much greater than the effort he has to put into the work of rehabilitation itself.

In a similar vein, Participant #10, a middle-aged woman with MS, joked rather bitterly about how much of her time was spent arranging care and rehabilitation:

> I can’t retire – I’m very fed up because my husband’s retired and I can’t, I’m still [laughs] going on and on. (Participant #10)

Although this is a joke, it highlights an important point: organising rehabilitation *is work* and it *takes time*. Like Participant #4, for Participant #10, organising rehabilitation involves a huge amount of her time and energy, in the face of shifting goalposts and eligibility arrangements. In her case, this has meant fighting to be allowed access to specialist treatment, as well as struggling to maintain access to ongoing physiotherapy in the face of scepticism that this is a worthwhile treatment for her, as well as attempts to limit the number of sessions she could have before being re-referred. She describes feeling as though she is ‘not worth…helping’: this utterance draws attention to her experience of being seen as someone who has a low social status and whose quality of life is not a high priority.

Participants #12, #4, #10, #8, #18 all discussed the time spent trying to arrange the therapy they needed. These participants wanted to invest in their bodies to optimise their health and abilities, but were frustrated by the difficulties of ensuring an ongoing offer from the NHS, or by the time they had to spend going via their GP for a ‘re-referral’ because only a short course of physiotherapy or hydrotherapy was available. One participant (#8), who had had a physical impairment since birth, chose private physiotherapy at one stage because of the problematic timeframe of the NHS offer in the semi-rural area where she lived. Meanwhile, Participant #15, a man who had been living with progressive sight loss since childhood and had been registered blind for many years, highlighted the bureaucracy of the referral system for sensory rehabilitation, which he felt could be simplified so that the administrative burden was lessened for the disabled person seeking to access training. He told me that there was various paperwork he would have to complete each time, and that, ‘you can’t just book a mobility lesson like you could a GP appointment’.

Administrative time was also highlighted as burdensome by other individuals: Participant #9 gave an account of the difficulties involved in trying to find out whether he was entitled to a continuing healthcare budget, given that he was managing a range of long-term conditions. He told me ‘I went round in circles’. This participant used this term to describe his experience of the difficulty of actually moving forward with an issue: healthcare professionals and social workers kept informing him that the decision was someone else’s responsibility, so he found himself unable to locate the person who had the authority to make the decision. Organising rehabilitation was also a prominent theme in the narrative of Participant #18:

> I literally got referred to every department, because the condition doesn't have clinicians that do everything in one place, it has to be multi-disciplinary. That does, however, mean that it's a lot of resources that I have to use up […] it needs to be multi-disciplinary and we just don't have that in [name of place]. (Participant #18)

Here, the participant's mention of being referred 'to every department' suggests that her rehabilitation is both time-consuming for her and resource-intensive for the NHS (as she points out). The lack of specialists who 'do everything in one place' meant that, as she later told me, she did a lot of work relaying information between practitioners. The treatment she received for one aspect of her condition sometimes had a 'knock-on effect' for another aspect of it, and sometimes clinicians 'didn't really take [this] into consideration'. These phrases from the transcript conjure up an individual who has come to be an expert-by-experience about her condition and about what she needs from rehabilitation. By contrast with the clinicians who, in her account, treat just one part of her body-mind, she experiences the whole of that body-mind, and knows what works and what does not. Participant #18's account of the many different specialists she had seen suggested that the journey to become an expert-by-experience had taken up a huge amount of her time and energy. Participants' journeys through rehabilitation are in themselves are time-intensive and depicted as such. These accounts suggest that participants can make the most of what they see as their investment of time in the process, if and when clinicians and practitioners support them to understand the pathway that lies ahead in terms of decisions, interventions, and where and how to access different services.

Participant #17 spoke of the burden of time associated with trying to adapt her house to meet her needs as her sight loss became more pronounced:

> It takes up so much of my time trying to find information. I just wish there was somebody switched on with a brain, who's done all this research for me. I just find it exhausting and so frustrating. (Participant #17)

Here the stated desire for someone else doing the research tells us that the participant is tired of always having to be a pioneer. She refers directly to the time taken up by looking for what she needs, and to the fact that this exhausts and frustrates her.

These accounts suggest that the disabled people I spoke to had, to a greater or lesser extent, a sense of their own time as something which was viewed at a cultural level as an expendable commodity, as something which, despite their best efforts, was being used up on the time-consuming business of arranging their rehabilitation, which was sometimes much more complicated than it needed to be. These individuals were often trying to use services that, in their experience, seemed to be set up without attention to the needs of people with disabilities, and as a result of the time-intensive struggles they encountered, these participants frequently felt that their time was not valued by services as highly as that of non-disabled people. The valuing of disabled people's time therefore emerges as a key issue for a rights-based rehabilitation to consider.

The data discussed in the section also suggest that rehabilitation can often be an elongated experience, requiring engagement from the disabled person over an extended period. In the final sub-section of this chapter, I look in more detail at the temporality of rehabilitation itself as described by participants.

8.7 'We're dealing with it every day': Rehabilitation time as ongoing maintenance time

A key aspect of the temporality of rehabilitation for a number of participants in the study was the question of how long they would be able to continue to access services they relied on. A number of participants gave voice to a concern that rehabilitation practices and systems were set up to work for people who needed short-term access for an acute issue, but this arrangement was not always appropriate for the disabled people I spoke to in my study. This section considers participants' sense that they might not have adequate time within services to meet their rehabilitation needs.

Participant #10 recounted what happened when the NHS tried to withdraw her ongoing physiotherapy:

> They said, 'oh, we realise that you may have a problem when we discontinue it, but you can refer yourself back to us, [right], um, so you'll have six weeks treatment and then you can refer yourself back,' so I said how long would it take to get back on, and it would be another six weeks or something, we worked out the amount of time […]. I said 'look it's easier to keep me on a regular treatment than to, for me to keep referring myself back, because I will do, because I will be so desperate, but each time I will have got worse'. And they agreed […] but that was so traumatic, and during that time I didn't have any physio, so I went downhill again… (Participant #10)

By bringing this conversation to life, the participant highlighted how unhelpful this inflexible six-week arrangement was for her, and drew attention to the way in which the rigidity of the bureaucracy – in terms of having to wait six weeks for a new set of sessions – was itself causing her condition to deteriorate. For this individual, a system of short courses was not always a good use of NHS resources, because she needed physiotherapy to *maintain* as much mobility as she could, so that her condition did not worsen, which would mean she would use up more NHS resources. Instead, she needed to be able to rely on ongoing provision without gaps. The participant also notes the effect of this system on her mental health, with her reference to it being 'traumatic'.

In a similar vein, Participant #4 stated:

> Mine is an ongoing condition so in their mind they can't cure me, or fix me, so it's not their issue any more. But actually, what they don't realise is [it's] preventative, so […] it means that I can remain independent, I can be less of a burden on other resources, i.e. NHS, because if I have a big problem, then I'm going to have to go in to hospital again. (Participant #4)

This account presents the participant's sense that an orientation towards cure is a medical ideal in the NHS, emphasising his sense that his own 'ongoing condition' is not seen as a priority. According to this individual, the body that cannot be entirely cured, but is *ongoingly* disabled, has an awkward place within this culture. The notions of *preventing* a body from deteriorating, or *maintaining* a degree of mobility, seem to have low status within a medical hierarchy, yet they may be highly prized by disabled people, and, as this participant argues, preventative medicine is experienced as helping him to maintain agency in his own life, and it is also perceived to play a role in saving NHS resources in the long-term. Here, a long-term investment of a health professional's time in this participant is understood as a long-term investment in the participant and his ongoing health.

The issue of maintaining one's health with a long-term condition was given a slightly different inflection in the transcript of Participant #2, who had lived with a spinal cord injury for a number of years. She referred to concept once widespread within disability activism: that one might reject a cure for disability because it would mean embracing the maligned medical model of disability. She told me that her views on this had changed over time:

> The whole challenge of, you know, what if there was a cure tomorrow, would you do it or not? And I remember very boldly saying, 'Oh, yes, I wouldn't.' I have to say, **now**, I think because as I'm getting older I feel I'm having all sorts of other issues, where I think, 'Oh, for Heaven's sake! If only I could stop this. I've had enough! Can I just stop being this disabled person now?'. And I'd

> quite like, just magically, go back to being the walking person I was originally, which would be really quite a relief. I feel as though I've done my time now. Can I please stop!? And then I have to give myself permission to say that, in a way, because it was kind of a proud thing we all said, 'Oh, yes, we wouldn't choose to be any different, but, actually, yes, I would choose now. (Participant #2)

Temporality has multiple functions in this excerpt. Firstly, the passage of time is perceived by the participant to have led to 'all sorts of other issues', in addition to her impairment, which lead her to feel far less sure that she would reject a cure. Secondly, the speaker highlights role of time's passage in altering her view of what she wants from rehabilitation: her view 'now' is contrasted with what she 'remember[s]' about how she used to feel. Thirdly, the notion of cure is associated with immediate, rapid relief ('tomorrow'; 'magically'), in contrast with her experience of her impairment, which is connected with ongoing endurance through the use of a metaphor associated with imprisonment ('I've done my time'). This phrase constructs the experience of having a long-term condition as a punishment from which the participant wants to be released; cure is seen as having the potential to intervene in the seemingly never-ending temporality of disability experience. Yet, for this participant to actively desire a 'cure' feels to her like a betrayal of the politics of the disability movement (she has to give herself 'permission'), and of her transformative discovery of the social model of disability, to which she referred at another point in the interview. She is suggesting that the disability movement should not necessarily reject the rapid relief of cure if it is something that can help disabled people to make their time more liveable.

The excerpts analysed in this section draw attention to the way in which rehabilitation was perceived by participants in this study as something that needs to be ongoing, if it is to serve them, because their experience of disability is ongoing. Rehabilitation was often understood by participants as a long-term endeavour, taking place over many years, yet disabled people's experience of services reflected a different stance in relation to time. The participants cited in this section identify the social status associated with, and desirability of, a ‘cure’. They recognise the way in which their own experiences of engaging with services were shaped by both a perceived cultural emphasis on cure in medicine, and the lack of availability of a cure or a quick fix in their case. Having a condition that is not amenable to cure might in itself alter the way that one is seen in the healthcare encounter, as one participant observed. This is a crucial point for rights-based rehabilitation, because it highlights the role of one’s positionality in judgements about quality of life over time and about rehabilitation goals. Participants drew my attention to goals which were linked with maintaining health and mobility *over time*, and preventing future ill-health by having *ongoing access* to rehabilitation services, but the services they used often prescribed short-term treatment courses, and were not always able to respond flexibly to their needs.

8.8 Chapter summary

In this chapter, I aimed to explore the temporal features of rehabilitation experience that participants foregrounded in the fieldwork, and to analyse their relevance to a notion of rights-based rehabilitation. The analysis set out here showed that accounts of rehabilitation experience were frequently marked by the participant’s sense of time’s passage during the process, or time’s effect on the process. The experience of time’s passage in the context of waiting for services, or in the context of trying to come to grips with the new contours of one’s capacity in the aftermath of acquired impairment, was highly significant for many of the people who took part in this research, and has importance implications for how we understand rights-based rehabilitation. In this conclusion I briefly review the key temporal themes that have been discussed in the chapter, indicating what they may tell us about disabled people’s lived experience of rehabilitation and about rights-based rehabilitation.

The pervasiveness of implicit references to biographical time mean that it was significant across the data. The majority of interviewees chose to discuss rehabilitation issues which were connected with time in some way. There were 6 interviewees (#3, #5, #11, #13 #16, #20) for whom references to time were minimal. For the other 14 participants, time was either one theme discussed among several (#1, #2, #6, #8, #9, #12, #14, #15, #17, #18, #19), or, in a few cases, one of the most dominant issues in the interview (#4, #7, #10). The temporality of rehabilitation, especially waiting time, adjustment and change over time, also arose in the focus groups. The topic arose in particular when people described what went well and badly in their rehabilitation, and their experiences of transitions, which were topics I explicitly introduced into the groups. In the creative writing group, time was seen to be in play in participants' writing, perhaps because these writing tasks supported people to think about their lived experiences as narratives.

The **meanings that participants attributed to their experiences of time were crucial** to their sense of what their rehabilitation was like, and whether they felt they had agency and control in the process. For Participant #17, the wait for a guide dog was more bearable when it was understood as an effect of others working with care through a bespoke and complex process; for Participant #7, who was suddenly unable to work, the act of structuring time was experienced as a painful facet of the work of rehabilitation, which seemed only to highlight to him what he had lost. As the latter example suggests, rehabilitation was frequently associated by participants with adjustment, both in the sense that **rehabilitation was 'adjustment work' that took time**, and in the sense that **participants needed to take time to be able to adjust to life with a disability** and so to be psychologically available to the resources on offer via rehabilitation services. To be experienced as successful, rehabilitation needed to be timely. A rights-based rehabilitation would need to recognise and understand how considerations of time and temporality mediate rehabilitation experience.

Time was often indexed to value in participants accounts; it was seen as **a limited resource**. In the case of Participant #14, the literal investment of NHS staff time in rehabilitating his body gave him a sense of having been valued, and gave him motivation to stay engaged with rehabilitation. Other participants felt that their time was not being recognised as valuable by their interlocutors in rehabilitation services. Participants connected this experience with the sense that they were being perceived as unemployed, or as unproductive, members of society. Yet very often these same participants were investing huge amounts of their time, that is, their work, their agency, in making their rehabilitation happen. Managing the time taken to administer rehabilitation seemed, in these participants' experience, to be falling on the shoulders of disabled people, rather than on those employed to administer rehabilitation services. This may be a key finding for a rights-based rehabilitation policy to consider.

The temporality of rehabilitation was also focal point in the data discussed in this chapter. For the participants in this study, rehabilitation needed to be **ongoing and enduring**. Many participants emphasised their sense that services were structured to attend to the needs of an individual who could be 'cured' by a six-week intervention, rather than to the needs of someone with a chronic condition. Yet, to meet their needs, the participants in this study emphasised that rehabilitation should be continuous over longer periods of time, to manage chronic conditions and to prevent further deterioration in their functioning. Sometimes, participants' time was taken up engaging with bureaucratic re-referral processes. It appeared that if services could be less insistent on rigid timeframes, this would encourage a simple shift towards building services that prioritised supporting people with the **ongoing work of maintaining their health** over a long period. This could be one way of shaping services in response to disabled people's lived experiences of rehabilitation.

Chapter Nine
Discussion

9.1 Introduction and chapter outline

The data I have presented in this thesis reveal that timely and well-resourced rehabilitation practices which promote disabled people's full involvement in decision-making, and which support them to take up agency in the rehabilitation process, can be transformative in the lives of disabled people. This chapter will consider in detail what knowledge this thesis has produced about rights-based rehabilitation, contextualising these findings in relation to existing research, and evaluating the epistemological status of the findings and the strengths and weaknesses of this study design. The contribution to knowledge is discussed in two main sections, each corresponding to one of these two project research questions:

- **How do disabled people who have been through rehabilitation describe their experiences? What is rehabilitation like for people in this group?**

- **How can disabled people's views and experiences of the rehabilitation process:**
    - **shape rehabilitation services, and**
    - **help to develop a 'rights-based rehabilitation' policy.**

The first section examines my contribution to academic knowledge, explaining what the analysis of data from this study tells us about the standing of current theories underpinning our knowledge of the sociology of rehabilitation. The second section then seeks to characterise what 'rights-based rehabilitation' would mean for policy and practice, on the basis of both the evidence from this study and existing evidence. Within this second section, I also make a case for the value of PPI within the rehabilitation sciences. Then, by discussing a number of methodological issues, including the project's PPI and the learning this generated, I critically evaluate the strengths and weaknesses of my study design and the effects of these factors on how we interpret the knowledge produced. I consider how I might have designed the study differently in light of my learning during the research. Subsequently, I reflect briefly on my personal journey within the project, and on how doing this research has shaped my own views about disability and rehabilitation. This chapter concludes by summarising the contribution of this work to academic and policy knowledge about rights-based rehabilitation.

9.2 What new knowledge did my research generate about disabled people's lived experiences of rehabilitation?

The primary contribution to knowledge of this thesis is the insight it offers into participants' lived experience of feeling themselves to be, or not to be, actors in their rehabilitation in the East of England in recent years and in the past. When successful, **rehabilitation was, in itself, a process that supported participants to (re)discover their agency in life**. Being enabled to act was, in the accounts given by study participants, an experience that was mediated by access to resources and services, by practices that promoted patient involvement in decision-making, by the quality of rehabilitation relationships, and by factors associated with timing and time's passage in rehabilitation. The next three sub-sections characterise the knowledge generated through this study about rights-based rehabilitation and situate it within existing academic debates.

9.2.1 Conceptualising involvement

This study's focus on disabled people's involvement in shaping both rehabilitation services and research has responded to a research need identified in the *World Report on Disability* (WHO, 2011, p. 105), which highlights the 'absence of engagement with people with disabilities' in the design, delivery and evaluation of rehabilitation services. An analysis of the depiction of patient involvement, and of the voice of the patient, was thus a key feature of my literature reviews; the concept of 'involvement' did not appear to be routinely invoked in disability studies, and only rarely in rehabilitation science. On this basis, involvement was an issue that this project sought to explore from the outset both methodologically, in terms of developing a study design that deployed PPI in ways that could improve the quality and accessibility of the research, and in terms of inquiring into participants' lived experiences of involvement in rehabilitation. The thesis adds to knowledge by purposefully **making visible the integrated relationship between how patient involvement is deployed in developing methods that go on to generate more epistemically inclusive data about involvement**. These connections were discussed in Chapter Seven, where the relationship between the affordances of an unconventional fieldwork set-up, and the interactions and reflections it produced, were considered. This meant undertaking some 'discussion' work in a space designated for 'analysis', to show how knowledge production depends on a context that may include or exclude people from it (see also Fricker, 2007; Reason & Bradbury, 2001; Oliver, 1992). Involving disabled people in the design of the research helped me to attune myself to rehabilitation issues of which I had no personal knowledge. This enabled me to become aware of epistemic injustices (Fricker, 2007) that I might be at risk of reproducing, for example via the use of creative writing as a data collection activity, but also via the use of the spoken word as my main vehicle for data gathering. By gaining a better understanding of what was unfamiliar to me, I had more information with which to be able to develop more inclusive protocols for my fieldwork, and to attend closely to variations in conceptualisations of involvement as they emerged in the data.

This research highlights the **significance of interpersonal relationships as a key feature of involvement in rehabilitation,** a finding which chimes with the small body of existing evidence on the lived experience of rehabilitation examined in the qualitative synthesis, where the benefits of peer support are noted (Jannings & Pryor, 2012; Bourke et al., 2015; Brookfield & Mead, 2016) and the centrality of good working relationships with healthcare professionals is highlighted (Bourke et al, 2015; Norrbrink & Löfgren, 2016; Hanga et al., 2017)**.** Additionally, **enduring working relationships** were emphasised: some of the most positive accounts of involvement in rehabilitation were those in which a relationship with a particular member of staff was established over time. While Bourke et al. (2015) do not refer to the importance of prolonged relationships, Hanga et al. (2017) refer to participants wanting specialists to spend more time getting to know the disabled people with whom they worked, and this issue is also a feature of the study of disabled people's personal assistance relationships, mentioned by Shakespeare et al. (2017) in their review of the relevant literature. This could be a key issue for future research on rights-based healthcare to study.

In my study, the supportive rehabilitation worker was characterised as someone who met the patient at the stage they were at, listening and seeking to understand the patient's perspective. These were qualities that were also valued by study participants in other research (e.g. Bourke et al., 2015) or which were seen as missing from rehabilitation relationships (Hanga et al., 2017). Furthermore, in the *Rights-based Rehabilitation* study, the development of rapport was linked to the health professional having a shared experience of impairment; this theme of the insights of the disabled rehabilitation worker resonates with the findings of Bevan (2014), who studied the professional experiences of disabled occupational therapists.

Participants often demonstrated their sense that **'involvement' might be a buzzword in contemporary discourses of patient-centred care**, but its use did not always mean that they had felt involved. Those who recounted positive experiences of being consulted about decisions distinguished these from a version of involvement that they associated with 'paying lip-service'. Participants may have been drawing attention to their lived experience of the tensions I documented in the review of the patient and public involvement literature. For example, theorists of PPI have argued that grassroots activism for the inclusion of disabled people in decisions about their lives has sometimes been incorporated into institutional policies in ways that are tokenistic, or have led to change at the level of rhetoric, and not always at the level of practice (Beresford, 2014; Turner & Gillard, 2012). Within 'emancipatory research', there is a long tradition of querying the 'social relations of research production' (Oliver, 1992, p. 101): that is, the question of who holds institutional power and how this affects how research is done and what it finds. Analogously, the problem of ‘lip-service’ – raised by certain participants in my research – highlights that it is possible for the language of involvement to be present in the rehabilitation encounter, without any real shift of power towards the patient (see also Beresford, 2019).

My study suggests that for the disabled people I spoke to, a rights-based rehabilitation practice would **cultivate the human, interactional qualities of the healthcare encounter**. These qualities were experienced as conferring full personhood upon the patient, potentially undoing (internalised) stigma of the kind that may be associated with disability (see Coleman-Fountain & McLaughlin, 2013; Goffman 1963). In this context, rights-based rehabilitation would involve listening to the individual and seeking to intuit ways of supporting that person to expand his or her personal agency (see Van de Velde et al., 2012). It would also involve working together to produce a rehabilitation programme rather than following a rigid set of guidelines and ‘telling’ a person what they could or could not do. For many, the continuity of the same relationship was invaluable for instilling a sense of being cared for by the system.

Notably, getting involved was in some cases about a **desire for the professional to draw on their own expertise** and enable the participant to learn from it – for example, a ‘pupil/teacher relationship’ could be very valuable to a participant. I did not find existing evidence of similar findings, which may indicate that this is an under-explored topic due to the aforementioned tendency within sociological disability research to de-emphasise medical models of disability and their associated expertise. In my study, equality of expertise between the parties was not a prerequisite for participants becoming fully involved in the relationships they built with rehabilitation professionals. Nonetheless, opportunities for reciprocity were; it was also important for both sides to acknowledge that each party brought their own expertise, whether professional or experiential. This finding bears out the importance of the maxim, common in disability activism, that experts should be ‘on tap, not on top’ (e.g. see Harrison, 2013), yet it also highlights the important role that healthcare expertise has to play in disabled people's accounts of their rehabilitation. The data thus throws into question the rejection of medical expertise seen in certain influential accounts of rehabilitation in disability studies, such as Oliver's (1993) work on walking.

Importantly, my research also highlights how **involvement in rehabilitation was not necessarily a 'given' in these experiences**, but instead might have to be fought for to make part of rehabilitation, and which in turn might depend on the participant's individual capacity to speak up or push for access, a theme which is consonant with other research in disability studies (see also Long, 2015). Access to health is already a major theme in health service research (e.g. Williams, 2003), with academics examining how factors including, but not limited to, geography, demography, disability, race, and poverty all contribute to unequal health outcomes and experiences of healthcare (e.g. Hardeman & Karbeah, 2020; Barker & Li, 2020). Therefore, this project develops an existing literature, by drawing attention to some of the specific issues faced by disabled people, and by analysing how these participants conceptualised such issues. For example, I noted the prevalence of battle metaphors in my data and their deployment in conjunction with the theme of accessing healthcare. For many of the participants in this study, involvement was something that needed to start at the point where the person was embarking on their rehabilitation journey, rather than in the clinic.

To summarise this subsection: one of the distinctive features of this project's attempt to explore 'involvement' has been a recognition of the way in which this concept is relevant both thematically and methodologically to a study of disabled people's experiences of rehabilitation. I argued, drawing on the logic of emancipatory and participatory research paradigms (Reason & Bradbury, 2001; Oliver, 1992), that an iterative and collaborative approach to designing the research would have an impact on what the research found out (see also Fricker, 2007). While there are, no doubt, ways in which the research could have been made even more inclusive, my discussion of the creative writing fieldwork activity in Chapter Seven sought to make visible how meaning-making happens in a particular context, where actors experience themselves as differently empowered (to speak, or to write, for example). This issue of perceived hierarchies of social status may not be fully separable from the question of who is fully involved in rehabilitation decisions, which was also discussed in this section. The theme of ‘involvement’ being used rhetorically but without substance emerged in the data, reinforcing existing evidence for this problem (Beresford, 2014; Turner & Gillard, 2012). Yet when participants did feel fully involved in rehabilitation, this seemed to be connected with the development of a supportive relationship with an individual healthcare professional over time (see Shakespeare et al., 2017), who consulted the patient and was good at listening (see Hanga et al., 2017). Such relationships did not have to be ‘equal’, but it was important that different kinds of expertise (professional and experiential) were valued in these relationships. Although such accounts were infrequent in the data, where relationships based in reciprocity and mutual understanding developed, participants often emphasised the potential of these rehabilitation relationships to transform their lives for the better.

9.2.2 Narrating agency

In working with participants’ accounts of being involved in rehabilitation decision-making, I noticed the emphasis they placed on experiences of being enabled to take up agency in the process. This theme appeared to merit closer scrutiny; additionally, my experience of running the creative writing group also drew my attention to the connections participants made between narrative-building and being in control of rehabilitation. Here I discuss how this focus on the narration of agency develops the sociology of rehabilitation.

When reviewing the literature, I had become aware of ‘agency’ as an issue that emerged in a handful papers I looked at when synthesising the qualitative data across disability studies and rehabilitation science. Certain authors highlighted the idea of ‘agency’ as a more useful term than ‘autonomy’ for rehabilitation patients adjusting to a loss of function (Van de Velde et al., 2012; see also Löfgren & Norrbrink, 2012; Bezmez, 2016; Norrbrink & Löfgren, 2016;

Papadimitriou, 2008). Van de Velde et al. (2012) argue that having a sense of agency is more empowering than striving for (a potentially unachievable) autonomy in rehabilitation: for these authors, agency is about being empowered to make decisions whilst coming to terms with new embodied limitations, whereas an emphasis on autonomy may encourage patients to evaluate their progress, and find themselves failing in relation to a dominant, liberal individualist ideal of independence. While patient agency is an important theme in health sociology as seen in Chapter Four, the connections between agency and creativity were under-explored in the various literatures I reviewed for this thesis; in this thematic area, my own study makes significant new contributions, which will be discussed in this section.

The emergence of the theme of **(re)finding agency** in this data must be understood in relation to a widely reported sense, among these participants, of **loss or diminution of status in the social world associated with disability**. This in itself is not a new theme, either in medical sociology or in disability research; indeed it is foundational to the formation of disability politics and activism in the UK. Goffman's (1963) work exploring the relationship between stigma and social status has influenced these fields (see also Coleman-Fountain & McLaughlin, 2013). In medical sociology, Charmaz's (1983) concept of 'loss of self' has been influential on a subsequent generation of researchers exploring the connections between illness and altered identity, while in disability studies, the collective which wrote the document which effectively founded the social model of disability in the UK (UPIAS, 1976) were seeking to alter the hierarchical social relations which led to disabled people's marginalisation in society. The *Rights-based Rehabilitation* study bears witness to the fact that disabled people continue to experience being (or becoming) disabled as being linked with a sense of having a lower social status than their able-bodied peers.

In my study, it appeared that a core aspect of the work of rehabilitation involved processing a loss of social status, and exploring how to locate the self as an actor in the social world again. This could be understood as an example of biographical disruption (Bury, 1982) which demands narrative reconstruction

(Williams, 1984): that is, the idea that acquired impairment precipitates the need for the individual to revisit and reconstruct their personal narrative. Rehabilitation then comes to be about articulating a changed, or changing, relationship to the world. For certain participants, being unable to return to work, or to the same sort of work, led initially to a crisis of identity (see also Hay-Smith et al., 2013; Charmaz, 1983) and to a sense of temporal disorientation (Bourke et al., 2015; Bury, 1982). In some cases it led participants to reassess what it was that made their lives meaningful, and indeed what it meant to be an actor in their own lives (Williams, 1984). Most of the participants who had an acquired impairment articulated a trajectory of this kind, although references to the place of paid employment in one's identity appeared linked to gender and to the age at which the impairment had been acquired: they were most frequent among men who had become disabled in middle age. My study has therefore identified a **connection between narrative reconstruction (Williams, 1984) and participant agency**; this is a cross-cutting theme in the analysis chapters, which I proceed to discuss in more detail here.

The emphasis placed by certain participants' on skills and re-skilling within a narrative of re-gaining confidence or a sense of identity after an acquired impairment appears to be distinctive to this study, in the context of the literature I studied. In my data, it was often creative practices, including handicrafts, that supported the work of narrative reconstruction (Williams 1984) and the restoration of a sense of personal narrative (Bourke et al., 2015) in rehabilitation. For some, the work of helping with research or teaching in the health service, including via communicating their own stories, played a role in restoring agency and purpose. This finding resonates with those of Swart and Horton's (2015) study, which documented the positive impact on aphasia patients of participating in a conversation partners scheme to train health professionals to better communicate with patients with aphasia. There, participants described an increased sense of purpose and self-worth, as well as referring to the rewards of 'giving back' (Swart & Horton, 2015, abstract). In analysis of my data, I also noticed an emphasis on opportunities for reciprocity and 'giving back' in supporting participants to re-find agency; this may be especially important for people experiencing stigmatised identities and associated isolation, as Swart and Horton also suggest. They refer to participants 'reconnecting to their previous self' through participation in the conversation partners scheme, drawing attention to the way in which rehabilitation involved rebuilding identity and reconstructing one's personal narrative.

One of the participants in my study explicitly described rehabilitation as a 'narrative process', emphasising both the role of the unfolding of time, and the role of creative meaning-making, in successful rehabilitation. This emphasis resonates with other work in the emergent sociology of rehabilitation. For example, Bezmez (2016) discusses the way in which disabling cultural narratives about re-learning to walk have an impact on how patients in Turkish rehabilitation hospitals imagine and measure their trajectory through rehabilitation. Meanwhile, in a qualitative study in New Zealand with people with spinal cord injuries, one theme that emerged in analysis was the need for rehabilitation to enable the restoration of a personal narrative (Bourke et al., 2015). Such work builds on a longer history, within medical sociology, of research exploring the impact of chronic illness on identity, initiated by influential papers in the early 1980s (Williams, 1984, Charmaz, 1983, Bury, 1982), and taken up within the small body of work on the embodied, lived experience of rehabilitation (e.g. Bourke et al., 2015; Papadimitriou & Stone, 2011). **The findings of my study build on this body of work, highlighting the role of rehabilitation in supporting the story-building work** of coming to take up an identity as a person with a long-term condition. The creation of narrative was indeed a '*sense-making* device' (Greenhalgh, 2016, p. 7) for participants in my study.

The act of *processing* disability, and of incorporating it into one's identity, emerged as a vital component of successful rehabilitation in the data I collected. This finding is consonant with previous sociological studies (Bourke et al., 2015; Papadimitriou & Stone, 2011), as well as bearing out conceptual work in the field of narrative medicine, which highlights the role of understanding illness as a narrative in patient outcomes (see Hurwitz et al., 2012, Greenhalgh & Hurwitz, 1999). In the study I undertook, support with processing seemed to be an important part of what participants value in their intersubjective, durational relationships with rehabilitation professionals. It is also what is at stake in participants' work of adjusting to life with a disability. Although this theme was more apparent in the data I collected from those with acquired impairments, even for those with lifelong impairments, the act of engaging with rehabilitation seemed to mean engaging with aspects of their lived experience that were frustrating and hard to process. Disabled people's frustration with their impairments in and of themselves has often been overlooked in disability research (Shakespeare, 2014). Yet it was often present in the data as the implicit or explicit driver for people's participation in this research, or their anger that services were not meeting their needs.

This study enabled analytic insights into agency through the analysis of participants' discussions about writing. An unexpected aspect of the creative writing discussion group was the emergence of data which characterised **writing itself as playing a role in the processing of the experiences of disability and rehabilitation**. Participants saw writing as an activity that helped them to shift or develop their thinking and feeling about what it meant to live with disability and to access rehabilitation services. Although this study did not set out to use writing in a therapeutic way, these qualitative findings echo those of the psychologist Pennebaker (1997), who has examined the value of expressive writing (see also Costa & Abreu, 2018). In the fieldwork activities I ran, writing seemed to allow some people to explore their feelings about rehabilitation in ways that were not only liberating but transformative of the very texture of those feelings, sometimes in ways that made it easier for a person to think clearly about what they felt, or to accept something difficult about disabled embodiment, or to leave difficult feelings and blockages behind. To write was experienced as attaining agency within one's own narrative, for some people. The structured writing tasks in this fieldwork activity appeared to offer an opportunity to shift authorial agency within the research towards participants. My own practice-based learning from this fieldwork activity, around the distribution of agency within the research process, chimed with what I had learnt from reading the work of 'emancipatory researchers' who sought to change the social relations of research production (Oliver, 1992, Zarb, 1992).

The participants' positive feedback about the writing group, and their commitment to it and enthusiasm for it, was part of what inaugurated my own thinking about the relationship between creativity, processing and agency in this study. Thus my reading of the data was iteratively guided by my learning from the field (Mason, 2018). Ethnographic insights about an **agency-producing process** led me to look again at participants' stories about creative activities in the data, and to see that, whilst there were few stories of this kind, those that existed emphasised a particular sense of agency that emerged through an experience of producing something that was appreciated by others. The **experience of being appreciated as someone who could 'act' in the social world** was also important for participants who made reference to getting involved in the training of healthcare students, or contributing to research. The potential for reciprocity, and for being able to make a valued contribution to the social world, gave participants a sense of being an actor in their own lives. This finding affirms the importance of modes of inclusion that seek to go beyond rhetoric and enable action, such as (in the research arena) participatory action research (Reason & Bradbury, 2001) and emancipatory research (Oliver, 1992), although as Beresford (2019) has noted, it may be difficult to bring about thoroughgoing institutional change in this regard without greater democracy in all aspects of life. In the teaching and service delivery arena, this might translate, at a policy level, into attempts to employ more disabled health professionals and academics (see e.g. Bulk et al., 2017, Bevan, 2014) and finding ways to more fully value peer support (Jannings & Pryor, 2012; Bourke et al., 2015; Brookfield & Mead, 2016).

Furthermore, the data about writing suggested that part of what had been powerful about the creative writing process had been the way in which it **allowed participants to witness their own lived experience**, by reflecting on it and finding the right words for it. Plummer (1995) writes about the fact that stories require audiences, and notes that communities are built through the sharing of stories (see also Shakespeare, 1996b). Contrary to my expectations, participants were very keen to share their writing with each other in the writing group. All listened very carefully to each other's stories and poems. The emphasis placed on writing's role in facilitating a shift of perspective in the data made me think that it created a space between the person and their experience, such that the experience could be witnessed by the author. The role of the rehabilitation professional may be as much about **enabling and witnessing the patient's articulation of this shift** as it is about offering specific interventions. Discussing the place of the study of narrative in medicine, Greenhalgh and Hurwitz (1999) highlight the role of the doctor or nurse as witness to the patient's story. As such, rights-based rehabilitation could be said to position the rehabilitation professional as the facilitator of the patient's narrative-making work.

The concept of witnessing links together some of the disparate strands associated with personal agency in this data. The desire expressed by some participants to get involved in shaping research or healthcare education, and to 'give back' to the system, can also be interpreted as a desire to share their story and to have it witnessed by an Other who will hopefully incorporate it into their understanding of the world. Creative activities were partly significant to participants because they led to concrete, visible outputs that could be witnessed by others (and by the self) as a marker of progress or of (re)finding capacity. Moreover, the value of being challenged to think differently, or of experiencing an external demand, could also be understood as an appreciation of having been witnessed.

To summarise this section: **this doctoral study has made visible the significance of participants' rediscovery of agency through rehabilitation**, and detailed the role of creativity, narrative-making and witnessing within these processes. It augments existing evidence from narrative medicine and medical sociology about the relationship between patients' story-making and their sense of agency. Activities that helped participants to reconnect with parts of themselves that they thought they had lost, or which entailed creative absorption and the creation of a valued object, seemed to empower them as actors. Activities that promoted narrative reconstruction seemed to play a role in the construction of an agentic identity, but the timing of such interventions was crucial.

9.2.3 Temporality as a defining feature of rehabilitation experience

Although I had been aware, from the literature review process, that the temporality of illness has long been an important site of study in medical sociology, with influential concepts such as ‘biographical disruption’ (Bury, 1982) making their way into the emerging sociology of rehabilitation (Papadimitriou & Stone, 2011; Bourke et al., 2015), I had not designed this study with the intention of focusing on time in particular. Instead I had expected to focus more on themes such as power and control, as I had imagined at the outset that such issues would be more frequently referenced in relation to discussions of rights and involvement in decision-making – topics I was referencing in my fieldwork schedules. However, what I found as I worked on the data was how frequently markers of time, or references to temporality, were also sites where ‘control’ was being invoked. This finding is in tune with those of contemporary researchers of SCI rehabilitation experience (Papadimitriou & Stone, 2011; Bourke et al., 2015): in these papers, time and the disruption of its anticipated flow are closely linked with the experience of control over rehabilitation. The emphasis I found on time’s significance in the data also gave weight to my interpretation of the importance of narrative-building as an agentic practice, discussed in the previous subsection.

Temporal disruption, and its management, was key theme in this study. Rehabilitation was characterised as a time-intensive process involving adjustment to changed circumstances and to re-evaluation of what the future held. Waiting for rehabilitation, or adjusting to a life that involved a lot of waiting, was often experienced as disorientating and linked to a loss of status and a loss of a secure sense of agency in the world. These findings affirm the significance of these established themes in the sociology of rehabilitation (Bury, 1982; Charmaz, 1983; Williams, 1984).

Furthermore, there was a clear connection in this data between participants' sense of being in control of their time, or having the physical, economic and psychological resources to value and communicate **the value of their own time, and the feeling of having agency in rehabilitation**. This study develops the sociology of time in rehabilitation for disabled people by drawing attention to the ways in which **time was felt to be a resource** that is invested with value by society or by individuals including health professionals (see Strazdins et al., 2016; Strazdins et al., 2011). These aspects of the temporal experience of rehabilitation emerged as major themes during the analysis of the data. Strazdins et al. (2011) have argued that time scarcity has an impact on health outcomes, while Strazdins et al. (2016) have sought to develop measures for exploring the relationship between time and health. Yet within the sociology of rehabilitation, the question of time as a resource appears under-researched.

Although the conceptual frame of 'biographical disruption' (Bury, 1982) helps us to analyse some participants' sense of temporal disorientation post-diagnosis, or even experiences of waiting for rehabilitation, a second useful framework, which is referenced much less frequently in medical sociology and not at all in the review of qualitative evidence for this thesis, is **Flaherty's (2003) notion of 'time work'**. Flaherty defines such work as 'one's effort to promote or suppress a particular temporal experience' (p. 19). This is a concept that brings together 'time' and 'agency', exploring how they interact in context. Flaherty undertook fieldwork examining the strategies that participants use to manipulate or customise their experience of clock time. McCoy (2009) expands Flaherty's definition in the context of her study of the work involved in adhering to a medication regime, describing time work as 'anything people do, deliberately and with some acquired skill, that in some way orients to time, whether this be inner temporal experience or common clock time' (p. 131). Coventry et al. (2014), using this term in discussing patients' temporal experiences of multimorbidity, observe that in their data, the experience of feeling in control of one's time was linked to a greater sense of self-determination in relation to managing one's illness.

The data from this study revealed participants referring to the **need for a capacity to customise challenging experiences of time**, or even discussing the support they received (or did not receive) to develop such a capacity. We could think of the **time-related work in that disabled people do in rehabilitation as a) adjustment work; and b) maintenance work**. **Adjustment work** is the time-intensive labour of adapting to life with an (acquired) impairment: this theme is already a feature of the qualitative rehabilitation literature, although it is not framed as 'work' (see Van de Velde et al., 2012; Bourke et al., 2015). In this doctoral study, adjustment work is seen to involve, on the one hand, formal rehabilitation activities administered by health services, supported by figures such as psychologists and occupational therapists when it goes well. On the other hand, it includes activities that happen in other spaces and create the potential for '"light-bulb" moments' (Participant #2). The latter may involve disabled people's organisations, advocacy groups and peer support, all of which featured in this data as playing an important and positive role in adjustment work. Adjustment work may also involve rehabilitation workers who work hard to meet disabled people where they are in their adjustment trajectory, and offer them what they need next in a timely manner.

Maintenance work, on the other hand, describes participants' commonly held perception of rehabilitation's role in disabled people's lives, which was that **long-term maintenance, rather than cure, should be the goal**. Participants emphasised the need for long-term access to services as a way of helping them to manage their conditions and maintain quality of life: this need was sometimes at odds with a system that prioritised short-term treatment of acute conditions. Maintenance work involved disabled people making repeated attempts to insist on access to services, or to find out what was available, as well as the ongoing physical work of rehabilitation itself, and the ongoing psychological labour of waiting for treatment. Baraitser (2017, p. 52) argues that '[maintenance] is not revolutionary time, but the lateral time of 'on-go' that tries to sustain an elongated present': maintenance involves the work of keeping something going, which is not glamorous work, but it was an everyday requirement for a number of the disabled people in this study.

Both of these types of work I have described involve attempts to shape the experience of time: the work of trying to elongate access to a service, or to shorten a period of waiting, or to adjust to a new embodiment or cognitive state in order to begin imagining what the future might be like, or make peace with a past that can no longer continue as it was. The conceptual framework of **'time work' (Flaherty, 2003) enables the work of rehabilitation to become visible**, highlighting the active role that these participants took in seeking to engage both with services, and with their own experience of their condition. Even when participants appeared to exist passively in time, the fact that they drew my attention to this in the fieldwork underscored something else. When participants reflected on their sense that they lacked the social status they once had, or felt themselves to be perceived as unproductive members of society, or lamented the lack of structure in their day, they were highlighting to me something about the time work they were doing just by existing in new time-experiences that made them feel passive. These participants were implicitly or explicitly making a statement about this as a social burden that they found themselves bearing and wanting to change.

As these discussions show, disabled people's time in rehabilitation is deeply connected with the work they do on their own rehabilitation. The project findings affirm and extend an emerging sociology of the health-related work that patients do in contemporary health institutions (Armstrong, 2014; Wyatt et al., 2010; Wilcox, 2010). As discussed in the review of patient and public involvement, Armstrong (2014) contends that, within the contemporary healthcare landscape we have witnessed a discursive shift towards patient agency, as part of a broader transformation of health into a matter of personal responsibility and self-management. It is in this context that the idea of the 'expert patient' has come to the fore in health policy and education discourses in the UK (Tritter, 2011; see also Wilcox, 2010). Yet an emphasis on expertise and empowerment can sometimes mask the ways in which this discursive shift also interpellates patients to undertake health-related work, as these authors have argued. The emphasis placed on time and work by participants in the *Rights-based Rehabilitation* study creates a bridge between the PPI literature and its antecedents such as the emancipatory disability research paradigm on the one hand (Oliver, 1992; Zarb, 1992), and discussions of ‘time work’ and health work within medical sociology on the other. In the former, questions of valuing service users’ time are foregrounded, while in the latter, patienthood itself is problematised as a site in which time-consuming work takes place.

To summarise this subsection: this study affirmed existing evidence of the significance of biographical disruption (Bury, 1982, see also Bourke et al., 2015) and loss of self (Charmaz, 1982) in the lives of people who are managing both acquired impairments and long-term conditions that may be worsening over time. In this section I also discussed the relevance of ‘time work’ (Flaherty, 2003) as a concept to describe the efforts undertaken by disabled people to mitigate biographical disruption, and to lessen the effects of a loss of social status which had impacted on how their time was valued. Disabled people’s input into their rehabilitation was also discussed as a form of ‘health work’, drawing on recent sociological work highlighting how discourses of patient agency and responsibility may mobilise an unseen imperative to perform time-consuming health-related labour.

9.3 How can disabled people’s views and experiences of the rehabilitation process shape rehabilitation services, and help to develop a ‘rights-based rehabilitation’ policy?

In this section, I will discuss what this study contributes to defining and elucidating an idea of ‘rights-based rehabilitation’, as well as explaining what patient and public involvement could contribute to rehabilitation science. I will lay out what the study offers to policy and practice knowledge. The concept of a rights-based rehabilitation policy is rooted in the recognition of disabled people’s equal entitlement to access rehabilitation services, as enshrined in the *UN Convention on the Rights of People with Disabilities* (United Nations, 2008). It requires a conceptual shift for disability studies to think of rehabilitation in this way (Shakespeare et al., 2018), because of the longstanding influence of a ‘strong’ social model of disability on research in this field, which has led to a paucity of evidence of disabled people's experiences of engaging with health services from a disability rights perspective (Shakespeare, 2014). This thesis has made a valuable contribution to an emerging body of work which is seeking to redress this balance: by exploring the views of 36 disabled study participants in the East of England, I have generated data which both affirms existing evidence about the lived experience of rehabilitation, and sheds light on under-explored aspects of the process.

9.3.1 What PPI can offer the rehabilitation sciences

One such under-explored aspect of the process is the potential role of PPI in building a more substantial body of scientific and sociological evidence about rehabilitation techniques and practices. The review of the rehabilitation science literature revealed minimal evidence of the use of formalised PPI in rehabilitation research, in spite of an institutional shift towards patient involvement in health research over the last twenty years in the UK and elsewhere. While this absence may, to some extent, reflect the persistence of certain conventions in relation to the writing of the academic article, where a discussion of PPI is yet to be regarded as an expectation, it is notable that even authors who appear in other ways aligned with the fields of disability studies and medical sociology do not discuss formalised PPI.

In spite of the limitations of PPI, which, as previously discussed, stem from its status as an institutional and institutionalised practice, activities that involve patients in knowledge production have a powerful potential to help shape research agendas that are relevant to service users. For example, if we look at autoethnographic work from the disability studies literature, we can see that Inahara (2013) seeks to reframe the intelligibility of speech as a joint enterprise, rather than as the sole responsibility of the speaker who has been diagnosed with a language 'pathology'. Such an insight could profoundly affect how a study of a speech and language intervention might be carried out, because it reverses received wisdoms about roles and hierarchies in healthcare delivery. The health professional is positioned here as someone who may need to be learning from the patient. Such role-reversals have in fact been pioneered in the field of speech and language research by figures committed to PPI research (see for example, Horton & Wellings, 2014; Horton et al., 2016; Swart & Horton, 2015), with clear benefits for stroke patients, who have been empowered as teachers of supported communication through these processes. Such research seeks to re-position service users as experts with useful knowledge about their condition and the barriers they face, but it is the exception rather than the rule in rehabilitation research. Drawing on the insights of such research, rights-based rehabilitation would seek to reframe the relationship between the healthcare professional and the patient such that rehabilitation comes to be understood as a joint enterprise, to which both parties bring expertise.

The question of what PPI may offer to rehabilitation science can also be considered in relation to research with disabled children. My scoping review in Chapter Two indicated that rehabilitation research with children may often have a particularly intense focus on functional and motor gains, rather than on the psychosocial aspects of rehabilitation experience; meanwhile, in Chapter Three, I observed that while literature on rehabilitation was scarce within disability studies, that which does exist often appears to focus on children's rehabilitation. I hypothesised that these findings might highlight the way in which disabled children are culturally constructed as being in need of physical rehabilitation, in order that their functional potential is maximised during their development. Children's physical development may be understood as timebound, and hence as occasioning particular sorts of intervention (Cooper, 2020, Burman, 2008). Elsewhere, I have argued that these kinds of perspectives shape normative and medicalised expectations about what rehabilitation is and what it does, but that they may operate without the child's input (Cooper, 2020). The child is perhaps more easily positioned as an outsider to rights discourses and is instead seen as having 'needs' that must be met (Runwick-Cole et al., 2018; Curran & Runswick-Cole, 2013). Yet, as Moll and Cott's (2013) research with adults with cerebral palsy (a congenital condition) showed, rehabilitation that is geared towards mimicking 'normal' bodies might not be what disabled people themselves find most helpful (see also Oliver, 1993); this point is also affirmed in autoethnographic studies discussed in the review of the disability studies literature (Inahara, 2013, Beauchamp-Prior, 2011). Therefore, within this context PPI has the potential to address epistemic injustices (Fricker, 2007) experienced by disabled people whose perspectives may have, until recently, been neglected due to the dominance of medical models of impairment within rehabilitation science (Oliver, 1993).

The inclusion of disabled people's voices within research design processes may offer an opportunity to challenge medical norms about the kinds of bodies that rehabilitation should be aspiring to produce, as well as challenging epistemic norms about the kind of knowledge, skills and perspectives that trainees in the rehabilitation professions need to perform their jobs well. In this sense, as I stated in my review of the history and theory of PPI, the question of who participates in research is always a question about epistemology. If knowledge is conceptualised only as, for example, medical knowledge, this will shape the nature of the enquiry that follows (Reason & Bradbury, 2001), and it may contribute to the subordination of the perspective of those with lived experiences of a condition. Rights-based rehabilitation may thus signify an epistemic shift for certain professions, in that the health sciences may need to invite students to self-reflexively pose the question 'what kinds of body-minds should rehabilitation aspire to produce?'.

In the following section I explain how the findings of this project may help to further elucidate and stake out a concept of 'rights-based rehabilitation' in policy and practice. Might the findings of this project necessitate a re-think for the disability rights movement, in terms of how it positions rehabilitation? What do the findings mean for services, for healthcare education and training, and for future research? The discussion which follows is structured around five sub-headings, including three which focus on the superordinate themes that structured my analysis chapters (*involvement*, *agency* and *temporality*), and two which draw out themes that emerged as substantial and relevant to policy. These were: the need for *stories to be witnessed*, and the need for *sufficient resources for rehabilitation*.

9.3.2 Rights-based rehabilitation as full involvement in decision-making, via enduring relationships

The evidence from this study demonstrates that disabled people accessing rehabilitation services benefit from opportunities to be fully involved in decision-making, especially when these are in the context of enduring relationships with healthcare professionals who seek to work in partnership with patients (Bourke et al, 2015; Norrbrink & Löfgren, 2016; Hanga et al., 2017). Rights-based rehabilitation would prioritise opportunities for disabled people to build long-lasting interpersonal relationships with rehabilitation professionals who come to know and understand the individuals they work with.

On the evidence of this study, rehabilitation relationships work best when all actors feel themselves to have a role in the process, and understand their responsibilities and commitments. Relationships which make the most of both the patient’s expertise-by-experience and the professional expertise of the practitioner are likely to be especially transformative. Absolute equality in the relationship was not necessarily what participants sought, because the relationship was about learning, but it was important to participants to be consulted and to have their voices heard. A rights-based rehabilitation policy would thus promote full involvement by recognising that some people may need more support than others to be able to communicate in the clinical encounter, and throughout the process of accessing services generally (Horton et al., 2016).

Rehabilitation services could be improved by recognising when and where ‘involvement’ is being used rhetorically without substance, since this may undermine patients’ faith in the commitment of healthcare professionals to working with patients in sustainable and thoroughgoing ways (see Beresford, 2014; Turner & Gillard, 2012). Participants emphasised that when their own experience could be treated as a resource and a form of expertise, this led to outcomes that were based on what they themselves wanted and needed from rehabilitation (see Inahara, 2013). Such a strategy may be more likely to take hold if it is fostered in and through healthcare education, via the direct involvement of disabled people in teaching and training (see Swart & Horton, 2015; Jannings & Pryor, 2012). Indeed, this was an activity that some of the participants in this study expressed an interest in undertaking, associating it with gaining a greater sense of personal agency.

9.3.3 Rights-based rehabilitation as re-finding agency in life

According to analysis of data undertaken as part of this study, rehabilitation can support disabled people to (re)find agency and direction in their lives. Motivational support and encouragement can be transformative for disabled people going through rehabilitation. This finding suggests that engaging with rehabilitation can be compatible with the goals of the independent living movement, which supports disabled people to make their own decisions and assert control over their lives (Evans, 2002). Therefore, a 'right-based' rehabilitation can be understood as radically re-conceptualising rehabilitation as a practice that could serve and emancipate disabled people, rather than oppressing them via a medical model that positions them as victims (see Oliver, 1993). In a number of the accounts discussed across the analysis chapters, rehabilitation professionals helped people to reframe disability experience in their minds, so that they would be able to choose how to manage. This evidence suggests that disabled people could benefit enormously from greater collaboration between health services and disabled people's organisations, as advocated by organisations such as Shaping our Lives, for example (Shaping Our Lives website, 2021). Such collaboration might sometimes entail an acceptance that support to maximise physical or psychological function is an enabler of equality for some people, just as support to dismantle social barriers to access is an enabler (Shakespeare, 2014). A rights-based rehabilitation policy would thus look to support disabled people to rediscover agency in their own lives in ways that are meaningful for the individual in question, without placing a normative emphasis on either a medical or a social model of disability, but instead recognising that each model has value in accordance with context. Yet, it would be important to distinguish a rights-based rehabilitation policy from a person-centred strategy. While there might be some synergies between the two concepts, rights-based rehabilitation would place greater emphasis on a recognition of the work disabled people do themselves within their rehabilitation to (re)connect with their agency. As the PPI review chapter demonstrated, the trend towards personalisation in health and social care has to be situated within a wider socioeconomic context in which the patient is increasingly positioned as a consumer rather than as a citizen (Breimo, 2016; Beresford, 2014); within such arrangements the patient's work may become a necessary part of an entrepreneurial self-presentation and is not always understood as work. Future research might seek to explore how rights-based rehabilitation could be implemented without reinforcing a contractualised mode of delivery for care (see Breimo, 2016).

Relatedly, data from this research shows that a 'rights-based' rehabilitation might confer agency upon disabled people by assuming they already have it, rather than by behaving in ways that assume their passivity or offer tokenistic involvement. Experiencing an external demand for reciprocity or input, or a challenge to rethink something, was very powerful for certain study participants; it helped them to see themselves differently and to find motivation. The fact that this data stood out as illustrative of transformative rehabilitation suggests that stigma, including internalised stigma, about disability may still be playing a significant role in disabled people's lived experiences of engaging with services (Coleman-Fountain & McLaughlin, 2013, Goffman, 1963). As a result of such feelings and experiences, disabled people may not feel a sense of entitlement to rehabilitation, and may lack confidence in navigating a system in which they have to 'fight' to get what they need. Staff training, delivered by disabled people themselves (Swart & Horton, 2015), on the key issues emerging from this study could be part of a strategy to implement rights-based rehabilitation, although it is likely that resource issues would also need to be addressed to see long-term improvements.

Opportunities to (re)build a sense of personal agency during rehabilitation may promote an orientation towards disability rights. In this study, this included reconnecting with creative impulses and having the chance to make a beautiful object for a family member, or to write a poem about rehabilitation experience. Whilst these might not seem like conventional rehabilitation activities, they seemed to support individuals in this study to be motivated to engage with other aspects of rehabilitation, or to get to grips with a new identity as a disabled person. Indeed, in the context of the writing group I held, it appeared that participants prized the opportunity to process and make sense of their lived experiences of rehabilitation through creative writing. For some participants in my study, narrative work came to be synonymous with rehabilitation. This suggests that there is scope for more research into interventions that support participants to reflect on and (re)build their own rehabilitation narratives (Bourke et al., 2015; Williams, 1984), especially in the aftermath of an acquired impairment. Future qualitative research could also explore the relationship between creativity, motivation and personal agency in rehabilitation, and services should consider how opportunities for creative and narrative-building activities can be resourced.

9.3.4 Rights-based rehabilitation creates space for stories to be witnessed

On the evidence from this study, the rehabilitation professional may be appreciated by the patient for acting as a witness: both in the sense of being a witness to the patient’s unfolding or reconstructed life narrative, and in the sense of being a witness to the patient’s full humanity and personhood. At various points in the fieldwork, and especially in the creative writing group, I found that participants’ narratives suggested that they had sought to take part in the project in order to have their stories, and their personhood, witnessed and acknowledged. Such data provide varied evidence of a need for rehabilitation services to be able to support people in this way: the professional may play a powerful role simply by witnessing patients’ suffering, and by listening to their stories of what it is like to go through rehabilitation and to have their biographical narratives disrupted (Williams, 1984, Bury, 1982). Witnessing could also be thought of as an activity that would engage with the testimonial injustice that disabled people might have experienced by virtue of having been stereotyped in ways that potentially reduce their social capital, to draw on Fricker’s (2007) work.

9.3.5 Rights-based rehabilitation as recognition of disabled people’s time work

This study affirms existing evidence that becoming disabled can entail a disruption to lived time and to biographical identity (Bury, 1982; see also Bourke at al., 2015; Coventry et al., 2014; Papadimitriou & Stone, 2011). Rights-based rehabilitation needs to acknowledge the work involved in managing time (Flaherty, 2003), and in reshaping biographical narratives, in the aftermath of these disruptions (Williams, 1984, Bury, 1982). The way in which participants prized the creative writing group in my study suggests that opportunities to engage in narrative reconstruction with a supportive therapist or peer supporter are likely to be valuable. Rehabilitation services could be improved by allowing sufficient resources to help participants with this work, which is itself time-intensive. Support for the work of adjusting both takes time, and needs to happen in at the right time. Furthermore, incorporating teaching on key concepts from the sociology of rehabilitation, such as biographical disruption (Bury, 1982) and narrative reconstruction (Williams, 1984), could support a new generation of rehabilitation professionals to develop their practice with an awareness of how important temporality is within the lived experience of rehabilitation.

A rights-based rehabilitation policy would recognise that for many disabled people rehabilitation means retaining physical functioning over the long-term and seeking to maintain this. This requires ongoing access to services so that disabled people can stay well and prevent any unnecessary deterioration of their condition. Many participants in this study drew attention to treatment regimes whose temporality assumed an entirely different understanding of rehabilitation. Six-week treatment courses, a term I heard participants invoke frequently during the fieldwork, were not appropriate for someone managing a lifelong condition. The need for appropriately designed treatment regimes appears to be an urgent issue for a rights-based rehabilitation policy to take up: when rehabilitation means *maintaining* a level of physical functioning rather than *regaining* it, that indicates a need for ongoing access to services. As one of the participants highlighted, such a preventative strategy would be likely to decrease the burden of demand on the health service in the long-term.

On the evidence of this study, disabled service users in the UK may be doing a lot of time-consuming work to administer their rehabilitation, often in the face of an expectation that as a disabled person they must have time on their hands, and would be able to be flexible at short notice. A rights-based rehabilitation would be better placed to promote widespread understanding, among NHS staff and within local authorities, of the amount of work done by disabled people on a long-term basis, not only to maintain their physical functioning and prevent deterioration, but also to get what they need from services. Such an orientation could also intersect with the objectives of PPI, where there has been an attempt to institutionalise recognition of patients' work within health research and service provision contexts (see, for example, Keenan et al., 2019). Disabled people's disadvantage expresses itself both as a generalised devaluing of their time in the public sphere, via stereotypes of disabled people as unemployed, and as a failure to recognise disabled people's time-consuming rehabilitation work, and access work, as *work*. A rights-based rehabilitation policy would look to address this through awareness campaigns, staff training, and future research to explore the social valuing of time as a health inequality issue (see also Van den Berg, 2017, Strazdins et al., 2011).

9.3.6 Rights-based rehabilitation as a demand for more resources

It was notable in this study that some of the more positive experiences of enduring rehabilitation relationships and timely interventions appeared to have happened in the early 2000s, whereas accounts of more recent experiences were often marked by a sense of overstretched services and the shrinking availability of resources. The austerity programme of the UK coalition government (2010-2015) and of the Conservative government (from 2015) was an importance context for this research and a sizeable number of participants made reference to it and to their perception of its direct, or indirect, impact on their lived experience of disability and rehabilitation. For a rights-based rehabilitation policy to be effective at the level of service provision, much more investment in NHS services would be required and detrimental public spending cuts would need to be reversed.

9.4 Evaluating the study and its methodology: What is the status of the knowledge I produced, and how did PPI help me think about this?

In this section, I examine the intertwined methodological and ethical issues that I addressed in the course of my work on this study, considering their impact on the knowledge I produced. I critically evaluate my study design, paying special attention to the role of PPI, given the status I sought to give to involvement throughout my work on the project.

9.4.1 Evaluating the deployment of methodological pragmatism

As described in the Methodology chapter, I explicitly adopted a ‘pragmatic’ approach whereby I analysed the research problem and made decisions about method on the basis of this analysis (Morgan, 2014; Creswell & Poth 2016; Mason, 2018). As someone new to the social sciences, I judged this approach to have logic on its side. Pragmatism also enabled me to think about knowledge as something that is produced in a context, in response to particular goals, demands or structuring questions (Kaushik and Walsh, 2019). Pragmatism could therefore facilitate an approach that centred participants’ contextual meaning-making about rehabilitation, and allowed me to explore how participants conveyed and narrativised their experiences. Nevertheless, at certain points in the project I found myself querying how a pragmatic approach can and should account for its relationship with concepts, and indeed with conceptual frameworks such as, for example, interpretative phenomenological analysis, or a Foucauldian approach. The deeper I have gone into analysis of both the research problem and the data, the more I have moved away from analytical induction and towards an abductive strategy which acknowledges that analytical practices are always in dialogue with conceptual frames of different kinds. I could have adopted one specified conceptual framework from the outset, as a way of seeking to structure my reading of the data. This could have had the advantage of standardising my interpretive practices and making them legible and transparent within a particular agreed way of working. I chose not to do this, as I judged that it would close down creative thinking and constrain my ability to approach the data with an open mind. I also believed that it might make my analysis less accessible to those without prior knowledge of the chosen theoretical framework; I was thinking in particular of colleagues such as PPI members who are situated outside of academia. Instead, I sought to use careful explanation and substantiation to show how I had reached each interpretation. Yet, if we agree that analysis can never happen outside of a conceptual framework of some kind, it could be said that this approach masks its reliance on concepts that are nevertheless posited as belonging to a shared common sense. Even if I tried always to demonstrated how I was reaching the readings I made, this will have been a culturally situated process of meaning-making, reliant upon certain assumptions about how language works. I shall continue to think about this dialogical issue in future research.

9.4.2 Whose voices did this study include and who might have been excluded?

A major strength of this study was its consideration of questions of access and inclusion at every stage of the process, which helped to ensure that the research represented a wide range of different voices. The work was supported by the involvement of disabled people who had been through different sorts of rehabilitation. For example, when designing an ‘easy-read’ information sheet, I discovered I knew very little about how an aphasic person might work to make sense of such information. My aphasic PPI colleagues filled in the gaps in my knowledge and pointed to invaluable resources, but this part of the work also revealed to me that I did not know how I would support an aphasic person to take part in the fieldwork. Aphasic people are not always supported to be included in decisions about their care, or in research (Horton et al., 2016, Horton & Wellings, 2014). I was lucky to be able to attend a short, practical introduction to supported communication alongside UEA Speech and Language Therapy students, which helped me to plan inclusion with an awareness of the communication needs of aphasic people. Working closely with disabled people with a range of different access needs, and arranging events involving them, gave me practical experience of how to do inclusion well.

The question of whose voices are ultimately represented in this study is an important consideration when evaluating the scope and breadth of the knowledge I produced. Integrating PPI into this project from the beginning made it much easier to recruit a diverse group of participants, because I had built trust with well-connected members of the disability community in the local area, who could reach out to their own networks. Nevertheless, the question of who felt able to participate in this project, and then to speak or communicate their experience, is inseparable from the question of how this project ultimately frames involvement in rights-based rehabilitation. The celebrated literary theorist Gayatri Spivak has posed the question ‘can the subaltern speak?’ (1988), highlighting the paradox whereby, when a peripheral or marginalised position becomes intelligible to those in the mainstream, it is no longer expressing something wholly marginal to that culture. This framing offers an important reminder that the voices that can be heard in this thesis may not be those that are most socially marginalised; taking part in academic research is something that is daunting to many people and that requires people both to believe in the value of their own narratives and to be invested in the notion of research, and universities, *per se*. Even though I sought to make this project as inclusive as possible, accessing it might still have been difficult, perhaps in ways that are not intelligible to me, otherwise I would have tried to mitigate them. One of the focus group participants observed: ‘We are the disabled people who are able to vocalise because we’re able to actually get here; we speak on behalf of those who can’t’. She was making an important point about inclusion. Whose voices are not reflected in this project, and why? Is it really possible for others to speak ‘on behalf’ of those who were not ‘able to get here’?

A participant in another focus group said that the project would attract people with positive experiences of rehabilitation, implying that people with more complex experiences would not want to speak of these to a researcher. The rest of the data does not bear out this participant's speculation, since some participants appear to have sought out the project partly because they were *keen* for their negative experiences to go on record in order to show how systems are failing or desperately need improvement. Nevertheless, it is worth asking: how is the framing of the research influencing the kinds of voices it contains? How does (for example) the title, *Rights-based Rehabilitation* persuade or dissuade potential participants from contacting me?

Although I may not be able to answer all of the questions I pose about inclusion, I sought to remain aware, throughout the research, of power differentials that might make it difficult for some participants to get involved, and the ways in which language choices in the promotional literature might affect who wanted to take part. As explained in the Methodology (Chapter Five), I did succeed in recruiting participants with a range of impairments, across a spectrum of ages, from a variety of walks of life. Roughly equal numbers of men and women were involved. Some participants identified strongly with the disability rights movement while others did not appear to do so, and a few expressed a dislike of terminology such as 'disability'. Therefore it does not appear that using disability rights movement terminology discouraged those who dis-identify with this language from taking part. The sample was therefore in some senses heterogeneous, and could be seen to offer wide-ranging insights about the lived experience of rehabilitation.

In the context of the literature I reviewed, this study is unusual in terms of its deployment of an inclusive sampling strategy whereby disabled people with a wide range of physical and sensory impairments were all eligible to participate. Most comparable studies have focused on one impairment group. Although this study design gives me less authority to speak about, for example, the lived experience of rehabilitation for spinal cord injury than a study involving 36 people with spinal cord injury, the advantage of the wider scope of this study is that I have been able to compare and contrast accounts of various kinds of services, and various kinds of impairment, in this data from one region of the UK (the East of England). Sampling participants with a range of impairments has enabled me to build a picture of what rehabilitation was like for users across a spectrum of services, and to characterise certain key features of rehabilitation experience which emerged as significant in this study, regardless of impairment type. The findings of this study can therefore be relevant to a wide range of disabled people and health professionals who support rehabilitation.

Although the patient and public involvement activities were designed to support me to recruit a diverse cohort of study participants, the project advisory group was not ethnically diverse. Had the group comprised people from a range of ethnic backgrounds, it is possible that the study might in turn have attracted participants from a more diverse spectrum of ethnicities. In terms of geography and ethnicity, this sample was homogeneous. All participants were white, so this sample was not varied in terms of ethnicity. In terms of their geographical characteristics, all of these participants lived in the East of England, with most based in Norfolk. The project findings might have been different in another part of the country, or if participants had been drawn from a range of ethnic backgrounds. The sample of participants might have been more ethnically diverse if this project had been carried out in another, less rural, part of the UK.

9.4.3 Variation promoted by different fieldwork activities

A further strength of this study was its use of three strands of fieldwork (interviews, focus groups, creative writing groups), which set up different kinds of interactions with research participants, enabling me to elicit different sorts of data, including: involved narratives about biographical experience (interviews); shared and dissenting views on aspects of engaging with services (focus groups); poems and prose pieces (writing groups), as well as views on the creative process itself (writing groups). Using these different methods promoted variation, which allowed me to compare and contrast how phenomena were being conceptualised in the various encounters, and thus to explore points of commonality and difference. This multi-stranded approach led to insights that might not have been possible with only one form of fieldwork. For example, the insights about the relationship between creativity and agency in rehabilitation might have been harder to recognise in the data without the use of a creative writing group.

Following Mason, I cautiously name this process ‘triangulation of method’ (2018, p. 238), while noting, as Mason does, that this approach does not allow me to straightforwardly compare the ‘products’ of this research as if they are all ontologically similar, but rather underscores the need to understand and interpret the interactional and situational specificity of each fieldwork activity, as well as the question of how the data for each activity would be shaped by the sample. Doing PPI also helped me to think this through, because some of the PPI members were rightfully dubious about using creative writing because it might not be inclusive for all, and might lead certain members of the disability community to self-exclude. The cognitive or physical act of writing might not be available to everyone. Reflecting on this feedback, I decided that it would be important to adapt processes and practices so as to be inclusive for people whether or not they wanted to share their own writing, or were able to read out their writing themselves, in the sharing group. I used the PPI feedback to amend to project accordingly. I was aware that this would only mitigate the issues and was unlikely to resolve them completely for all potential participants. I judged that all fieldwork activities have the potential to be exclusive and that my modified aim should therefore be to make all of my activities as inclusive as possible, while acknowledging what limitations remain. In the process of running the group, I became aware that there were speakers and writers who were more confident than others; I sought to facilitate everyone’s participation. In the analysis process, I knew that the data I ultimately chose to discuss illuminated only certain people’s feelings about writing as a technique for processing, and that I should not present this as a universal experience.

9.4.4 Producing a large amount of data was a strength and a limitation

This project generated a large amount of data with a lot of repetition of similar themes. I would hesitate to denote this as theoretical saturation (Bloor and Wood, 2006), because it is always possible that new data collection activities would generate unexplored themes. I nevertheless stress that the themes that became the subjects of the analysis chapters emerged strongly as significant in a process that involved reading and sifting a lot of textual material that was not ultimately quoted in those chapters, but which nevertheless forms a relevant hinterland to support the theme-selection process. Therefore, the analysis chapters present ‘reiterated’ themes, that emerged again and again across different contexts, as well as some examples of phenomena that stood out in the study, describing an aspect of rehabilitation that had clearly been transformative for one (or more) individual. In these senses, the wealth of data collected was indisputably a strength of the project.

Having a lot of data to sift meant that I could not showcase all of the rich textual data that I would have liked to; I will explore opportunities to highlight such data in future publications. I also had to be selective about what to prioritise thematically in this thesis. I discussed the abductive process for doing this at the start of the chapter. When I began this research project, I had been intending to work inductively with the data, but later I realised that my approach would be more accurately described as abductive, in the sense that my own understanding of rehabilitation, and of health services, and of disability, would influence the way I both conducted fieldwork and analysed data. Doing PPI also played an important role in teaching me to think about this research from angles I had not visited before, and this work contributed to my abductive process. For example, even the process of selecting data to discuss in the PPI data analysis meeting made me think deeply and carefully about what I was selecting and why; then, in the group itself, I learned new information about rehabilitation practices, which threw new light on the data extracts in question.

Having a large amount of data to sift made it essential to deploy an abductive strategy, because of the need to make reasoned choices about what was most relevant to this research problem. The process of doing the research has taught me much about the importance of attending to what is put in play by the set-up of the interactional encounter, and about why the work that is done to introduce themes and topics matters and affects the data that emerges. If I were to do this research again, I might deploy a theoretical sampling method more actively from the start, to ensure both that this data collection was more focused, and that I was making use of as much data as possible in the analysis. I could have worked with the PPI members to develop a strategy for theoretical sampling, using their insights about different types of rehabilitation experience to help me plan this.

9.4.5 Constraints on PPI activity

Integrating involvement into the project methodology supported me to interrogate what involvement meant in the context of rehabilitation. Nonetheless, with more resources, I think my PPI could have been improved. Running PPI events was time-consuming, and after my maternity leave, when I had a young child, was working on this thesis part-time, and also trying to earn a living and kickstart other parts of my academic career, I did not always maintain links with the project advisory group as frequently as I would have liked. It would have helped enormously to be able to share the administrative work associated with doing PPI with a colleague such as a research assistant. However, a PhD is not a collaborative piece of work, and in this sense, while the form I am using for presenting this research is a well-established one in academia, it contains no mechanism for demonstrating and accounting for the contribution made by PPI members, or for the showing ways in which PPI has enhanced a researcher’s professional development. Again, by virtue of the fact that this was a single-authored doctoral project, thoroughgoing co-production did not seem to be an option. However, I did seek ways to involve disabled people at all the crucial junctures of the project, when I was making decisions.

9.4.6 Upholding clear boundaries: The line between research and therapy

Theoretically, it should be possible to clearly delineate the aims of a research project as distinct from a therapeutic intervention. In researching and writing my methodology chapter I had become aware of a literature documenting the use of creative writing as a therapeutic intervention (Costa & Abreu, 2018; Pennebaker, 1997), and therefore I sought to make it clear in my participant information that the creative writing was a research activity, and to explain that any therapeutic benefits associated with participation were purely incidental.

However, as previously mentioned, this research project took place in the context of funding cuts to public services in the UK. A frequent refrain in the research encounters was scarcity of resources and lack of availability of support services. At times, it seemed that some participants had sought out this research project as an opportunity to share their stories with someone who had time to listen and to witness what they had been through, in the absence of the availability of a therapeutic service within the NHS. Participants sometimes indicated that a fieldwork activity had had therapeutic value for them, and such remarks were associated in particular with the creative writing group. While I had a robust protocol in place to deal with any safeguarding concerns, the experience of doing the fieldwork brought into sharp relief for me questions about what it means to act ethically as a health services researcher operating in the midst of an NHS funding crisis. In the context of the fieldwork itself, I sought to uphold boundaries in ways that would be supportive and sincere for participants, as well as manageable for me. I was grateful for the clarity of the protocol I had in place, and to have supervisors and senior colleagues who made themselves available to discuss my concerns as soon as they arose. This made all the difference to my ability to learn from experience and to act ethically in each situation. In terms of the wider issue of delineating research and therapy in this contemporary social landscape, these are questions that I continue to think about and to discuss with colleagues, as I do not believe that there are any easy answers.

9.4.7 Creative writing and inclusive knowledge production

When writing a rationale for the inclusion of creative writing within my methodology, I focused mainly on the question of whether creative writing might liberate participants to narrate their rehabilitation experience with more freedom and creativity (Barone and Eisner, 2012; Leavy 2009). Yet in fact, as discussed in the chapter on narrating agency (Chapter Seven), the experience of designing and implementing the creative writing group led me to ask more fundamental questions about how we imagine inclusion and knowledge production in social research. Specifically, it prompted me to consider the metaphors commonly used to describe how knowledge comes about, and how it ‘gets to be’ in a place such as this PhD thesis. The creative writing participants demonstrated that writing was a process of discovery for them as much as it was for me, and that it was *through the very process of creating writing* that they made meaning about rehabilitation. Meaning was not an objectified, pre-existing ‘thing’ that participants ‘had’ and which they could give researchers access to; instead it was something we were exploring together in the group, and which was negotiated or constructed in a context. These discoveries helped me to think further about knowledge production, comparing processes and practices across disciplines. In future writing, I will look to consider this question of how different disciplines frame the terms of their intellectual inquiries and interventions, and what the impact of such framings are on the knowledge produced.

9.5 How has my work on this project affected my own perspective on disability and rehabilitation, and how has it altered my view of research processes and practices?

My work on this project has highlighted to me how diverse people’s experiences of disability and rehabilitation may be. I came to this project having written autoethnographically about my own experience of childhood (re)habilitation in the PhD that was to become my book (Cooper, 2020). The process of working with a small project advisory group of disabled services users, and then of doing fieldwork with disabled people, developed and reinforced my understanding of the diversity of disability experience. While disabled people who go through rehabilitation may have experiences in common, there are many factors that make people's experiences different, including social class, race, gender, economic status, geographical and temporal location of the rehabilitation, type of impairment, and the stage in the life-course when disability occurred. Some of the people I spoke to identified with the term 'disabled', and with the language of the disability rights movement, while others did not. The experience of working with and alongside a group of people from all walks of life has led me to ask myself a lot of questions about what we do when we mobilise the language of 'disability' (see also Watson, 2002), as well as what we do when we seek to make comparisons and claims in the social sciences.

Both the diversity of lived experiences I have encountered in doing this project, and the amount of data I have sifted, have led me to reflect on the interconnected epistemological and ethical considerations associated with the process of synthesising information in research that uses real people's testimony. I have always been interested in the question of voice in research, the question of positionality, and the question of who gets to speak. Yet my work on this project has raised a lot of questions for me about what it means to try to represent, adequately, the voice and the perspective of the Other. In part due to these questions, I have strived to be as reflexive, and as transparent, as possible about what I did at each stage of the process in this project.

Doing this project has also led me to think deeply about access and inclusion in research as complex and multi-layered issues without one-size-fits-all answers. By definition, they are issues that one person cannot resolve alone, because they are experienced differently according to one's standpoint. In this sense, the process of working with a project advisory group has been a unique and invaluable experience for me, which has offered me opportunities to explore issues I would never otherwise have considered.

9.6 Conclusions of this study

This study sought to understand what constitutes successful rehabilitation for a sample of disabled people living in the East of England, in order to begin to conceptualise what a ‘rights-based’ approach to rehabilitation might look like. I have argued in this chapter that the data analysis undertaken in this study has advanced existing knowledge about rehabilitation, underscoring in particular participants’ representations of successful rehabilitation as a (re)discovery of personal agency. The sub-themes discussed in each analysis chapter almost all speak to this over-arching thematic area. Re-finding agency was often was helped by the formation of enduring relationships with healthcare professionals who involved the patient in decision-making, while also drawing on their own expertise. While themes such as consultative relationships, and indeed the significance of agency over autonomy are touched upon in existing literature (e.g. Hanga et al., 2017; Bourke et al., 2015; Van de Velde et al., 2012), this study has examined in detail how such concepts animated disabled people’s accounts of what rehabilitation was like, thus substantially developing existing theories of the social aspects of rehabilitation. The lived temporality of rehabilitation was also a key theme in the qualitative evidence generated within this study, with participants citing time as a resource that was felt to be scarce within the NHS, as well as linking their sense of control over rehabilitation with their sense of being in control of their time. In this domain, this research extends existing sociological evidence on the relationship between time and agency (Flaherty, 2003) and narrative and agency (Williams, 1984; Bury, 1982).

For the participants in this study, the features of a well-resourced, high-quality rights-based rehabilitation practice would include:

- Rehabilitation relationships which are built over time, attending to patients’ views about what rehabilitation should help them achieve, but also drawing on the healthcare professional’s expertise. These can transform a disabled person’s quality of life. They include peer support relationships.

- Opportunities for disabled people to be fully involved in making decisions about their rehabilitation. These opportunities might need to include adjustments that support communication.
- Timely access to rehabilitation services. These study participants emphasised that rehabilitation is a process of adjustment, requiring different kinds of support at different times.
- Access to services on an ongoing basis. This is described as essential for many disabled people, helping them to maintain a level of fitness and function that makes their lives meaningful. Services that insist inflexibly on short courses and on re-referral processes may not be designed with the long-term needs of disabled people in mind.
- Greater support with, and recognition of, the time-consuming work that disabled people must do to gain access to services, to adjust to life with a disability, and to maintain their health. This work needs to be understood and treated as *work*, and disabled people's time needs to be valued as they seek to engage with services. A disability awareness campaign for health service workers could help to reframe disabled people's input into their rehabilitation as work.
- Opportunities for disabled people to exercise agency in their lifeworld, including opportunities for reciprocity. The data from this project showed that at its best, rehabilitation was not simply about being a service *user* but about giving something back to a service, to a family member, to research, or to education. The evidence underpinning this theme suggests that participants themselves would like to see a more substantial role for PPI in healthcare education and health services research.
- Opportunities for disabled people to explore, nurture and value their creativity as part of a planned rehabilitation pathway. These processes often seemed to be linked with narrative-building in this study.
- Rehabilitation relationships which bear witness to disabled people's experiences of living with a long-term condition, and of engaging with rehabilitation services. In this study, this theme was also linked with the importance of narrative-making rather than simply following prescribed

protocols: it seemed that the process of creating a narrative could enable the participant to bear witness to their experience.

These findings form the basis for further purposeful research to extend our understanding of the sociology of rehabilitation. For example, the findings open up the possibility of an intervention looking at the role of the arts in supporting disabled people's narrative reconstruction work in rehabilitation. The results of this study could also be used to develop policy that sees more roles for disabled people in health research, in the delivery of health education and indeed in the rehabilitation professions themselves. Although only one participant commented on how powerful it had been to have a course of treatment delivered by a person with a comparable impairment, several noted that peer support was an invaluable and irreplaceable part of the rehabilitation process. Moreover, my own experience of doing PPI shows that working with people who have different sorts of lived experiences of rehabilitation can help to make a research protocol more inclusive, and more relevant, to the group it is intended to serve, even when the principal investigator is disabled herself. Having more disabled voices in all parts of the health service could lead to a new generation of healthcare professionals and researchers who have benefited from opportunities to re-think how to make their practice inclusive.

Finally, the findings of this project could and should inaugurate a conceptual shift for disability studies (Shakespeare et al., 2018), whereby questions of equality of access to healthcare are brought to the fore, and health and rehabilitation research is no longer unduly constrained by the legacy of the 'strong' social model of disability (Shakespeare, 2014). Such a shift would allow for the emergence of synergies with medical sociology and health services research among other disciplines. This could lead to novel research into disabled people's lived experiences of medicine and health, and so create a more robust evidence base for introducing rights-based knowledge and practices into healthcare.

Reference List

Aadal, L., Kirkevold, M., & Borg, T. (2014). Neurorehabilitation analysed through ‘situated learning’ theory. *Scandinavian journal of disability research*, *16*(4), 348-363. doi: 10.1080/15017419.2013.781956

Abberley, P. (1995). Disabling ideology in health and welfare - The case of occupational therapy. *Disability & society*, *10*(2), 221-232. doi: 10.1080/09687599550023660

Almasri, N., & Saleh, M. (2015). Inter-rater agreement of the Arabic Gross Motor Classification System Expanded & Revised in children with cerebral palsy in Jordan. *Disability & rehabilitation*, *37*(20), 1895-1901. doi: 10.3109/09638288.2014.986589

Arksey, H., & O'Malley, L. (2005). Scoping studies: towards a methodological framework. *International journal of social research methodology*, *8*(1), 19-32. doi: 10.1080/1364557032000119616

Armstrong, D. (2014). Actors, patients and agency: A recent history. *Sociology of health & illness*, *36*(2), 163-174. doi: 10.1111/1467-9566.12100

Arnstein, S. R. (1969). A ladder of citizen participation. *Journal of the American institute of planners*, *35*(4), 216-224. doi: 10.1080/01944366908977225

Arntzen, C., Hamran, T., & Borg, T. (2015). Body, participation and self transformations during and after in-patient stroke rehabilitation. *Scandinavian journal of disability research*, *17*(4), 300-320. doi: 10.1080/15017419.2013.868823

Badia, M., Orgaz, B., Gómez-Vela, M., & Longo, E. (2014). Environmental needs and facilitators available for children and adolescents with cerebral palsy: adaptation and validation of the European Child Environment Questionnaire (ECEQ) Spanish version. *Disability & rehabilitation*, *36*(18), 1536-1548. doi: 10.3109/09638288.2013.847124

Baraitser, L. (2017). *Enduring time*. London: Bloomsbury Academic.

Barbour, R. (2008). *Doing focus groups*. London: Sage.

Barnes, C. (1996). Disability and the myth of the independent researcher. *Disability & society*, *11*(1), 107-112. doi: 10.1080/09687599650023362

Barnes, M. (2008). Is the personal no longer political? *Soundings*, (39), 152. doi: 10.3898/136266208786879227

Barnes, M., & Cotterell, P. (2012a). From margin to mainstream. In M. Barnes, & P. Cotterell (Eds.), *Critical perspectives on user involvement* (pp. xv-xxvi). Bristol: The Policy Press.

Barnes, M., & Cotterell, P. (2012b). User involvement in research. In M. Barnes, & P. Cotterell (Eds.), *Critical perspectives on user involvement* (pp. 143-147). Bristol: Policy Press.

Barone, T., & Eisner, E. W. (2012). *Arts based research*. London: Sage.

Barker, A. R., & Li, L. (2020). The cumulative impact of health insurance on health status. *Health Services Research*, *55*, 815-822. doi: 10.1111/1475-6773.13325

Beauchamp-Pryor, K. (2011). Impairment, cure and identity: 'Where do I fit in?'. *Disability & society*, *26*(1), 5-17. doi: 10.1080/09687599.2011.529662

Bekken, W. (2014a). The role of objects in understanding children's participation in paediatric rehabilitation. *Scandinavian journal of disability research*, *16*(2), 159-178. doi: 10.1080/15017419.2012.761155

Bekken, W. (2014b). ‘I want them to see that I feel normal’: three children’s experiences from attending consultations in paediatric rehabilitation. *Disability & society*, *29*(5), 778-791. doi: 10.1080/09687599.2013.874329

Beresford, P. (2019). Public participation in health and social care: exploring the co-production of knowledge. *Frontiers in sociology*, *3*, 41. doi: 10.3389/fsoc.2018.00041

Beresford, P. (2014). Personalisation: From solution to problem? In P. Beresford (Ed.), *Personalisation* (pp. 1-26). Bristol: Policy Press.

Beresford, P. (2013). From ‘other’ to involved: user involvement in research: an emerging paradigm. *Nordic social work research*, *3*(2), 139-148. doi: 10.1080/2156857X.2013.835138

Beresford, P., & Branfield, F. (2012). Building solidarity, ensuring diversity: Lessons from service users and disabled people’s movements. In M. Barnes, & P. Cotterell (Eds.), *Critical perspectives on user involvement* (pp. 33-45). Bristol: The Policy Press.

Berthou, A. (2012). Quand l’un reçoit l’autre. La reconstruction de l’intimité conjugale au sein d’un centre de rééducation. *Alter*, *6*(3), 188-200. doi: 10.1016/j.alter.2012.06.001

Bertilsdotter Rosqvist, H. (2012). Practice, practice: notions of adaptation and normality among adults with Asperger syndrome. *Disability studies quarterly, 32*(2). Retrieved from https://dsq-sds.org/article/view/3191. doi: 10.18061/dsq.v32i2.3191

Bevan, J. (2014). Disabled occupational therapists–asset, liability… or ‘watering down’ the profession? *Disability & society*, *29*(4), 583-596. doi: 10.1080/09687599.2013.831747

Bezmez, D. (2016). Looking for a ‘cure’: Negotiating ‘walking’ in a Turkish rehabilitation hospital. *Disability & society*, *31*(3), 389-405. doi: 10.1080/09687599.2016.1167670

Bezmez, D., & Yardımcı, S. (2016). Rehabilitation technology and the reproduction of bodily normality: A critical analysis of robotic gait training in Turkey. *Scandinavian journal of disability research*, *18*(4), 343-353. doi: 10.1080/15017419.2015.1114964

Bezmez, D., & Yardımcı, S. (2015). Social experiences of physical rehabilitation: the role of the family. In T. Shakespeare (Ed.), *Disability research today* (pp. 25-42). Abingdon, Oxon: Routledge. doi: 10.4324/9781315796574

Biggerstaff, D., & Thompson, A. R. (2008). Interpretative phenomenological analysis (IPA): A qualitative methodology of choice in healthcare research. *Qualitative research in psychology*, *5*(3), 214-224. doi: 10.1080/14780880802314304

Blaikie, N. (2007). *Approaches to social enquiry: Advancing knowledge*. Cambridge: Polity.

Bloor, M. & Wood, F. (2006). Theoretical saturation. In M. Bloor, & F. Wood, *Keywords in qualitative methods* (pp. 165-166). London: SAGE Publications Ltd. doi: 10.4135/9781849209403

Bolton, G. (1999). *The therapeutic potential of creative writing: writing myself*. London: Jessica Kingsley Publishers.

Boote, J., & Carr, S. (2019). Rapid response: Is PPI being privatised? *BMJ*, 365, l4044. doi: *10.1136/bmj.l4044*

Bøttcher, L., Stadskleiv, K., Berntsen, T., Christensen, K., Korsfelt, Å., Kihlgren, M., & Ödman, P. (2016). Systematic cognitive monitoring of children with cerebral palsy–the development of an assessment and follow-up protocol. *Scandinavian journal of disability research*, *18*(4), 304-315. doi: 10.1080/15017419.2015.1091035

Bourdieu, P. (1990). Structures, habitus, practices. In P. Bourdieu, *The Logic of practice* pp. (52-65). Cambridge: Polity.

Bourke, J. A., Hay-Smith, E. J. C., Snell, D. L., & DeJong, G. (2015). Attending to biographical disruption: the experience of rehabilitation following tetraplegia due to spinal cord injury. *Disability & rehabilitation*, *37*(4), 296-303. doi: 10.3109/09638288.2014.918188

Bowman, D. (2015). What is it to do good medical ethics? Minding the gap (s). *Journal of medical ethics*, *41*(1), 60-63. doi: 10.1136/medethics-2014-102299

Bradley, Q. (2013). 'Putting our mark on things': the identity work of user participation in public services. *Critical social policy*, *33*(3), 384-402. doi: 10.1177/0261018312468306

Breimo, J. P. (2016). Planning individually? Spotting international welfare trends in the field of rehabilitation in Norway. *Scandinavian journal of disability research*, *18*(1), 65-76. doi: 10.1080/15017419.2014.972447

Brodersen, S., & Lindegaard, H. (2014). Ability or disability–design for whom? *Scandinavian journal of disability research*, *16*(3), 267-279. doi: 10.1080/15017419.2013.803499

Brookfield, K., & Mead, G. (2016). Physical environments and community reintegration post stroke: Qualitative insights from stroke clubs. *Disability & society*, *31*(8), 1013-1029. Doi: 10.1080/09687599.2016.1223606

Brunson, J., & Loeb, M. (Eds.) (2011). Mediated communication [Special issue]. *Disability studies quarterly*, *31*(4). doi: 10.18061/dsq.v31i4

Brunton, L. K., & Bartlett, D. J. (2013). The bodily experience of cerebral palsy: a journey to self-awareness. *Disability & rehabilitation*, *35*(23), 1981-1990. doi: 10.3109/09638288.2013.770080

Bulk, L., Easterbrook, A., Roberts, E., Groening, M., Murphy, S., Lee, M. … & Jarus, T. (2017). “We are not anything alike”: Marginalization of health professionals with disabilities. *Disability & society*, *32*(5), 615-634. doi: 10.1080/09687599.2017.1308247

Burman, E. (2008). *Deconstructing Developmental Psychology* (2nd ed.). Hove, East Sussex: Routledge. doi: 10.4324/9780203946169

Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of health & illness*, *4*(2), 167-182. doi: 10.1111/1467-9566.ep11339939

Butler, J. (1997). *Excitable speech: A politics of the performative*. New York and Abingdon, Oxon: Routledge.

Butler, J. (1993). *Bodies that matter: On the discursive limits of sex.* London: Routledge.

Byrnes, M., Beilby, J., Ray, P., McLennan, R., Ker, J., & Schug, S. (2012). Patient-focused goal planning process and outcome after spinal cord injury rehabilitation: quantitative and qualitative audit. *Clinical rehabilitation*, *26*(12), 1141-1149. doi: 10.1177/0269215512442669

Campbell, D. J., Coll, N., & Thurston, W. E. (2012). Considerations for the provision of prosthetic services in post-disaster contexts: the Haiti Amputee Coalition. *Disability & society*, *27*(5), 647-661. doi: 10.1080/09687599.2012.669109

Campbell, J., & Oliver, M. (2013 [1996]). *Disability politics: Understanding our past, changing our future*. London: Routledge. doi: 10.4324/9780203410639

Care Quality Commission (2020). *Experts by experience*. Retrieved December 1, 2020 from https://www.cqc.org.uk/about-us/jobs/experts-experience

Carel, H. (2018). *Illness: The cry of the flesh*. Stocksfield: Acumen Publishing. doi: 10.4324/9781315197999

Carr, S. (2019). 'I am not your nutter': a personal reflection on commodification and comradeship in service user and survivor research. *Disability & society*, *34*(7-8), 1140-1153. doi: 10.1080/09687599.2019.1608424

Carr, S. (2014). Personalisation, participation and policy construction: A critique of influences and understandings. In P. Beresford (Ed.), *Personalisation*. Bristol: Policy Press.

Charlton, J. I. (2000). *Nothing about us without us: Disability oppression and empowerment*. Berkeley, CA: University of California Press.

Charmaz, K. (1983). Loss of self: a fundamental form of suffering in the chronically ill. *Sociology of health & illness*, *5*(2), 168-195. doi: 10.1111/1467-9566.ep10491512

Chiarello, L. A., Palisano, R. J., McCoy, S. W., Bartlett, D. J., Wood, A., Chang, H. J., ... & Avery, L. (2014). Child engagement in daily life: a measure of participation for young children with cerebral palsy. *Disability & rehabilitation*, *36*(21), 1804-1816. doi: 10.3109/09638288.2014.882417

Chun, S., & Lee, Y. (2013). “I am just thankful”: the experience of gratitude following traumatic spinal cord injury. *Disability & rehabilitation*, *35*(1), 11-19. doi: 10.3109/09638288.2012.687026

CLAHRC East of England (2018). *Researching the IMPlementation and evaluation of Patient and Public Involvement (PPI) in CLAHRC East of England RESearch (IMPRESS)*. Retrieved December 12, 2020 from https://www.clahrc-eoe.nihr.ac.uk/2015/03/researching-the-implementation-and-evaluation-of-patient-and-public-involvement-ppi-in-clahrc-east-of-england-research-impress/

Clinical rehabilitation (2020). Journal description. Retrieved December 12, 2020 from https://journals.sagepub.com/description/cre

Clifton, S. (2014). Grieving my broken body: An autoethnographic account of spinal cord injury as an experience of grief. *Disability & rehabilitation*, *36*(21), 1823-1829. doi: 10.3109/09638288.2013.872202

Coleman-Fountain, E., & McLaughlin, J. (2013). The interactions of disability and impairment. *Social Theory & Health*, *11*(2), 133-150. doi: 10.1057/sth.2012.21

Cohen, E. (2012). From phantoms to prostheses. *Disability studies quarterly*, *32*(3). Retrieved from https://dsq-sds.org/article/view/3269. doi: 10.18061/dsq.v32i3.3269

Colver, A. F., Dickinson, H. O., Parkinson, K., Arnaud, C., Beckung, E., Fauconnier, J., ... & Thyen, U. (2011). Access of children with cerebral palsy to the physical, social and attitudinal environment they need: a cross-sectional European study. *Disability & rehabilitation*, *33*(1), 28-35. doi: 10.3109/09638288.2010.485669

Cooper, H. (2020). *Critical disability studies and the disabled child: Unsettling distinctions*. London: Routledge.

Cooper, H. (2017). [Review of the book *Rehabilitation: A post-critical approach*, by B. E. Gibson]. *Disability & society*, 32(5), pp. 759–760. doi: 10.1080/09687599.2017.1309140

Cooper, H. (2015). *Making the disabled child: Critical disability studies at the intersection of cultural representation and lived experience* [Unpublished doctoral dissertation]. Birkbeck, University of London.

Corbin Dwyer, S., & Buckle, J. L. (2009). The space between: On being an insider-outsider in qualitative research. *International journal of qualitative methods*, *8*(1), 54-63. doi: 10.1177/160940690900800105

Costa, A. C., & Abreu, M. V. (2018). Expressive and creative writing in the therapeutic context: From the different concepts to the development of writing therapy programs. *Psychologica*, *61*(1), 69-86. doi: 10.14195/1647-8606_61-1_4

Coventry, P. A., Dickens, C., & Todd, C. (2014). How does mental–physical multimorbidity express itself in lived time and space? A phenomenological analysis of encounters with depression and chronic physical illness. *Social science & medicine*, *118*, 108-118. doi: 10.1016/j.socscimed.2014.07.068

Craig, A., Tran, Y., & Middleton, J. (2009). Psychological morbidity and spinal cord injury: a systematic review. *Spinal cord*, *47*(2), 108-114. doi: 10.1038/sc.2008.115

Creswell, J. W., & Poth, C. N. (2016). *Qualitative inquiry and research design: Choosing among five approaches* (3rd ed.). London: Sage.

Crisp, R. (2000). A qualitative study of the perceptions of individuals with disabilities concerning health and rehabilitation professionals. *Disability & society*, *15*(2), 355-367. doi: 10.1080/09687590025720

Crow, L. (2014). Scroungers and superhumans: Images of disability from the summer of 2012: A visual inquiry. *Journal of visual culture*, *13*(2), 168-181. doi: 10.1177/1470412914529109

Curran, T., & Runwick-Cole, K. (Eds.) (2013). *Disabled children's childhood studies: Critical approaches in a global context*. Basingstoke: *Palgrave* MacMillan.

Cussen, A., Howie, L., & Imms, C. (2012). Looking to the future: adolescents with cerebral palsy talk about their aspirations–a narrative study. *Disability & rehabilitation*, *34*(24), 2103-2110. doi: 10.3109/09638288.2012.672540

Damgård, R., Sørensen, K., Vestrheim, I. E., Lerdal, B., Skranes, J., & Rohde, G. (2016). Optimism and sense of coherence in mothers and fathers of children with cerebral palsy participating in an intensified habilitation programme. *Scandinavian journal of disability research*, *18*(3), 245-255. doi: 10.1080/15017419.2015.1064025

Danieli, A., & Woodhams, C. (2005). Emancipatory research methodology and disability: A critique. *International journal of social research methodology*, *8*(4), 281-296. doi: 10.1080/1364557042000232853

Darcy, S., Maxwell, H., & Green, J. (2016). Disability citizenship and independence through mobile technology? A study exploring adoption and use of a mobile technology platform. *Disability & society*, *31*(4), 497-519. doi: 10.1080/09687599.2016.1179172

Davis, L. J. (1995). *Enforcing normalcy: Disability, deafness, and the body*. London and New York: Verso.

Dépelteau, F. (2008). Relational thinking: A critique of co-deterministic theories of structure and agency. *Sociological theory*, *26*(1), 51-73. doi: 10.1111/j.1467-9558.2008.00318.x

Desjardins, M., Ville, I., & Mazurik, K. (2014). De quelques constructions théoriques et méthodologiques des obstacles à la participation sociale, le cas du projet CRIR-Living lab vivant. *Alter*, 8(3), 141-145. doi: 10.1016/j.alter.2014.05.002

Dew, A., Llewellyn, G., & Balandin, S. (2014). Exploring the later life relationship between adults with cerebral palsy and their non-disabled siblings. *Disability & rehabilitation*, *36*(9), 756-764. doi: 10.3109/09638288.2013.816786

Dickinson, H. O., Colver, A., & Sparcle Group. (2011). Quantifying the physical, social and attitudinal environment of children with cerebral palsy. *Disability & rehabilitation*, *33*(1), 36-50. doi: 10.3109/09638288.2010.485668

Disability & Rehabilitation (2020). Aims and scope. Retrieved December 12, 2020 from https://www.tandfonline.com/action/journalInformation?show=aimsScope&journalCode=idre20

Disability & society (2020). Aims and scope. Retrieved December 9, 2020 from https://www.tandfonline.com/action/journalInformation?show=aimsScope&journalCode=cdso20

Duffy, S. (2013). *A fair society? How the cuts target disabled people*. Sheffield: Centre for Welfare Reform.

Edelist, T. (2015). Listen and speak: Power-knowledge-truth and Cochlear implants in Toronto. *Disability studies quarterly*, *35*(1). Retrieved from https://dsq-sds.org/article/view/4312. doi: 10.18061/dsq.v35i1.4312

Edelman, L. (2004). *No future: Queer theory and the death drive.* Durham, NC: Duke University Press.

Eklund Nilsen, A. C., & Jensen, H. C. (2012). Cooperation and coordination around children with individual plans. *Scandinavian journal of disability research*, *14*(1), 1-14. doi: 10.1080/15017419.2010.507376

Emirbayer, M. (1997). Manifesto for a relational sociology. *American journal of sociology*, *103*(2), 281-317. doi: 10.1086/231209

Emmel, N. (2013). *Sampling and choosing cases in qualitative research: A realist approach*. London: Sage.

Evans, J. (2002). *The independent living movement in the UK*. Retrieved from https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/evans-Version-2-Independent-Living-Movement-in-the-UK.pdf

Evans, P. (2000). Boundary oscillations: epistemological and genre transformation during the 'method' of thesis writing. *International journal of social research methodology*, *3*(4), 267-286. doi: 10.1080/13645570050178576

Fatudimu, M. B., Hamzat, T. K., & Akinyinka, O. O. (2013). Comparative quality of life of Nigerian caregivers of children with cerebral palsy. *International journal of therapy & rehabilitation*, *20*(3), 131-135. doi: 10.12968/ijtr.2013.20.3.131

Finkelstein, V. (2004). Representing Disability. In J. Swain, S. French, C. Barnes, & C. Thomas (Eds.), *Disabling barriers – Enabling* *environments* (2nd ed.) (pp. 13-20). London: Sage. doi: 10.1017/S0047279406379779

Flaherty, M. G. (2003). Time work: Customizing temporal experience. *Social psychology quarterly*, *66*(1) 17-33. doi: 10.2307/3090138

Fleischer, D., & Zames, F. (2011). *The disability rights movement*: *From charity to confrontation* (Updated ed.). Philadelphia: Temple University Press.

Foucault, M. (2003). *"Society must be defended": Lectures at the Collège de France, 1975-1976* (Vol. 1). Basingstoke: Macmillan.

Frakt, A., & Nerenz, D. (Eds.) (2020). Drivers of health [Special issue]. *Health services research*, *55*(S2).

Frank, A. W. (1995). *The wounded storyteller: Body, illness, and ethics*. Chicago: University of Chicago Press. doi: 10.7208/chicago/9780226260037.001.0001

Fraser, S., Valentine, K. and Seear, K. (2018 [2016]). Emergent publics of alcohol and other drug policymaking. *Critical policy studies, 12*(1), 61-81. doi: 10.1080/19460171.2016.1191365

French, S. (1988). Experiences of disabled health and caring professionals. *Sociology of health & illness*, *10*(2), 170-188. doi: 10.1111/1467-9566.ep11339941

Fricker, M. (2007). *Epistemic injustice: Power and the ethics of knowing*. Oxford: Oxford University Press.

Fritz, H. A., Lysack, C., Luborsky, M. R., & Messinger, S. D. (2015). Long-term community reintegration: concepts, outcomes and dilemmas in the case of a military service member with a spinal cord injury. *Disability & rehabilitation*, *37*(16), 1501-1507. doi: 10.3109/09638288.2014.967415

Gannotti, M. E., Minter, C. L., Chambers, H. G., Smith, P. A., & Tylkowski, C. (2011). Self-concept of adults with cerebral palsy. *Disability & rehabilitation*, *33*(10), 855-861. doi: 10.3109/09638288.2010.514017

Gaskin, C. J., Andersen, M. B., & Morris, T. (2012). Physical activity in the life of a woman with cerebral palsy: Physiotherapy, social exclusion, competence, and intimacy. *Disability & society*, *27*(2), 205-218. doi: 10.1080/09687599.2011.644931

Gibson, B. (2018). Author reflection: Rehabilitation: A post-critical approach. *Journal of humanities in rehabilitation*. Retrieved from https://www.jhrehab.org/2018/04/30/author-reflection-rehabilitation-a-post-critical-approach/

Gibson, B. (2015). *Rehabilitation: A post-critical approach*. Florida: Taylor and Francis Group. doi: 10.1201/b19085

Giddens, A. (1984). *The constitution of society: Outline of the theory of structuration*. Berkeley and Los Angeles: University of California Press.

Glintborg, C., Mateu, N. C., & Høgsbro, K. (2016). Contradictions and conflicts in brain injury rehabilitation. A systematic inquiry into models of rehabilitation. *Scandinavian journal of disability research*, *18*(4), 369-383. doi: 10.1080/15017419.2016.1182943

Goffman, E. (1963). *Stigma: Notes on the management of a spoiled identity*. Englewood Cliffs, NJ: Prentice-Hall.

Goodley, D. (2011). *Disability studies: An interdisciplinary introduction*. London: Sage.

Goodridge, D., Rogers, M., Klassen, L., Jeffery, B., Knox, K., Rohatinsky, N., & Linassi, G. (2015). Access to health and support services: perspectives of people living with a long-term traumatic spinal cord injury in rural and urban areas. *Disability & rehabilitation*, *37*(16), 1401-1410. doi: 10.3109/09638288.2014.972593

Grasso, F., Desjardins, M., Labbé, D., Barbic, S., & Kehayia, E. (2014). Opérationnaliser l'inclusion dans les projets innovants. L'expérience du «MALL» à l'aune de la classification internationale du fonctionnement. *Alter*, *8*(3), 158-169. doi: 10.1016/j.alter.2014.04.002

Greenhalgh, T. (2016). *Cultural contexts of health: the use of narrative research in the health sector.* Copenhagen: WHO Regional Office for Europe.

Greenhalgh, T. (1999). Writing as therapy. *BMJ*, *319*, 270. doi: 10.1136/bmj.319.7205.270

Greenhalgh, T., & Hurwitz, B. (1999). Why Study Narrative? Narrative Based Medicine. *BMJ*, *318*(7175), 48-50. doi: 10.1136/bmj.318.7175.48

Griffiths, R. (1988). *Community care: Agenda for action. A report to the secretary of state for social services*. London: HMSO.

Guilcher, S. J., Craven, B. C., McColl, M. A., Lemieux-Charles, L., Casciaro, T., & Jaglal, S. B. (2012). Application of the Andersen's health care utilization framework to secondary complications of spinal cord injury: a scoping review. *Disability & rehabilitation*, *34*(7), 531-541. doi: 10.3109/09638288.2011.608150

Hamed, N. S., & Abd-elwahab, M. S. (2011). Pedometer-based gait training in children with spastic hemiparetic cerebral palsy: a randomized controlled study. *Clinical rehabilitation*, *25*(2), 157-165. doi: 10.1177/0269215510382147

Hammell, K. W. (2006). *Perspectives on disability and rehabilitation*. London: Churchill Livingstone.

Hanga, K., DiNitto, D. M., Wilken, J. P., & Leppik, L. (2017). A person-centered approach in initial rehabilitation needs assessment: Experiences of persons with disabilities. *Alter*, *11*(4), 251-266. Doi: 10.1016/j.alter.2017.06.002

Hardeman, R. R., & Karbeah, J.M. (2020). Examining racism in health services research: A disciplinary self-critique. *Health Services Research*, *55*(Suppl 2), 777. doi: 10.1111/1475-6773.13558

Harrison, M. (2013, December 2). Let disabled people speak for themselves. *The Guardian*. https://www.theguardian.com/society/2013/dec/02/disabled-people-speak-for-themselves

Hawk, B. (2018). Prosthesis: From grammar to medicine in the earliest history of the word. *Disability studies quarterly*, *34*(4). Retrieved from https://dsq-sds.org/article/view/5398/5132.

Hay-Smith, E. J. C., Dickson, B., Nunnerley, J., & Anne Sinnott, K. (2013). “The final piece of the puzzle to fit in”: an interpretative phenomenological analysis of the return to employment in New Zealand after spinal cord injury. *Disability & rehabilitation*, *35*(17), 1436-1446. doi: 10.3109/09638288.2012.737079

Hearn, J. H., Cotter, I., Fine, P., & A. Finlay, K. (2015). Living with chronic neuropathic pain after spinal cord injury: an interpretative phenomenological analysis of community experience. *Disability &*

rehabilitation, *37*(23), 2203-2211. doi: 10.3109/09638288.2014.1002579

Hemming, L. (n.d.). Who are the ‘experts by experience’ in mental health research? [blog post]. Retrieved from https://mcpin.org/who-are-the-experts-by-experience-in-mental-health-research-a-personal-reflection/

Hennink, M. M. (2007). *International focus group research: A handbook for the health and social sciences*. Cambridge: Cambridge University Press.

Herrero, P., Gómez-Trullén, E. M., Asensio, Á., García, E., Casas, R., Monserrat, E., & Pandyan, A. (2012). Study of the therapeutic effects of a hippotherapy simulator in children with cerebral palsy: a stratified single-blind randomized controlled trial. *Clinical rehabilitation*, *26*(12), 1105-1113. doi: 10.1177/0269215512444633

Hirsche, R. C., Williams, B., Jones, A., & Manns, P. (2011). Chronic disease self-management for individuals with stroke, multiple sclerosis and spinal cord injury. *Disability & rehabilitation*, *33*(13-14), 1136-1146. doi: 10.3109/09638288.2010.523103

Hodge, S. (2005). Participation, discourse and power: a case study in service user involvement. *Critical social policy*, *25*(2), 164-179. doi: 10.1177/0261018305051324

Hogg, C. N. (2007). Patient and public involvement: what next for the NHS?. *Health expectations*, *10*(2), 129-138. doi: 10.1111/j.1369-7625.2006.00427.x

Hollway, W., & Jefferson, T. (2012). *Doing qualitative research differently: A psychosocial approach* (2nd ed.). London: Sage.

Hoogsteyns, M., & Van Der Horst, H. (2013). Wearing the arm (or not). Reconceptualising notions of in-and exclusion in Disability Studies. *Scandinavian journal of disability research*, *15*(1), 58-69. doi: 10.1080/15017419.2012.679687

Horton, S., Lane, K., & Shiggins, C. (2016). Supporting communication for people with aphasia in stroke rehabilitation: transfer of training in a multidisciplinary stroke team. *Aphasiology*, *30*(5), 629-656. doi: 10.1080/02687038.2014.1000819

Horton, S., & Wellings, A. (2014) Perspectives on a student-stroke survivor research collaboration. Paper/poster presented at INVOLVE, Changing Landscapes, 26-27 November, 2014. Retrieved from: https://www.invo.org.uk/posttypeconference/perspectives-on-a-student-stroke-survivor-research-collaboration/

Huang, I. C., Wang, Y. T., & Chan, F. (2013). Employment outcomes of adults with cerebral palsy in Taiwan. *Disability & rehabilitation*, *35*(3), 228-235. doi: 10.3109/09638288.2012.691935

Hunter, J., Franken, M., & Balmer, D. (2015). Constructions of patient agency in healthcare settings: Textual and patient perspectives. *Discourse, context & media*, *7*, 37-44. doi: 10.1016/j.dcm.2015.01.002

Hurwitz, B., Cushing, A., & Chisnall, B. (2012). Narrative medicine. *BMJ*, *344*. doi: 10.1136/sbmj.e2743

Hutton, E., & King, A. (2018). Parent/carer views on personal health budgets for disabled children who use rehabilitation therapy services. *Disability & society*, *33*(2), 254-271. doi: 10.1080/09687599.2017.1398636

Inahara, M. (2013). The rejected voice: towards intersubjectivity in speech language pathology. *Disability & Society*, *28*(1), 41-53. doi: 10.1080/09687599.2012.695524

International journal of therapy & rehabilitation (2020). About. Retrieved December 12, 2020 from https://www.magonlinelibrary.com/page/ijtr/about

INVOLVE (2020a). website: www.invo.org.uk

INVOLVE (2020b). *What is public involvement in research*. Retrieved December 14, 2020 from http://www.invo.org.uk/find-out-more/what-is-public-involvement-in-research-2/

INVOLVE (2018). *Guidance on co-producing a research project*. Retrieved from https://www.invo.org.uk/wp-content/uploads/2019/04/Copro_Guidance_Feb19.pdf

INVOLVE (2013a). *Bridging the gap between memory decline and medication in Parkinson's disease (PD)*. Retrieved from https://www.invo.org.uk/wp-content/uploads/2013/10/Example1-publicinvolvement-in-funding-app2013-2.pdf

INVOLVE (2013b). *Optimising adult mental health service configurations across health and social care*. Retrieved from https://www.invo.org.uk/optimising-adult-mental-health-service-configurations-across-health-and-social-care/

INVOLVE (2013c). *Health care innovations from policy to practice: A case study of rapid HIV testing in General Practice*. Retrieved from https://www.invo.org.uk/wp-content/uploads/2013/11/Example-10-public-involvement-in-a-funding-application-2013.pdf

INVOLVE (2013d). *Supporting Excellence in End of life care in Dementia – SEED programme*. Retrieved from https://www.invo.org.uk/wp-content/uploads/2013/10/Example-8-public-involvement-in-funding-app-20131.pdf

INVOLVE (2013e). *Exploring the impact of public involvement on the quality of research: examples*. Retrieved from https://www.invo.org.uk/wp-content/uploads/2014/11/INVOLVEExploringImpactQualityResearchExamples_updated-July-2014.pdf

INVOLVE (2012). *Briefing notes for researchers: Public involvement in NHS, public health and social care research*. Eastleigh: INVOLVE. Retrieved from https://www.invo.org.uk/wp-content/uploads/2014/11/9938_INVOLVE_Briefing_Notes_WEB.pdf

Jannings, W., & Pryor, J. (2012). The experiences and needs of persons with spinal cord injury who can walk. *Disability & rehabilitation*, *34*(21), 1820-1826. doi: 10.3109/09638288.2012.665126

Järvikoski, A., Puumalainen, J., & Härkäpää, K. (2015). Client participation in medical rehabilitation for adults with severe disabilities. *Scandinavian journal of disability research*, *17*(3), 240-257. doi: 10.1080/15017419.2013.859176

Jonasson, M. (2014). The AKKA-board–performing mobility, disability and innovation. *Disability & society*, *29*(3), 477-490. doi: 10.1080/09687599.2013.823079

Kafer, A. (2013). *Feminist, queer, crip*. Bloomington and Indianapolis: Indiana University Press.

Kaushik, V. & Walsh, C. (2019). Pragmatism as a research paradigm and its implications for social work research. *Social sciences*, *8*(255), 1-17. doi: 10.3390/socsci8090255

Keenan, J., Poland, F., Boote, J., Howe, A., Wythe, H., Varley, A., ... & Wellings, A. (2019). ‘We’re passengers sailing in the same ship, but we have our own berths to sleep in’: Evaluating patient and public involvement within a regional research programme: An action research project informed by Normalisation Process Theory. *PloS ONE*, *14*(5), e0215953. doi: 10.1371/journal.pone.0215953

Kehayia, E., Swaine, B., Longo, C., Ahmed, S., Archambault, P., Fung, J., ... & Overbury, O. (2014). Creating a rehabilitation living lab to optimize participation and inclusion for persons with physical disabilities. *Alter*, *8*(3), 151-157. doi: 10.1016/j.alter.2014.03.006

Keyes, S.E., Webber, S.H., & Beveridge, K. (2015). Empowerment through care: Using dialogue between the social model of disability and an ethic of care to redraw boundaries of independence and partnership between disabled people and services. *Alter, 9*(3), 236-248. doi: 10.1016/j.alter.2015.05.002

Kim, H. R., & Shin, H. I. (2012). When is it appropriate to deliver a prognosis to Korean persons with acute spinal cord injury? *Disability & rehabilitation*, *34*(16), 1396-1403. doi: 10.3109/09638288.2011.637605

Koch, T., & Kralik, D. (2006). *Participatory action research in healthcare*. Oxford: Blackwell.

Kwek, E., & Choi, M. (2016). Is a prosthetic arm customized PRADA? A critical perspective on the social aspects of prosthetic arms. *Disability & society*, *31*(8), 1144-1147. doi: 10.1080/09687599.2016.1235308.

Lancaster, K., Seear, K., Treloar, C., & Ritter, A. (2017). The productive techniques and constitutive effects of ‘evidence-based policy’and ‘consumer participation’discourses in health policy processes. *Social science & medicine*, *176*, 60-68. doi: 10.1016/j.socscimed.2017.01.031

Lapadat, J. C., & Lindsay, A. C. (1999). Transcription in research and practice: From standardization of technique to interpretive positionings. *Qualitative inquiry*, *5*(1), 64-86. doi: 10.1177/107780049900500104

Latour, B. (2005). *Reassembling the social: An introduction to actor-network theory*. Oxford: Oxford University Press.

Lauruschkus, K., Nordmark, E., & Hallström, I. (2015). “It’s fun, but…” Children with cerebral palsy and their experiences of participation in physical activities. *Disability & rehabilitation*, *37*(4), 283-289. doi: 10.3109/09638288.2014.915348

Law, J. (2004). *After method: Mess in social science research.* Abingdon, Oxon: Routledge.

Leavy, P. (2009). *Method meets art: Arts-based research practice*. New York: The Guilford Press.

Leder, D. (1990). *The absent body*. Chicago: University of Chicago Press.

Lerdal, B., Sørensen, K., Vestrheim, I. E., & Skranes, J. (2012). Parental effects from participation in an intensified multimodal programme of habilitation for children with cerebral palsy. *Scandinavian journal of disability research*, *14*(1), 30-39. doi: 10.1080/15017419.2010.507385

Letherby, G. (2003). *Feminist research in theory and practice*. McGraw-Hill Education (UK). Buckingham: Open University Press.

Letherby, G., Scott, J., & Williams, M. (2013). *Subjectivity and objectivity in social research*. London: Sage.

Lindsay, S., & McPherson, A. C. (2012). Experiences of social exclusion and bullying at school among children and youth with cerebral palsy. *Disability & rehabilitation*, *34*(2), 101-109. doi: 10.3109/09638288.2011.587086

Löfgren, M., & Norrbrink, C. (2012). “But I know what works” – patients’ experience of spinal cord injury neuropathic pain management. *Disability & rehabilitation*, *34*(25), 2139-2147. doi: 10.3109/09638288.2012.676146

Löfvenmark, I., Norrbrink, C., Nilsson Wikmar, L., & Löfgren, M. (2016). ‘The moment I leave my home–there will be massive challenges’: Experiences of living with a spinal cord injury in Botswana. *Disability & rehabilitation*, *38*(15), 1483-1492. doi: 10.3109/09638288.2015.1106596

Long, S. (2015). Squashed dreams and rare breeds: Ableism and the arbiters of life and death. *Disability & Society*, *30*(7), 1118-1122. doi: 10.1080/09687599.2015.1070544

Lopes, E., Carter, D., & Street, J. (2015). Power relations and contrasting conceptions of evidence in patient-involvement processes used to inform health funding decisions in Australia. *Social science & medicine*, *135*, 84-91. doi: 10.1016/j.socscimed.2015.04.021

Löve, L., Traustadóttir, R., & Rice, J. G. (2018). Trading autonomy for services: Perceptions of users and providers of services for disabled people in Iceland. *Alter*, *12*(4), 193-207. doi: 10.1016/j.alter.2018.04.008

Maggs, J., Palisano, R., Chiarello, L., Orlin, M., Chang, H. J., & Polansky, M. (2011). Comparing the priorities of parents and young people with cerebral palsy. *Disability & rehabilitation*, *33*(17-18), 1650-1658. doi: 10.3109/09638288.2010.542875

Mason, J. (2018). *Qualitative researching*. London: Sage.

Matt, S. (2014). Perceptions of disability among caregivers of children with disabilities in Nicaragua: Implications for future opportunities and health care access. *Disability studies quarterly, 34*(4). Retrieved from https://dsq-sds.org/article/view/3863. doi: 10.18061/dsq.v34i4.3863

Mattar, A. A., Hitzig, S. L., & McGillivray, C. F. (2015). A qualitative study on the use of personal information technology by persons with spinal cord injury. *Disability & rehabilitation*, *37*(15), 1362-1371. doi: 10.3109/09638288.2014.963708

McCoy, L. (2009). Time, self and the medication day: a closer look at the everyday work of ‘adherence’. *Sociology of health & illness*, *31*(1), 128-146. doi: 10.1111/j.1467-9566.2008.01120.x

McKeever , P., Rossen, B. E., Scott, H., Robinson-Vincent, K., & Wright, V. (2013). The significance of uprightness: Parents’ reflections on children’s responses to a hands-free walker for children. *Disability & society, 28*(3), 380-392. doi: 10.1177/0038038504040867

McLuhan, M. (1964). *Understanding media: The extensions of man*. New York: McGraw-Hill.

McRuer, R. (2006). *Crip theory*. New York: New York University Press.

Mei, C., Reilly, S., Reddihough, D., Mensah, F., Green, J., Pennington, L., & Morgan, A. T. (2015). Activities and participation of children with cerebral palsy: parent perspectives. *Disability & rehabilitation*, *37*(23), 2164-2173. doi: 10.3109/09638288.2014.999164

Merleau-Ponty, M. (2002 [1962]). *Phenomenology of perception* (C. Smith, Trans.). London: Routledge.

Mills, C. W. (2000 [1959]). *The sociological imagination*. Oxford: Oxford University Press.

Mind (2020). *Expert by experience*. Retrieved December 1, 2020 from https://www.mind.org.uk/information-support/expert-by-experience/

Moll, L. R., & Cott, C. A. (2013). The paradox of normalization through rehabilitation: growing up and growing older with cerebral palsy. *Disability & rehabilitation*, *35*(15), 1276-1283. doi: 10.3109/09638288.2012.726689

Mollow, A. (2012). Is sex disability? Queer theory and the disability drive. In R. McRuer, R., & A. Mollow (Eds.), *Sex and disability* (pp. 285–312). Durham, NC: Duke University Press.

Morgan, D. J., Boniface, G. E., & Reagon, C. (2016). The effects of adapting their home on the meaning of home for families with a disabled child. *Disability & society*, *31*(4), 481-496. doi: 10.1080/09687599.2016.1183475

Morgan, D. L. (2014). Pragmatism as a paradigm for social research. *Qualitative inquiry*, *20*(8), 1045-1053. doi: 10.1177/1077800413513733

Morse, J. (2012). The implications of interview type and structure in mixed-method designs. In J. F. Gubrium, J. A. Holstein, A. B. Marvasti, & K. D. McKinney (Eds.), *The Sage handbook of interview research: The complexity of the craft* (pp. 193-205). Thousand Oaks, CA: SAGE. doi: 10.4135/9781452218403

Moustakas, C. (1994). *Phenomenological research methods*. London: Sage. doi: 10.4135/9781412995658

Nadeau, L., & Tessier, R. (2011). Self-concept in children with cerebral palsy: is there something in the wind? *Disability & rehabilitation*, *33*(10), 830-834. doi: 10.3109/09638288.2010.513421

National Institute for Health Research [NIHR] (2014). *Patient and public involvement in health and social care research: A handbook for researchers*. Retrieved from https://www.rds-yh.nihr.ac.uk/wp-content/uploads/2015/01/RDS_PPI-Handbook_2014-v8-FINAL-11.pdf

National Institute for Health Research [NIHR] (n.d.). Enabling people with aphasia to participate in research' section, under the 'Our Support' tab on this page https://www.nihr.ac.uk/explore-nihr/specialties/stroke.htm

Ndi, A. (2012). Setting the stage of 'ab/normality'in rehabilitative narratives: Rethinking medicalization of the disabled African body. *Disability studies quarterly*, *32*(2). Retrieved from https://dsq-sds.org/article/view/3195. doi: 10.18061/dsq.v32i2.3195

Needham, C., & Carr, S. (2009). *SCIE research briefing 31: Co-production: An emerging evidence base for adult social care transformation*. London: Social Care Institute for Excellence. Retrieved from http://www.scie.org.uk/publications/briefings/briefing31/.

New Economics Foundation (2008). *Co-production: A manifesto for growing the core economy*. London: New Economics Foundation.

NHS Improvement (n.d.). *Valued care in mental health: Improving for excellence*. Retrieved from https://improvement.nhs.uk/documents/3453/NHS_Mental_Health_Improvement_web.pdf

Norrbrink, C., & Löfgren, M. (2016). Needs and requests–patients and physicians voices about improving the management of spinal cord injury neuropathic pain. *Disability & rehabilitation*, *38*(2), 151-158. doi: 10.3109/09638288.2015.1035456

Nygren-Bonnier, M., Normi, L. L., Klefbeck, B., & Biguet, G. (2011). Experiences of decreased lung function in people with cervical spinal cord injury. *Disability & rehabilitation*, *33*(6), 530-536. doi: 10.3109/09638288.2010.505995

Nyssen, O. P., Taylor, S. J., Wong, G., Steed, E., Bourke, L., Lord, J., ... & Greenhalgh, T. (2016). Does therapeutic writing help people with long-term conditions? Systematic review, realist synthesis and economic considerations. *Health Technology Assessment*, *20*(27), 1-368. doi: 10.3310/hta20270

Oliver, M. (1983). *Social work with disabled people.* London: Macmillan.

Oliver, M. (1990). *The politics of disablement*. Basingstoke: Macmillan.

Oliver, M. (1992). Changing the social relations of research production?. *Disability, handicap & society*, *7*(2), 101-114. doi: 10.1080/02674649266780141

Oliver, M. (1993, February). *What's so wonderful about walking?* Inaugural professorial lecture, University of Greenwich, London. Retrieved from http://disability-studies.leeds.ac.uk/files/library/Oliver-PROFLEC.pdf

Oliver, S., Clarke-Jones, L., Rees, R., Milne, R., Buchanan, P., Gabbay, J., … & Stein, K. (2004). Involving consumers in research and development agenda setting for the NHS: Developing an evidence-based approach. *Health technology assessment*, *8*(15), 1-148. doi: 10.3310/hta8150

Oxford University Press (2005). Patient. In *Oxford English Dictionary*. Oxford: Oxford University Press.

Papadimitriou, C. (2008). Becoming en-wheeled: the situated accomplishment of re-embodiment as a wheelchair user after spinal cord injury. *Disability & society*, *23*(7), 691-704. doi: 10.1080/09687590802469420

Papadimitriou, C., & Stone, D. A. (2011). Addressing existential disruption in traumatic spinal cord injury: a new approach to human temporality in inpatient rehabilitation. *Disability & rehabilitation*, *33*(21-22), 2121-2133. doi: 10.3109/09638288.2011.555597

Parr, S. (2007). Living with severe aphasia: Tracking social exclusion. *Aphasiology*, *21*(1), 98-123. doi: 10.1080/02687030600798337

Parsons, T. (1951). *The social system.* New York: Free Press.

Pennebaker, J. (2011). *The secret life of pronouns: What our words say about us*. London: Bloomsbury.

Pennebaker, J. W. (1997). Writing about emotional experiences as a therapeutic process. *Psychological Science*, *8*(3), 162-166. doi: 10.1111/j.1467-9280.1997.tb00403.x

Perrier, M. J., Smith, B. M., & Latimer-Cheung, A. E. (2013). Narrative environments and the capacity of disability narratives to motivate leisure-time physical activity among individuals with spinal cord injury. *Disability & rehabilitation*, *35*(24), 2089-2096. doi: 10.3109/09638288.2013.821179

Petersen, K., Borg, T., Hounsgaard, L., & Vinther Nielsen, C. (2012). Learning via participation–a user perspective on user involvement in mental health rehabilitation. *Scandinavian journal of disability research*, *14*(2), 97-112. doi: 10.1080/15017419.2010.540927

Plummer, K. (1995). *Telling sexual stories: Power, change and social worlds*. London: Routledge.

Pozzebon, M. (2008). Structuration theory. In R. Thorpe, & R. Holt (Eds.), *The Sage dictionary of qualitative management research* (p. 216). London: Sage. doi: 10.4135/9780857020109.n102

Puar, J. (2017). *The right to maim: Debility, capacity, disability*. Durham, NC: Duke University Press.

Puar, J. (2015). The "right" to maim: Disablement and inhumanist biopolitics in Palestine. *Borderlands e-journal*, *14*(1), 1–27. Retrieved from www.borderlands.net.au/vol14no1_2015/puar_maim.pdf

Reason, P. & Bradbury, H. (2001). *Handbook of action research: Participative inquiry and practice*. London: SAGE Publications Ltd.

Riyahi, A., Rassafiani, M., AkbarFahimi, N., Sahaf, R., & Yazdani, F. (2013). Cross-cultural validation of the Persian version of the Manual Ability Classification System for children with cerebral palsy. *International journal of therapy & rehabilitation*, *20*(1), 19-24. doi: 10.12968/ijtr.2013.20.1.19

Røberg, A. S. B., Feiring, M., & Romsland, G. I. (2017a). Norwegian rehabilitation policies and the coordination reform's effect: a critical discourse analysis. *Scandinavian journal of disability research*, *19*(1), 56-68. doi: 10.1080/15017419.2016.1196242

Røberg, A. S. B., Hansen, H. P., Feiring, M., & Romsland, G. I. (2017b). Rehabilitation in momentum of Norwegian coordination reform: From practices of discipline to disciplinary practices. *Alter*, *11*(3), 193-207. doi: 10.1016/j.alter.2017.05.003

Rose, N. (1999). *Governing the soul: The shaping of the private self*. (2nd ed.). London: Routledge.

Runswick-Cole, K., Curran, T., & Liddiard, K. (Eds.) (2018). *The Palgrave handbook of disabled children's childhood studies*. London: Palgrave Macmillan.

Salecl, R. (2010). *The tyranny of choice*. London: Profile.

Sampson, F. (2004). *Creative writing in health and social care*. London: Jessica Kingsley Publishers.

Scandinavian journal of disability research (2020). Focus and scope. Retrieved December 9, 2020 from https://www.sjdr.se/about/

Scarry, E. (1985). *The body in pain: The making and unmaking of the world.* Oxford: Oxford University Press.

Schneider, M., & Young, N. (2010). “So this is my new life”: a qualitative examination of women living with multiple sclerosis and the coping strategies they use when accessing physical activity. *Disability studies quarterly*, *30*(3/4). Retrieved from https://dsq-sds.org/article/view/1269. doi: 10.18061/dsq.v30i3/4.1269

Scourfield, P. (2007). Social care and the modern citizen: client, consumer, service user, manager and entrepreneur. *British journal of social work*, *37*(1), 107-122. doi: 10.1093/bjsw/bch346

Sennett, R. (2008). *The craftsman*. London: Penguin, Allen Lane.

Shakespeare, T. (2014). *Disability rights and wrongs revisited* (2nd ed.). Abingdon, Oxon: Routledge.

Shakespeare, T. (2004). Social models of disability and other life strategies. *Scandinavian journal of disability research*, *6*(1), 8-21. doi: 10.1080/15017410409512636

Shakespeare, T. (2000). Helpful. In T. Shakespeare (Ed.) *Help* (pp. 63-84*)*. Birmingham: Venture Press. Retrieved from: https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/Shakespeare-help4.pdf

Shakespeare, T. (1996a). Rules of engagement: doing disability research. *Disability & society*, *11*(1), 115-121. Doi: 10.1080/09687599650023380

Shakespeare, T. (1996b). Disability, identity and difference. In C. Barnes, & G. Mercer (Eds.), *Exploring the divide: Illness and disability* (pp. 94-113). Leeds: Disability Press.

Shakespeare, T., Cooper, H., Bezmez, D., & Poland, F. (2018). Rehabilitation as a disability equality issue: a conceptual shift for disability studies? *Social inclusion*, *6*(1), 61-72. doi: 10.17645/si.v6i1.1175

Shakespeare, T., Porter, T, Stöckl, A. (2017). *Personal assistance relationships: Power, ethics and emotions*. Report on ESRC-funded study, produced by the University of East Anglia.

Shakespeare, T., & Watson, N. (2010). Beyond models: Understanding the complexity of disabled people's lives. In G. Scambler, & S. Scambler (Eds.) *New directions in the sociology of chronic and disabling conditions* (pp. 57–77). London: Palgrave Macmillan.

Shakespeare, T., & Watson, N. (2001). The social model of disability: An outdated ideology? In S. Barnartt and B. Altman (Eds.), *Exploring theories and expanding methodologies: Where are we and where do* *we need to go?* (pp. 9-28). Bingley: Emerald Group. doi: 10.1016/S1479-3547(01)80018-X

Shakespeare, T., & Watson, N. (1997). Defending the social model. *Disability & society*, *12*(2), 293-300. doi: 10.1080/09687599727380

Shaping Our Lives (2021). website: https://www.shapingourlives.org.uk

Sherry, M. (2008). Insider/outsider status. In L. M. Given (Ed.), *The SAGE encyclopedia of qualitative research methods* (pp. 433-434). Thousand Oaks, CA: Sage. doi: 10.4135/9781412963909

Shikako-Thomas, K., Bogossian, A., Lach, L. M., Shevell, M., & Majnemer, A. (2013). Parents' perspectives on the quality of life of adolescents with cerebral palsy: trajectory, choices and hope. *Disability & rehabilitation*, *35*(25), 2113-2122. doi: 10.3109/09638288.2013.770083

Slettebø, Å., Hellem, E., Bruusgaard, K. A., Madsen, V. H., Alve, G., & Langhammer, B. (2012). Between power and powerlessness–discourses in the individual plan processes, a Norwegian dilemma. *Scandinavian journal of disability research*, *14*(3), 270-283. doi: 10.1080/15017419.2011.574846

Smith, B., Papathomas, A., Martin Ginis, K. A., & Latimer-Cheung, A. E. (2013). Understanding physical activity in spinal cord injury rehabilitation: Translating and communicating research through stories. *Disability & rehabilitation*, *35*(24), 2046-2055. doi: 10.3109/09638288.2013.805821

Smith, J., Jarman, M, & Osborn, M. (1999). Doing interpretative phenomenological analysis. In M. Murray & K. Chamberlain (Eds.), *Qualitative health psychology: Theories and methods* (pp. 218-240). London: Sage. doi: 10.4135/9781446217870

Smyth, J. M., Stone, A. A., Hurewitz, A., & Kaell, A. (1999). Effects of writing about stressful experiences on symptom reduction in patients with asthma or rheumatoid arthritis: A randomized trial. *Jama*, *281*(14), 1304-1309. doi: 10.1001/jama.281.14.1304

Snell, L. (2015). Documenting the lived experiences of young adult cochlear implant users:‘feeling’sound, fluidity and blurring boundaries. *Disability & society*, *30*(3), 340-352. doi: 10.1080/09687599.2015.1014086

Solheima, J., Kværner, K. J., Sandvik, L., & Falkenberg, E. S. (2012). Factors affecting older adults' hearing-aid use. *Scandinavian journal of disability research*, *14*(4), 300-312. doi: 10.1080/15017419.2011.640411

Sontag, S. (2002 [1978 and 1989]). *Illness as metaphor, and AIDS and its metaphors*. London: Penguin Classics.

Soundy, A., Stubbs, B., Freeman, P., Coffee, P., & Roskell, C. (2014). Factors influencing patients' hope in stroke and spinal cord injury: A narrative review. *International journal of therapy & rehabilitation*, *21*(5), 210-218. doi: 10.12968/ijtr.2014.21.5.210

Spartacus Network (2015). Spartacus Response to Cuts in ESA. Retrieved from http://www.centreforwelfarereform.org/library/categories/disability/spartacus-response-to-cuts-in-esa.html

Spivak, G. C. (1999). Can the subaltern speak? In C. Nelson, & L. Grossberg (Eds.), *Marxism and the interpretation of culture* (pp. 271-313). Urbana: University of Illinois Press.

Staley, K. (2009). *Exploring impact: Public involvement in NHS, public health and social care research*. Eastleigh: INVOLVE.

Stanley, L., & Wise, S. (1993). *Breaking out again: Feminist ontology and epistemology*. Abingdon, Oxon: Routledge.

Stewart, H., & Watson, N. (2020). A sociotechnical history of the ultralightweight wheelchair: A vehicle of social change. *Science, technology, & human values*, *45*(6), 1195-1219. doi: 10.1177/0162243919892558

Stiker, H. J. (1999 [1997]). *A history of disability*. Ann Arbor: University of Michigan Press.

Strazdins, L., Welsh, J., Korda, R., Broom, D., & Paolucci, F. (2016). Not all hours are equal: Could time be a social determinant of health?. *Sociology of Health & Illness*, *38*(1), 21-42. doi: 10.1111/1467-9566.12300

Strazdins, L., Griffin, A. L., Broom, D. H., Banwell, C., Korda, R., Dixon, J., ... & Glover, J. (2011). Time scarcity: Another health inequality?. *Environment and Planning A*, *43*(3), 545-559. doi: 10.1068/a4360

Stucki, G., Bickenbach, J., Gutenbrunner, C., & Melvin, J. (2018). Rehabilitation: the health strategy of the 21st century. *Journal of rehabilitation medicine*, *50*(4), 309-316. doi: 10.2340/16501977-2200

Swart, J., & Horton, S. (2015). From patients to teachers: The perspectives of trainers with aphasia in a UK Conversation Partner Scheme. *Aphasiology*, *29*(2), 195-213. doi: 10.1080/02687038.2014.961893

Tebbet, M., & Kennedy, P. (2012). The experience of childbirth for women with spinal cord injuries: an interpretative phenomenology analysis study. *Disability & rehabilitation*, *34*(9), 762-769. doi: 10.3109/09638288.2011.619619

Thornton, J. (2018). Patients with cerebral palsy are being failed on multiple levels. *BMJ: British medical journal (online)*, *360*. Retrieved from https://www.bmj.com/content/360/bmj.k1134. doi: 10.1136/bmj.k1134

Tingvoll, W. A., & McClusky, L. M. (2015). Current status of rehabilitation activity and the new health care reform in Norway. *Scandinavian journal of disability research*, *17*(2), 115-129. doi: 10.1080/15017419.2013.817354

Toombs, S. K. (1993). The meaning of illness: A phenomenological account of the different perspectives of physician and patient. Dordrecht: Kluwer Academic Publishers.

Törnbom, M., Jonsson, U., & Sunnerhagen, K. S. (2013). Increasing symptoms, met and unmet needs in adults with cerebral palsy or meningomyelocele a longitudinal follow-up. *Scandinavian journal of disability research*, *15*(3), 249-263. doi: 10.1080/15017419.2012.703968

Tritter, J. Q. (2011). Public and patient participation in health care and health policy in the United Kingdom. *Health expectations*, *14*(2), 220-223. doi: 10.1111/j.1369-7625.2011.00697.x

Tritter, J. Q. (2009). Revolution or evolution: the challenges of conceptualizing patient and public involvement in a consumerist world. *Health expectations*, *12*(3), 275-287. doi: 10.1111/j.1369-7625.2009.00564.x

Tritter, J. Q., & McCallum, A. (2006). The snakes and ladders of user involvement: moving beyond Arnstein. *Health policy*, *76*(2), 156-168. doi: 10.1016/j.healthpol.2005.05.008

Turner, K., & Gillard, S. (2012). Still out there? Is the service user voice becoming lost as user involvement moves into the mental health research mainstream? In M. Barnes, & P. Cotterell (Eds.), *Critical perspectives on user involvement* (pp. 189-199). Bristol: Policy Press.

UK Government (2013). *Case study: The expert patients programme*. Retrieved 1 December, 2020 from https://www.gov.uk/government/case-studies/the-expert-patients-programme

UK Government (2005). *Mental Capacity Act 2005*. Retrieved from https://www.legislation.gov.uk/ukpga/2005/9/contents

UK Government (2001). *Health and Social Care Act 2001*. Retrieved from https://www.legislation.gov.uk/ukpga/2001/15/contents

UK Government Department of Health (2012). *Liberating the NHS: No decision about me, without me*. Retrieved from https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/216980/Liberating-the-NHS-No-decision-about-me-without-me-Government-response.pdf

UK Parliamentary Select Committee on Health (2007). *Third report: Recent history of patient and public involvement.* Retrieved from https://publications.parliament.uk/pa/cm200607/cmselect/cmhealth/278/27806.htm

United Nations [UN]. (2008). *UN Convention on the rights of persons with disabilities*. Retrieved from https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html

Unwin, P. F., Rooney, J. M., Osborne, N., & Cole, C. (2017). Are perceptions of disability changed by involving service users and carers in qualifying health and social work training? *Disability & society*, *32*(9), 1387-1399. doi: 10.1080/09687599.2017.1322498

UPIAS - The Union of the Physically Impaired Against Segregation, & The Disability Alliance (1976). The Union comments on the discussion. In *Fundamental principles of disability* (pp. 11-20). London: UPIAS and The Disability Alliance.

Van Den Berg, B., Gafni, A., & Portrait, F. (2017). Attributing a monetary value to patients' time: A contingent valuation approach. *Social science & medicine*, *179*, 182-190. doi: 10.1016/j.socscimed.2017.02.025

Van de Velde, D., Bracke, P., Van Hove, G., Josephsson, S., Devisch, I., & Vanderstraeten, G. (2012). The illusion and the paradox of being autonomous, experiences from persons with spinal cord injury in their transition period from hospital to home. *Disability & rehabilitation*, *34*(6), 491-502. doi: 10.3109/09638288.2011.608149

Veenstra, G., & Burnett, P. J. (2014). A relational approach to health practices: towards transcending the agency-structure divide. *Sociology of health & illness*, *36*(2), 187-198. doi: 10.1111/1467-9566.12105

Vehmas, S., & Watson, N. (2016). Exploring normativity in disability studies. *Disability & society*, *31*(1), 1-16. doi: 10.1080/09687599.2015.1120657

Vehmas, S., & Watson, N. (2014). Moral wrongs, disadvantages, and disability: A critique of critical disability studies. *Disability & society, 29*(4), 638-650. doi: 10.1080/09687599.2013.831751

Wästerfors, D. (2011). Stretching capabilities: children with disabilities playing TV and computer games. *Disability & society*, *26*(3), 337-349. doi: 10.1080/09687599.2011.560417

Watson, N. (2002). Well, I know this is going to sound very strange to you, but I don't see myself as a disabled person: Identity and disability. *Disability & Society*, *17*(5), 509-527. doi: 10.1080/09687590220148496

Watson, N., McKie, L., Hughes, B., Hopkins, D., & Gregory, S. (2004). (Inter) dependence, needs and care: The potential for disability and feminist theorists to develop an emancipatory model. *Sociology*, *38*(2), 331-350. doi: 10.1177/0038038504040867

Watson, R. (2015). De-reifying categories. In R. Fitzgerald, & W. Housley (Eds.), *Advances in membership categorisation analysis* (pp. 23-50). London: SAGE. doi: 10.4135/9781473917873

We are Spartacus (2013). *People's review of the Work Capability Assessment*. Retrieved from http://www.centreforwelfarereform.org/library/by-date/peoples-review-of-wca-further-evidence.html

Whitaker, G. P. (1980). Coproduction: Citizen participation in service delivery. *Public administration review*, 240-246. doi: 10.2307/975377

WHO - World Health Organization (2011). *World report on disability*. Geneva, Switzerland: World Health Organization.

WHO - World Health Organisation (2001). *International classification of functioning, disability and health (ICF)*. Retrieved from https://www.who.int/classifications/international-classification-of-functioning-disability-and-health

Williams, G. (2003). The determinants of health: structure, context and agency. *Sociology of Health & Illness*, *25*(3), 131-154. doi: 10.1111/1467-9566.00344

Wilcox, S. (2010). Lay knowledge: The missing middle of the expertise debates. In R. Harris, N. Wathen, & S. Wyatt (Eds.), *Configuring Health Consumers* (pp. 45-64). London: Palgrave Macmillan. doi: 10.1057/9780230292543

Williams, G. (1984). The genesis of chronic illness: narrative re-construction. *Sociology of health & illness*, *6*(2), 175-200. doi: 10.1111/1467-9566.ep10778250

Williams, O., Sarre, S., Papoulias, S. C., Knowles, S., Robert, G., Beresford, P., ... & Palmer, V. J. (2020). Lost in the shadows: reflections on the dark side of co-production. *Health research policy and systems*, *18*, 1-10. doi: 10.1186/s12961-020-00558-0

Wilson, P., Mathie, E., Keenan, J., McNeilly, E., Goodman, C., Howe, A., ... & Cowe, M. (2015). ReseArch with Patient and Public invOlvement: a realisT evaluation: the RAPPORT study. *Health service and delivery research, 3(38)*. Retrieved from https://uhra.herts.ac.uk/bitstream/handle/2299/20068/RAPPORT_Report_HS_DR_Wilson_et_al_2015.pdf?sequence=2&isAllowed=y. doi: 10.3310/hsdr03380

Wilson, P., Mathie, E., Poland, F., Keenan, J., Howe, A., Munday, D., ... & Goodman, C. (2018). How embedded is public involvement in mainstream health research in England a decade after policy implementation? A realist evaluation. *Journal of health services research & policy*, *23*(2), 98-106. doi: 10.1177/1355819617750688

Woodward, K. (2008). Hanging out and hanging about: Insider/outsider research in the sport of boxing. *Ethnography*, *9*(4), 536-560. doi: 10.1177/1466138108096991

Woolf, V. (2002 [1930]). *On being ill*. Ashfield, MA: Paris Press.

Wyatt, S., Harris, R., & Wathen, N. (2010). Health (y) citizenship: Technology, work and narratives of responsibility. In R. Harris, N. Wathen, & S. Wyatt (Eds.), *Configuring Health Consumers* (pp. 1-10). London: Palgrave Macmillan. doi: 10.1057/9780230292543

Ylvén, R., & Granlund, M. (2015). Collaborative problem solving in the context of early childhood intervention: The link between problems and goals. *Scandinavian journal of disability research*, *17*(3), 221–239. doi: 10.1080/15017419.2013.859175

Zarb, G. (1992). On the road to Damascus: First steps towards changing the relations of disability research production. *Disability, handicap & society*, *7*(2), 125-138. doi: 10.1080/02674649266780161

Appendices

Appendix 1: Ethical approval from Health Research Authority

NHS
Health Research Authority

Dr Harriet Cooper
Norwich Medical School
University of East Anglia, Norwich Research Park
Norwich
NR4 7TJ

Email: hra.approval@nhs.net

08 November 2016
Reissued 15 November 2016

Dear Dr Cooper,

Letter of HRA Approval

Study title:	**Rights-based Rehabilitation: A Qualitative Research Project Co-produced with Disabled People**
IRAS project ID:	**207584**
REC reference:	**16/NE/0295**
Sponsor	**University of East Anglia**

I am pleased to confirm that **HRA Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

Appendix 1: Ethical approval from Health Research Authority

IRAS project ID	**207584**

It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from www.hra.nhs.uk/hra-approval.

Appendices

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

After HRA Approval

The document *"After Ethical Review – guidance for sponsors and investigators",* issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

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

In addition to the guidance in the above, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the HRA website, and emailed to hra.amendments@nhs.net.
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the HRA website.

Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application

Appendix 1: Ethical approval from Health Research Authority

procedure. If you wish to make your views known please email the HRA at hra.approval@nhs.net. Additionally, one of our staff would be happy to call and discuss your experience of HRA Approval.

HRA Training

We are pleased to welcome researchers and research management staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

Your IRAS project ID is **207584**. Please quote this on all correspondence.

Yours sincerely

[redacted]

Senior Assessor

Email: hra.approval@nhs.net

Copy to: *Tracy Moulton, Sponsor's Representative*
Ms Helen Sutherland, Norfolk & Suffolk Primary & Community Care Research, Office Hosted by South Norfolk CCG, Lead R&D Sponsor
NIHR CRN Portfolio Applications Team

Appendix 1: Ethical approval from Health Research Authority

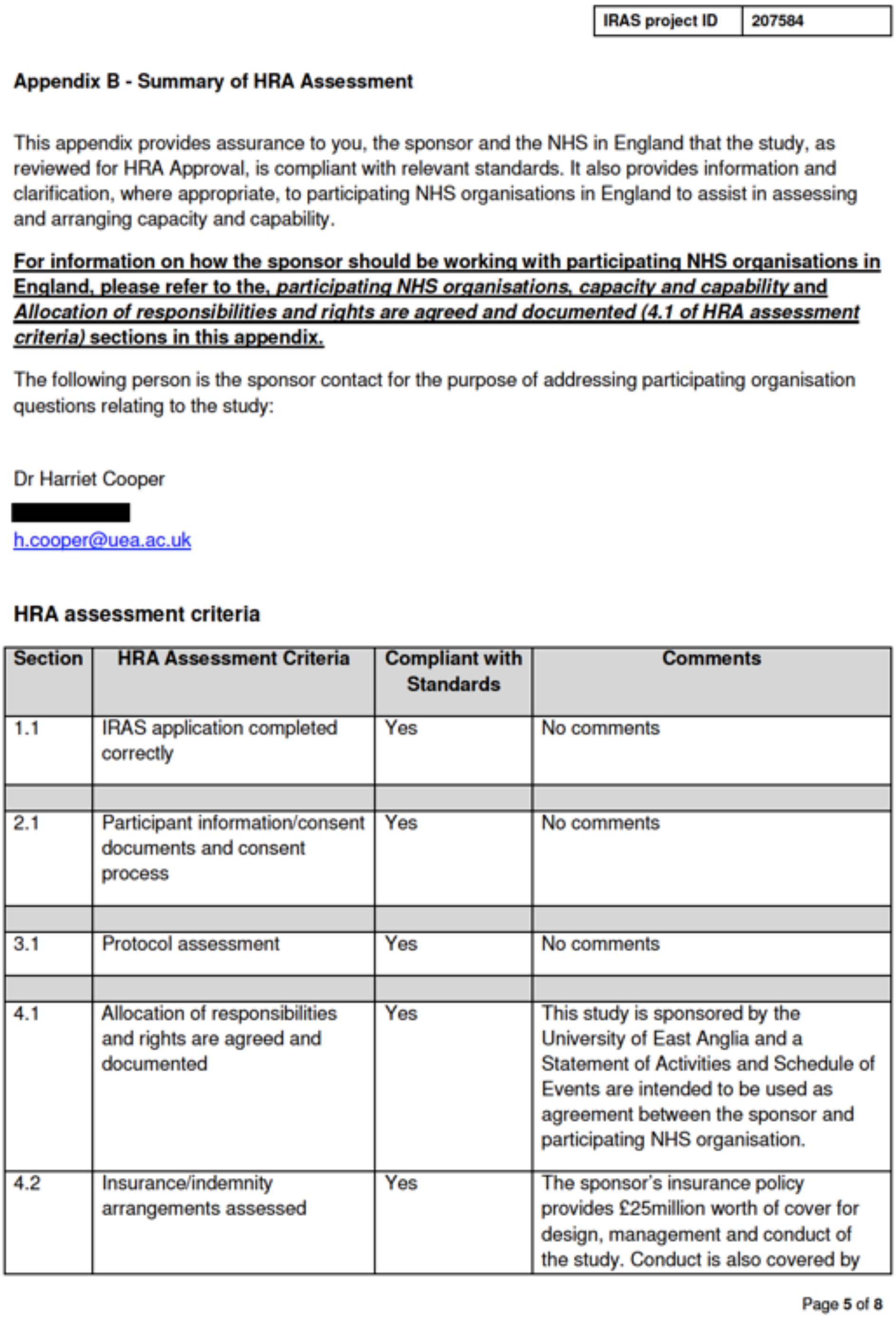
IRAS project ID	**207584**

Appendix A - List of Documents

The final document set assessed and approved by HRA Approval is listed below.

Document	*Version*	*Date*
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [UEA Insurance Letter]		11 August 2016
Interview schedules or topic guides for participants [Schedules for Data Collection Activities]	V1	05 August 2016
IRAS Application Form [IRAS_Form_16082016]		16 August 2016
IRAS Application Form XML file [IRAS_Form_16082016]		16 August 2016
IRAS Checklist XML [Checklist_16082016]		16 August 2016
Letter from funder [Letter from CLAHRC (funder)]		11 August 2016
Other [Statement of activities]	V1	11 August 2016
Other [Schedule of Events]	V1	11 August 2016
Other [Consent to Contact Table]	V1	10 August 2016
Other [List of debrief contacts]	V1	05 August 2016
Other [Easy Read Leaflet]	3	25 August 2016
Other [Rights-based Rehabilitation – Introduction letter]	4	25 August 2016
Other [Rights-based Rehabilitation Leaflet]	3	25 August 2016
Other [Rights-based Rehabilitation - Over-recruitment Letter]	4	25 August 2016
Other [Rights-based Rehabilitation Poster]	3	25 August 2016
Other [Response to issues raised]		25 August 2016
Participant consent form [Interview Consent Form]	V2	15 August 2016
Participant consent form [Easy Read Interview Consent Form]	V2	15 August 2016
Participant consent form [Focus Group-Creative Writing Group Consent Form]	V3	25 August 2016
Participant consent form [Easy Read FG-CWG Consent Form]	V3	25 August 2016
Participant information sheet (PIS) [Rights-based Rehabilitation Participant Information Sheet – Creative Writing Group]	4	25 August 2016
Participant information sheet (PIS) [Easy-read Rights-based Rehabilitation Patient Information Sheet - Creative Writing Group]	4	25 August 2016
Participant information sheet (PIS) [Rights-based Rehabilitation Participant Information Sheet - Focus Group]	4	25 August 2016
Participant information sheet (PIS) [Easy-read Rights-based Rehabilitation Patient Information Sheet - Focus Group]	4	25 August 2016
Participant information sheet (PIS) [Easy-read Rights-based Rehabilitation Patient Information Sheet – Interview]	4	25 August 2016
Participant information sheet (PIS) [Rights-based Rehabilitation Participant Information Sheet - Interview]	4	25 August 2016
Research protocol or project proposal [Protocol]	V1	05 August 2016
Summary CV for Chief Investigator (CI) [Harriet Cooper CV]		05 August 2016
Summary CV for supervisor (student research) [Fiona Poland CV]		11 August 2016

Appendix 1: Ethical approval from Health Research Authority



IRAS project ID	**207584**

Appendix B - Summary of HRA Assessment

This appendix provides assurance to you, the sponsor and the NHS in England that the study, as reviewed for HRA Approval, is compliant with relevant standards. It also provides information and clarification, where appropriate, to participating NHS organisations in England to assist in assessing and arranging capacity and capability.

For information on how the sponsor should be working with participating NHS organisations in England, please refer to the, *participating NHS organisations, capacity and capability* and *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* sections in this appendix.

The following person is the sponsor contact for the purpose of addressing participating organisation questions relating to the study:

Dr Harriet Cooper
[redacted]
h.cooper@uea.ac.uk

HRA assessment criteria

Section	HRA Assessment Criteria	Compliant with Standards	Comments
1.1	IRAS application completed correctly	Yes	No comments
2.1	Participant information/consent documents and consent process	Yes	No comments
3.1	Protocol assessment	Yes	No comments
4.1	Allocation of responsibilities and rights are agreed and documented	Yes	This study is sponsored by the University of East Anglia and a Statement of Activities and Schedule of Events are intended to be used as agreement between the sponsor and participating NHS organisation.
4.2	Insurance/indemnity arrangements assessed	Yes	The sponsor's insurance policy provides £25million worth of cover for design, management and conduct of the study. Conduct is also covered by

Page 5 of 8

Appendix 1: Ethical approval from Health Research Authority

Appendix 1: Ethical approval from Health Research Authority

IRAS project ID	**207584**

Section	HRA Assessment Criteria	Compliant with Standards	Comments
			NHS Indemnity. Where applicable, independent contractors (e.g. General Practitioners) should ensure that the professional indemnity provided by their medical defence organisation covers the activities expected of them for this research study
4.3	Financial arrangements assessed	Yes	No funding will be provided to sites. The study is funded by a CLAHRC, as detailed in the funding letter. Participants to receive shopping vouchers for taking part in workshops.
5.1	Compliance with the Data Protection Act and data security issues assessed	Yes	No comments
5.2	CTIMPS – Arrangements for compliance with the Clinical Trials Regulations assessed	Not Applicable	No comments
5.3	Compliance with any applicable laws or regulations	Yes	No comments
6.1	NHS Research Ethics Committee favourable opinion received for applicable studies	Yes	No comments
6.2	CTIMPS – Clinical Trials Authorisation (CTA) letter received	Not Applicable	No comments
6.3	Devices – MHRA notice of no objection received	Not Applicable	No comments
6.4	Other regulatory approvals and authorisations received	Not Applicable	No comments

Appendix 1: Ethical approval from Health Research Authority

IRAS project ID	**207584**

Participating NHS Organisations in England

This provides detail on the types of participating NHS organisations in the study and a statement as to whether the activities at all organisations are the same or different.
Study documents will not be shared with the participating NHS organisation in England because all study activities will be undertaken by the student. No specific arrangements are expected to be put in place at each organisation to deliver the study. If chief investigators, sponsors or principal investigators are asked to complete site level forms for participating NHS organisations in England which are not provided in IRAS or on the HRA website, the chief investigator, sponsor or principal investigator should notify the HRA immediately at hra.approval@nhs.net. The HRA will work with these organisations to achieve a consistent approach to information provision.

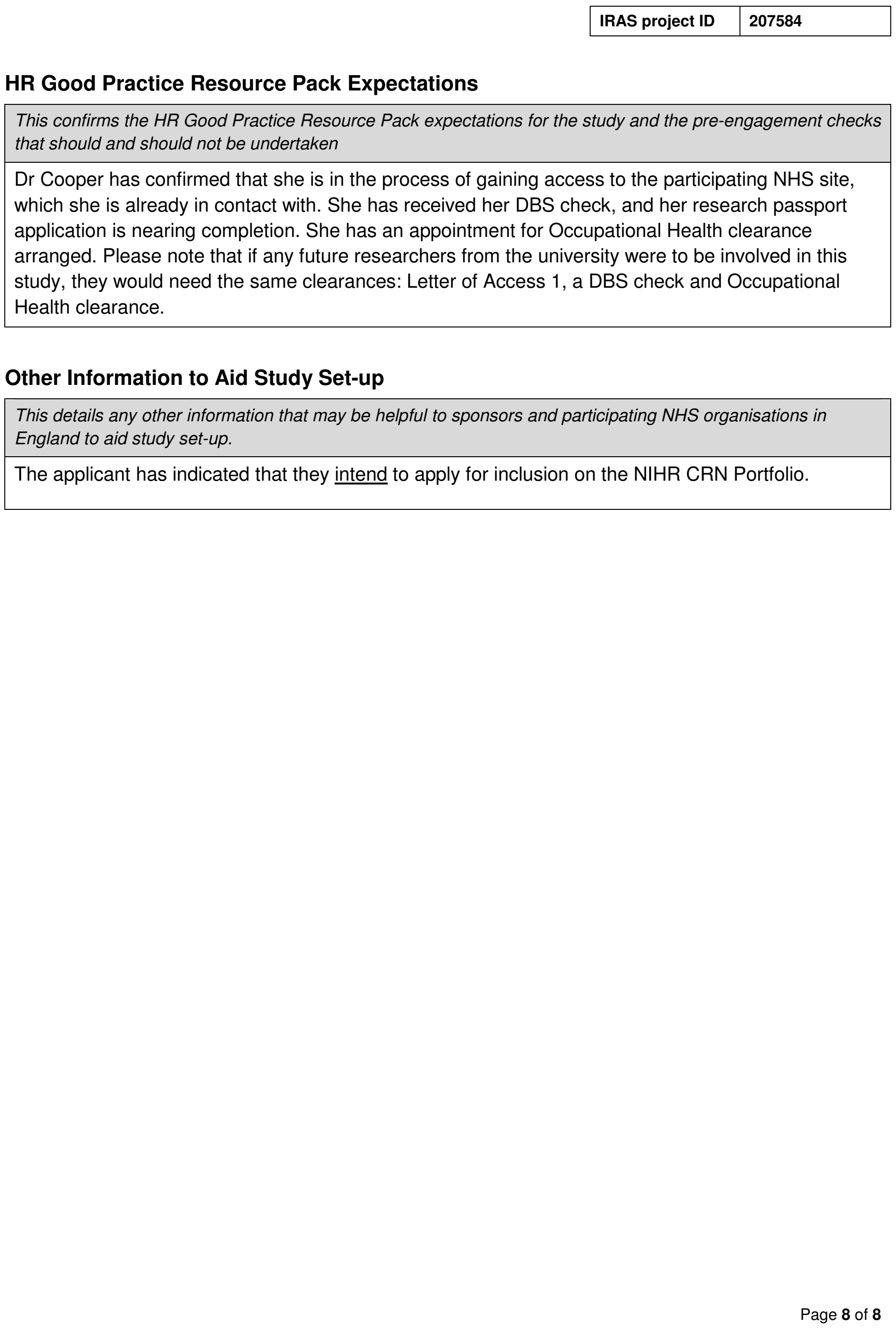
Confirmation of Capacity and Capability

This describes whether formal confirmation of capacity and capability is expected from participating NHS organisations in England.
The HRA has determined that participating NHS organisations in England **are not expected to formally confirm their capacity and capability to host this research,** because of the lack of involvement in Trust resources. • The HRA has informed the relevant research management offices that you intend to undertake the research at their organisation. However, you should still support and liaise with these organisations as necessary. • Following issue of the Letter of HRA Approval the sponsor may commence the study at these organisations when it is ready to do so. • The document "Collaborative working between sponsors and NHS organisations in England for HRA Approval studies, where no formal confirmation of capacity and capability is expected" provides further information for the sponsor and NHS organisations on working with NHS organisations in England where no formal confirmation of capacity and capability is expected, and the processes involved in adding new organisations. Further study specific details are provided the *Participating NHS Organisations* and *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* sections of this Appendix.

Principal Investigator Suitability

This confirms whether the sponsor position on whether a PI, LC or neither should be in place is correct for each type of participating NHS organisation in England and the minimum expectations for education, training and experience that PIs should meet (where applicable).
Dr Harriet Cooper will be undertaking all research activities for this single site study. GCP training is not a generic training expectation, in line with the HRA statement on training expectations.

Appendix 1: Ethical approval from Health Research Authority



IRAS project ID	**207584**

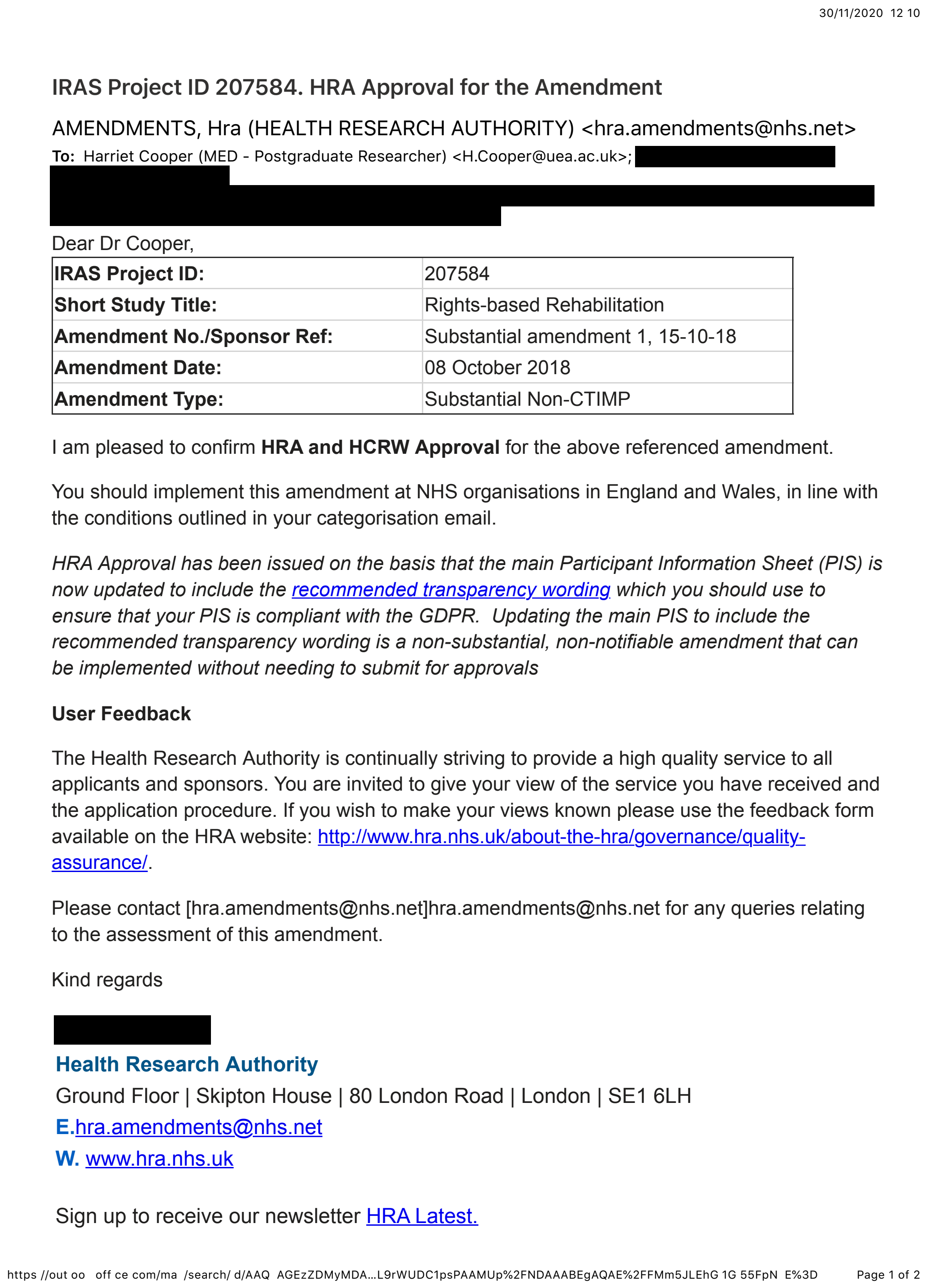
HR Good Practice Resource Pack Expectations

This confirms the HR Good Practice Resource Pack expectations for the study and the pre-engagement checks that should and should not be undertaken
Dr Cooper has confirmed that she is in the process of gaining access to the participating NHS site, which she is already in contact with. She has received her DBS check, and her research passport application is nearing completion. She has an appointment for Occupational Health clearance arranged. Please note that if any future researchers from the university were to be involved in this study, they would need the same clearances: Letter of Access 1, a DBS check and Occupational Health clearance.

Other Information to Aid Study Set-up

This details any other information that may be helpful to sponsors and participating NHS organisations in England to aid study set-up.
The applicant has indicated that they intend to apply for inclusion on the NIHR CRN Portfolio.

Appendix 2: Ethical approval for substantial amendment (relates to creative writing documents)



IRAS Project ID 207584. HRA Approval for the Amendment

AMENDMENTS, Hra (HEALTH RESEARCH AUTHORITY) <hra.amendments@nhs.net>

To: Harriet Cooper (MED - Postgraduate Researcher) <H.Cooper@uea.ac.uk>; [redacted]

Dear Dr Cooper,

IRAS Project ID:	207584
Short Study Title:	Rights-based Rehabilitation
Amendment No./Sponsor Ref:	Substantial amendment 1, 15-10-18
Amendment Date:	08 October 2018
Amendment Type:	Substantial Non-CTIMP

I am pleased to confirm **HRA and HCRW Approval** for the above referenced amendment.

You should implement this amendment at NHS organisations in England and Wales, in line with the conditions outlined in your categorisation email.

HRA Approval has been issued on the basis that the main Participant Information Sheet (PIS) is now updated to include the recommended transparency wording which you should use to ensure that your PIS is compliant with the GDPR. Updating the main PIS to include the recommended transparency wording is a non-substantial, non-notifiable amendment that can be implemented without needing to submit for approvals

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/.

Please contact [hra.amendments@nhs.net]hra.amendments@nhs.net for any queries relating to the assessment of this amendment.

Kind regards

[redacted]

Health Research Authority
Ground Floor | Skipton House | 80 London Road | London | SE1 6LH
E.hra.amendments@nhs.net
W. www.hra.nhs.uk

Sign up to receive our newsletter HRA Latest.

Appendix 3: Protocol (with revisions made after substantial amendment in highlighted text)

Rights-based Rehabilitation:

A qualitative research project co-produced with disabled people

Harriet Cooper

Abstract

This research project will work with disabled people who have experienced rehabilitation to explore how their views and experiences of the process can both shape rehabilitation services, and help to develop a 'rights-based rehabilitation' policy.

The UN Convention on the Rights of Persons with Disabilities includes the provision of 'comprehensive habilitation and rehabilitation services' (2008: n. pag.). Yet in many countries systemic barriers have hampered the implementation of rehabilitation programmes (WHO, 2011). One barrier identified by the WHO was a lack of involvement of disabled people in the design, delivery and evaluation of rehabilitation services (2011).

My literature review has revealed little evidence of the involvement of disabled people in the shaping of previous research on rehabilitation. Little is known about either disabled people's experiences of rehabilitation or their priorities for a research project of this kind.

Key aspects of the project will be co-produced with disabled people who have experienced rehabilitation. The Norfolk-based disabled people's organisation, Equal Lives, has advised on recruitment, on approaches to participatory research and on the wording of flyers; it has also raised awareness of the project. A well-attended roundtable of members of the patient group was held at UEA in February 2016 to discuss research priorities. From this, an advisory group has been set up, which includes a member of Equal Lives.

The roundtable agreed that a writing group could promote creative expression about experiences of rehabilitation, and that this should be considered as a data collection method alongside focus groups and interviews. Given that I want to explore embodied, lived experience, a theoretical framework informed by phenomenology will be an asset to the project.

Project objectives

The principal research objective is to investigate disabled people's views and experiences of rehabilitation, using qualitative methods: interviews, focus groups and a creative writing workshop. The research findings will guide the development of rehabilitation policy and practice, as well as guidance for services users.

Background, rationale and summary of literature review

Since the 1970s, the disability rights movement has sought to redefine disability in terms of social and environmental barriers to participation (seen as oppression), rather than in terms of a functional deficit (UPIAS and The Disability Alliance, 1976; Oliver, 1983). The 2008 Convention on the Rights of Persons with Disabilities, entitled 'Habilitation and Rehabilitation' calls upon all states to 'take effective and appropriate measures […] to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life' (United Nations, 2008: n. pag.). This includes the provision of 'comprehensive habilitation and rehabilitation services'. Yet in many countries, the full implementation of rehabilitation policies has 'lagged' due to a number of 'systemic barriers' (WHO, 2011: 104). Among these barriers, the WHO cites 'absence of engagement with people with disabilities' in relation to the design, delivery and evaluation of rehabilitation services (2011: 105).

Appendix 3: Protocol (with revisions made after substantial amendment in highlighted text)

My literature review revealed that while on the one hand, there is a lack of evidence of the views of disabled people in the rehabilitation sciences literature, on the other hand, the disability studies literature has tended to avoid rehabilitation as a topic. Prominent disability rights activists and academics have written of their experience of rehabilitation as oppressive, because of its emphasis on normalisation (Oliver, 1990, 1993; Abberley, 1995; Finkelstein, 2004). For example, Oliver (1993), in his inaugural lecture, posed the question 'what's so wonderful about walking?', thereby interrogating the very desirability of 'optimal functioning' as defined by the World Health Organisation (2011: 96). Disability studies has been, for many years, dominated by the social model of disability with the 'medical model' invoked pejoratively (Shakespeare, 2014). For Shakespeare (2014), a commitment to a 'strong' social model has hampered the development of disciplinary alliances (for example, with medical sociology) that could lead to research promoting the human rights of all disabled people. As Shakespeare notes, 'rehabilitation […] has been a very neglected topic in disability studies' (2014: 6-7). By doing research at the intersection of the two disciplines, assumptions on both sides can be challenged about what rehabilitation is for, and who decides what rehabilitation is: this could help to make rehabilitation more relevant to the patients who undergo it. Furthermore, evidence of stakeholder involvement in previous research is rare, and little is known about what disabled people's experiences of rehabilitation have been and what their priorities would be for a research project of this kind.

Methodology

At the heart of this research problem are the views and lived experiences of disabled people, as well as their agency (or lack thereof) in shaping rehabilitation services. Therefore it makes sense to use qualitative methods such as semi-structured interviews and focus groups. A purposive sample is also necessary to ensure that the data I collect speaks directly to the aims of the research (Bryman, 2012).

The research problem also requires a stance that is open to understanding lived experiences as embodied, and as culturally, historically and psychosocially situated. Such an approach might be given the label 'interpretivism' given that it will try to prioritise the meanings and interpretations that participants ascribe to their experiences (Mason, 2002), and to understand these within a particular context. Abductive reasoning – that is, the iterative movement back and forth from data to theory – is often associated with this approach (Mason, 2002), and it will be a useful strategy for ensuring that I both pay close attention to the data and draw on my personal and academic resources in the analysis process.

The research problem demands a theoretical framework which can facilitate the holistic analysis of data about the embodied experience of rehabilitation, and which invites the researcher to suspend the desire to jump too quickly into explaining, or making causal connections. Phenomenology, with its emphasis on description and on questioning when and how we come to deploy categories such as subject and object (Merleau-Ponty, 2002 [1962]), is likely to be very helpful. Qualitative health researchers have developed protocols for doing interpretative phenomenological analysis (IPA) (Smith *et al*, 1999; Biggerstaff and Thompson, 2008); I will draw on these as I design my data analysis strategy.

The use of creative writing as a research tool may help me to collect rich data about lived experiences of rehabilitation because the injunction to write 'creatively' or to write fiction could serve to liberate participants from anxiously focussing on producing a 'true' account, in such a way as to allow a focus more clearly on the *meaning* of the experience (see Leavy 2009; Barone and Eisner, 2012). The rehabilitation process may have evoked strong feelings which, for some people, may be more easily expressed in fiction than in an account of what actually happened. In this way, inviting participants to write may lead to insights about rehabilitation that are otherwise inaccessible to the research.

Appendix 3: Protocol (with revisions made after substantial amendment in highlighted text)

A number of attendees of the PPI roundtable felt that creative writing had merit as a research method on the grounds that it could promote greater inclusion: some participants might prefer to express themselves via the written word. One of the themes that was explored in the discussion was whether or not the products of the creative writing should be used as research data. Participants might feel inhibited by the knowledge that their writing would be analysed. My decisions in response to these ethical and methodological questions are detailed in the next section.

Recruitment, Informed Consent and Data Collection Methods

There are three separate strands of data collection activities: interviews, focus groups and a creative writing workshop. A participant can take part in just one strand, in two, or in all three. Priority will however be given to research participants who have not taken part in another strand of the research, in order to maximise the range of experiences captured by the research.

These are the recruitment pathways:

1) a) A patient will be identified as eligible patient by a member of healthcare staff within Norfolk Community Health and Care NHS Trust. The eligible patient will be given a leaflet informing them about the research by their healthcare professional. Healthcare professional will seek verbal consent from patient to be contacted to receive further information about the study. If patient consents to be contacted, his/her contact details will be passed on to me using the 'consent to contact' matrix attached and I will send out participant information sheet. The Trust's research manager has confirmed the acceptability of the above approach.

1) b) Healthcare professionals from Norfolk Community Health and Care NHS Trust will contact past patients whom they believe would be interested and eligible (from last 5 years, since 2011). Eligible patients will be sent a letter/email and leaflet by the healthcare professional. Interested patients will be asked to contact me directly.

1 c) Posters will be put up in the wards and waiting rooms in the Colman Centre for Specialist Rehabilitation Services, to promote the project. Interested patients will be invited either to contact me directly, or to let a member of hospital staff know that they would like to take part (the route will vary depending on the ward in question).

Both in-patients and outpatients are eligible to take part in this study.

2) a) Participant will find out out about research via promotional materials circulated by user groups, charities, and disabled people's organisations. The primary partner in this process is Equal Lives (Norfolk-based disabled people's group). Participant will make contact with me directly or via their contact to arrange participation.

2) b) Participant will find out about research via someone involved in my PPI network or wider network, and contact me directly for more information.

In each case, I will send out the participant information sheet promptly and no less than 24 hours before the data collection activity. I will aim to speak to each participant on the phone, or meet them in person before the data collection activity; if this is not possible I will contact them via email. The pre-meeting will be an opportunity for the participant to discuss any queries they have. Informed consent will be taken on the day of the data collection activity.

Strand 1: Interviews (n=20)

Participant provides written informed consent before the interview.

Appendix 3: Protocol (with revisions made after substantial amendment in highlighted text)

Interview takes place in a mutually convenient quiet place, such as the participant's home.

Semi-structured interview takes place.

Participant is debriefed.

Afterwards: participant is sent transcript and asked to check that it is an accurate representation of what they said.

Participant is sent information summarising the results of the research.

Strand 2: Focus group x 5 groups (n = 6 per group)

Focus group takes place in a bookable room at UEA or in a bookable room in a public venue such as Norwich Forum.

Participants provide written informed consent before the focus group.

Focus group discussion takes place.

Participants are debriefed.

Participants are sent information summarising the results of the research.

Group 1: acquired impairment: individuals with spinal cord injury

Group 2: acquired impairment: individuals who have had a stroke or brain injury

Group 3: individuals who have a degenerative neurological condition such as MS

Group 4: impairment from childhood: individuals who have cerebral palsy, spina bifida, or another condition that has affected them since childhood

Group 5: individuals who have a paediatric or acquired sensory impairment (e.g. blindness or deafness)

Strand 3: Creative Writing Group (n = 10)

I have designed this element of the study to ensure that individuals can take part in the creative writing workshop as a purely exploratory activity, without being expected to share their work either with the group or with the project as data. This will be achieved by holding two separate meetings of the same group - i.e. the same people will be attending both groups. The meetings will be as follows:

1) a writing meeting, in which there will be exercises to inspire people to write about rehabilitation using prose fiction or poetry; this will not be recorded and no data will be collected. This is to encourage free writing as stated above. I hope to invite a writer who is involved in the disability arts movement to help plan and lead the session.

I will send out the ‘Tasks for the Creative Writing Group’ document to participants in advance of the first meeting and in the session itself I will provide an example of each task that I have completed. I will provide the poem template on coloured paper as well as white paper. These adjustments are designed to make the group more accessible.

2) a sharing meeting, approximately 2-3 weeks later. Individuals who attended the first group would be invited to attend, but would be under no obligation to do so. Individuals will be encouraged to read their writing aloud and this will be used as a prompt for discussion about

Appendix 3: Protocol (with revisions made after substantial amendment in highlighted text)

the lived experience of rehabilitation. These discussions will be recorded and used as data, with permission from attendees. I will also request that participants give me paper copies of their writing, if they are comfortable to do so. These documents will be anonymised in discussions in my research, as will discussion transcripts.

If participants do not wish to share their own writing they would be free to read a poem or extract of published writing by an author they admire, that they see as relevant to the theme. Alternatively, they may choose for their writing to be read out anonymously by another participant, or by one of the facilitators, or they may put up their writing on the wall for others to read during the session.

The same procedure will be followed as with the focus groups. Participants will receive information sheets prior to the first meeting. Written informed consent will be taken at the start of the second meeting meeting.

Prior to the groups, I will explore with potential participants whether they need any adjustments in order to be able to take part. Potential adjustments might include, for example, the option to dictate writing to a facilitator in a separate room, to use a voice recorder or to work in pairs to write.

Planned Public and Patient Involvement

To meet the project objectives effectively, the project has two strands of PPI: a small core group of PPI members who will sit on the project advisory group and a wider network of members who may have occasional input. The first mode of working with the patient group will enable me to make informed decisions on a wide range of project matters (the wording of information sheets and consent forms, the schedule for interviews and focus groups, recruitment methods and locations, data analysis and dissemination) in a timely and efficient fashion, and is a widely used mode of collaboration (see INVOLVE, 2013a, b, c). The second mode of doing PPI – the development of a wider network of individuals who may attend occasional events, such as the roundtable at UEA on 18 February 2016 – will be a helpful means of raising awareness about the project and disseminating results. By raising awareness, the network is likely to reach potential participants who might not otherwise be informed of the research. Furthermore, the involvement of a larger group of individuals in the data analysis will improve the trustworthiness of my interpretations through a process of triangulation.

Purposive Sample

In order for the data to provide meaningful information about rehabilitation as a lived experience, participants must all identify as disabled people who have been through rehabilitation. Rehabilitation may have taken place at any stage of the life-course, and will include:

- physiotherapy
- occupational therapy
- speech and language therapy
- rehabilitation medicine and nursing
- rehabilitation counselling
- wheelchair services or training for use of other assistive devices

Appendix 3: Protocol (with revisions made after substantial amendment in highlighted text)

- experience of using orthotics and prosthetics
- other type of rehabilitation for a physical impairment
- rehabilitation for a sensory impairment.

As this is a qualitative study, a purposive approach to sampling is most appropriate (see Bryman, 2012). This means that I will be using my judgement to select individuals who have a lived experience of rehabilitation to take part in the study. I do not expect the sample to be representative of all disabled people who have experienced rehabilitation in Norfolk, but I do expect it to be able to illustrate and illuminate aspects of this experience (Mason, 2002). The diversity of the sample - in terms of factors including age, impairment and length of time spent living with the impairment - will be more important than the size of the sample itself.

In determining the sample size, I wanted to ensure that I would have enough data to achieve theoretical saturation, by which I mean that I start to have 'a picture of what is going on and can generate an appropriate explanation for it' (Mason, 2002, p. 134). In terms of the interview sample size, 20 interviews will provide a sufficiently wide range of relevant data for comparison, whilst being manageable within the project timeframe.

In terms of the focus groups, these are limited to 6 participants per group to ensure that everyone has a chance to speak. 5 groups, each recuiting participants with experience of a particular kind of rehabilitation, will enable me to collect data about rehabilitation experiences in relation to a number of physical impairments and to include a sensory impairments group as a comparator.

As regards the creative writing group, the decision to restrict the size to 10 participants has been made to help participants feel comfortable and confident in sharing their writing. This group size will allow a dialogue to develop in the sharing group - in a larger group, less confident people might feel inhibited from speaking.

Should the project become oversubscribed, I will send a letter to interested individuals explaining this (see attachment). Interested individuals could attend a data analysis event or dissemination event instead.

Exclusion Criteria

The following individuals will be excluded from the study:

- Children (anyone under 18)
- People who do not have mental capacity. In accordance with the Mental Capacity Act (2005) guidelines, it will be assumed that participants who have been selected or who have self-selected possess mental capacity. Should it become clear that a participant lacks mental capacity according to the definitions of the Act (2005), I will discontinue the interview and will delete any data I may have collected.
- Those whose rehabilitation experience relates to an intellectual disability (e.g. autism) or to a mental health issue (e.g. schizophrenia). The experience of physical impairment may be correlated with anxiety, depression, or other experiences of mental ill health (e.g. Craig et al, 2009). People will not be excluded from the research if they have experienced psychological distress, but only if the rehabilitation experience that constitutes their reason for approaching the project relates to mental ill health. This is primarily because the experience of rehabilitation may be very different for these groups, and due to limited resources and time, this may be more effectively explored in a separate project.

Appendix 3: Protocol (with revisions made after substantial amendment in highlighted text)

Remuneration

All participants will be offered a £10 shopping voucher for each interview and focus group they take part in (and one voucher for taking part in both meetings of the creative writing group). Reasonable travel expenses can be refunded. This level of remuneration is unlikely to act as a significant inducement, and will recognise what participants have contributed to the research.

PPI members will be paid £30 for each two-hourly meeting they attend, and can reclaim travel expenses. Meetings are unlikely to last a full two hours and as a result, members may be expected to offer feedback on documents between meetings on an occasional basis.

Confidentiality and Data Use

I will take all reasonable steps to ensure confidentiality and will act with the utmost integrity at all times. All the information I gather will be anonymised or pseudonymised during transcription. All identifying data will be removed, and if necessary fictionalised, to ensure anonymity.

I will quote from, discuss and analyse the anonymised transcripts in my PhD thesis and publications arising from this research. My PhD supervisors may also read the anonymised transcripts. Short sections of the anonymised transcripts may also be read by members of the project advisory group and by attendees of a roundtable event at UEA. All identifying data will be removed or fictionalised prior to being used at this event. The attendees will be other disabled people who have experienced rehabilitation. This process will help to make sure that the core research team have recognised all the important themes and have not overlooked anything.

Personal data including interview and focus group recordings will be stored within my folders on the password-protected University of East Anglia computer system. Recordings will be deleted from recording devices themselves as soon as they have been transferred to university computers. Recordings will be deleted from computers as soon as they have been transcribed.

Paperwork that includes personal data, including consent forms, will be stored in a locked cupboard within a locked office at UEA, and will be retained only as long as necessary and shredded as soon as they are no longer needed.

If my budget allows, an assistant may be employed to assist with transcription. This person will be bound by the same confidentiality commitments as myself, and will comply with the Data Protection Act. This person would sign a non-disclosure agreement.

Risks (to patients and the researcher)

This study has minimal risks, however, having given careful thought to identify those that might arise, I describe here the steps I would take to manage them in that case:

1) Participants may recall aspects of their rehabilitation experience which were distressing. I will inform participants that they do not have to answer all questions, and that they can take a break at any time should they need to do this for any reason. Throughout the data collection activities I will remain sensitive to the state of mind and behaviour of each participant, and will offer them opportunities to take a break if and when this is appropriate. If participants become distressed I will respond appropriately by pausing the interview and exploring whether or not it is appropriate to continue. If

Appendix 3: Protocol (with revisions made after substantial amendment in highlighted text)

appropriate I will offer participants information about potential sources of support. I will not leave a participant while they are distressed, but will explore how best to support them - for example, checking whether they have a friend or relative who can be contacted to support them. With inpatient participants I would explore whether a nurse could support the individual.

2) I will debrief all participants at the end of each data collection activity, asking them how they found it and addressing any immediate concerns or queries they may have.

3) Safeguarding: if, during the data collection activities, I become aware of actions which pose a significant risk of physical or mental harm to the participant or other people, I will take action to minimise this risk. This may include informing relevant authorities. If necessary I will discuss any issues that arise with one of my supervisors or with Bridget Penhale, an academic expert on safeguarding at UEA, to determine any external referral, e.g to the NHS Trust or to Adult Social Care. Participants will be informed during the consenting process that I may need to discuss safeguarding issues with senior colleagues, but that I will talk to them about this first.

4) Burden of time: this will be kept to a minimum. Participants are expected to have a one-off involvement in a single data collection activity, although they are free to take part in other activities if these are under-subscribed.

5) (For researcher) Lone-working: going into homes of interviewees alone. This is necessary as some participants have disabilities that make it difficult to meet at the university or on another site but can raise risks for the researcher. I will let one of my supervisors know the address where I will be, I will let this individual know when each interview starts and what the timescale is. I and will notify them that the interview has been successfully completed. Another colleague at UEA, Andrea Stockl, has offered to be a contact person within this process if my supervisors are away or busy. I will carry out all interviews during daylight hours as far as possible.

6) (For researcher) Hearing patients' stories may require emotional resilience on the part of the researcher. I will have the opportunity to debrief with one of the academic supervisors and will also be able to discuss any potential duty of care issues arising with the safeguarding leads.

Data Analysis

I will categorise the data into themes, using an approach informed by Interpretative Phenomenological Analysis (IPA). This means that the starting point for creating themes will be the data itself - that is, the meanings that participants ascribe to their lived experiences. Smith et al (1999) define the aim of IPA as: 'to explore in detail the participant's view of the topic under investigation'. The participant's perception of events is what this approach aims to highlight.

I will highlight words and themes in the transcripts, and will collect, order and index these using spreadsheets, as a way of managing all the themes that emerge. I will analyse the themes in the spreadsheets for patterns. I will use an iterative approach to data analysis, by which I mean that I will work from the data towards interpretation, returning to the data to check my interpretations. I will be sensitive to the provisional status of my own interpretations and will find ways to triangulate these (see below).

Throughout the process, I will be thoughtful and self-reflexive about my own role in giving meaning to the data by choosing certain themes and ways of categorising data over others. I

Appendix 3: Protocol (with revisions made after substantial amendment in highlighted text)

will also consider how my own presence as a researcher within the data collection activities is having an impact on the data I am producing: for example, I will consider which aspects of my own identity (and the extent to which these are known or unknown to the participants) play a role in what participants choose to tell me. My approach to data analysis is likely to evolve through the course of the project, based on my ongoing learning.

One point of evolution of my analysis process is the recognition that I will draw on my background in literary studies, and my knowledge of how to analyse literary texts, in the process of my analysis of the creative writing workshop data. This is the reason why I wish to collect hard copies of the writing where participants are happy to provide it – because I will want to explore how participants have chosen to write about rehabilitation (styles, emotions expressed, metaphors used, etc.). This may be difficult if I am relying only on a transcript, where one often misses words and or/requires knowledge of context to understand. It will be extremely helpful to see the written form of the writing. The writing will be discussed anonymously in the research, and participants retain the option not to provide hard copies.

My supervisors, the project advisory group and the wider PPI group will be involved in checking my analysis. This involvement is likely to take more than one form, and I will draw on the differing expertise of each group in this process. For example, my supervisors will advise me on methodological issues and analysis of themes. Members of the project advisory group and PPI group will offer their own analyses of what the data shows, and will help me to think about how and where to sample next in order to collect diverse purposive data.

I expect to have a roundtable data analysis session with the wider patient group, but in addition I might ask members of the project advisory group to read parts of my data analysis chapter.

Reference List

ABBERLEY, P. (1995). Disabling Ideology in Health and Welfare - the case of occupational therapy. *Disability and Society*, 10 (2), 221-232.

BARONE, T. and EISNER, E. (2012). *Arts based research*. London: Sage.

BIGGERSTAFF, D. and THOMPSON, A. (2008). Interpretative Phenomenological Analysis (IPA): A Qualitative Methodology of Choice in Healthcare Research, *Qualitative Research in Psychology*, 5:3, 214-224.

BRYMAN, A. (2012). *Social Research Methods*. 4th edition. Oxford: Oxford University Press.

CRAIG, A, TRAN. Y, MIDDLETON, J. (2009) Psychological morbidity and spinal cord injury: a systematic review. *Spinal Cord*. 47: 108–114.

FINKELSTEIN, V. (2004). 'Representing Disability' in *Disabling Barriers, Enabling Environments* ed. by Swain, J., French, S., Barnes, C., Thomas, C. London: Sage.

INVOLVE (2013a). Examples of public involvement in research funding applications: *Optimising adult mental health service configurations across health and social care*.

INVOLVE (2013b). Examples of public involvement in research funding applications: *Health care innovations from policy to practice: A case study of rapid HIV testing in General Practice*.

INVOLVE (2013c). Examples of public involvement in research funding applications: *Supporting Excellence in End of life care in Dementia – SEED programme*.

Appendix 3: Protocol (with revisions made after substantial amendment in highlighted text)

HM GOVERNMENT (2005). *Mental Capacity Act.*

LEAVY, P (2009). *Method Meets Art: Arts-Based Research Practice* (New York: The Guilford Press)

MASON, J. (2002). *Qualitative Researching*. London: Sage.

MERLEAU-PONTY, M. (2002 [1962]). *Phenomenology of Perception*, trans. by Colin Smith. London: Routledge.

OLIVER, M. (1990). *The Politics of Disablement*. Basingstoke: Macmillan.

OLIVER, M. (1993). What so wonderful about walking? Inaugural Professorial Lecture, University of Greenwich, February. http://disability-studies.leeds.ac.uk/files/library/Oliver-PROFLEC.pdf

SHAKESPEARE, T. (2014). *Disability Rights and Wrongs Revisited*. 2nd edition. Abingdon, Oxon: Routledge.

SMITH, J., JARMAN, M and OSBORN, M. (1999). Doing Interpretative Phenomenological Analysis. In Murray, M. and Chamberlain, K. (eds.), *Qualitative Health Psychology: Theories and Methods*, pp. 218-240.

UPIAS (The Union of the Physically Impaired Against Segregation) and THE DISABILITY ALLIANCE (1976), 'The Union Comments on the Discussion' in *Fundamental Principles of Disability* London: UPIAS and The Disability Alliance. pp. 11-20.

UNITED NATIONS (2008) *Convention on the Rights of Persons with Disabilities*. http://www.un.org/disabilities/convention/conventionfull.shtml.

WORLD HEALTH ORGANIZATION (WHO) (2011). *World Report on Disability*. Geneva: World Health Organization.

Appendix 4: Recruitment poster

Rights-based Rehabilitation
Poster V3, 25 Aug 2016
IRAS: 207584

Are you a disabled person who has experienced rehabilitation?

Your views and experiences could help shape future rehabilitation policy and practice.

‘Rights-based Rehabilitation’ is a social research project being undertaken by **Harriet Cooper at the University of East Anglia.** For a leaflet with more information about who can take part, contact a member of staff in [insert name of ward/organisation/HC’s details].

disability research @ UEA

Equal Lives
Free from disabling barriers

UEA
University of East Anglia

Funded by NHS
National Institute for Health Research

Appendix 5: Project leaflet – front and back of A5 folded leaflet

Are there any risks to you?

The risks to you are low. You might find it upsetting to recall your experiences of rehabilitation. If you do, I will refer you to appropriate support services. You can take a break at any time or change your mind about taking part.

This research has received ethical approval from the Health Research Authority.

After the interview or focus group, you will be offered a £10 voucher as a thank you for your time.

If you would like further information, or to have a conversation about what is involved in taking part, please contact Harriet Cooper.

Email: h.cooper@uea.ac.uk

Telephone: ___________.

Address: PhD Researcher, Norwich Medical School, University of East Anglia, Norwich Research Park, Norwich, NR4 7TJ.

If you need additional support or adjustments to be able to take part, please contact Harriet, so that appropriate arrangements can be made.

Rights-based Rehabilitation Leaflet
V3, 25 Aug 2016, IRAS: 207584

Take part in research into Rights-based Rehabilitation!

Are you a disabled person who has experienced rehabilitation?

Your views and experiences could help shape future rehabilitation policy and practice.

Appendix 5: Project leaflet – inside pages of A5 folded leaflet

Hello. I’m Harriet Cooper and I’m doing research at the University of East Anglia into disabled people’s experiences of rehabilitation. I have a personal experience of rehabilitation for hemiplegia.

A group of disabled people who have experienced rehabilitation is helping to make decisions about what this research should investigate and how.

What is the research for?

I am trying to find out about disabled people’s experiences of the process of rehabilitation, in order to understand how disabled people can be involved in shaping rehabilitation services.

What do you mean by ‘rehabilitation’?

Rehabilitation includes:

- physiotherapy, occupational therapy, speech and language therapy
- rehabilitation medicine and nursing
- rehabilitation counselling and psychology
- using wheelchair services
- training for use of other assistive devices
- experience of using orthotics and prosthetics
- another type of rehabilitation for a physical or sensory impairment.

Rights-based Rehabilitation Leaflet
V3, 25 Aug 2016, IRAS: 207584

Rehabilitation may have taken place at any stage of your life. You may have been an inpatient or an outpatient.

How can people participate?

I am interested in talking to disabled people who would like share their views on, and experiences of, rehabilitation.

You could take part in a one-to-one interview, or participate in a focus group – a group discussion with a few other people.

I am also holding a creative writing workshop on the theme of rehabilitation.

How will the information I gather be used?

I will **write about what people say** in my PhD thesis and in publications, but I will **not use anyone’s real name** and will remove any information that could be used to identify people.

How could your contribution be important?

I want to gather views, opinions and experiences from people from all walks of life. By taking part, your contribution could help to shape rehabilitation policies and practices to ensure that they take account of what disabled people think.

Appendix 6: Easy-read project leaflet – front and back of A5 folded leaflet

Are there any risks to you?

The **risks to you are low.** You might find it upsetting to recall your experiences of rehabilitation. If you do, I will offer you information about **support services.** You can **take a break** at any time or **change your mind** about taking part.

This research has received **ethical approval** from the Health Research Authority.

After the interview or focus group, you will be offered a £10 voucher as a thank you for your time.

If you would like further information, or to have a conversation about what is involved in taking part, please contact Harriet Cooper.

Email: h.cooper@uea.ac.uk Tel: ____________

Address: PhD Researcher, Norwich Medical School,
University of East Anglia, Norwich Research Park,
Norwich, NR4 7TJ.

If you need additional support to be able to take part, please contact Harriet, so that appropriate arrangements can be made.

Rights-based Rehabilitation Easy-read Leaflet
V3, 25 Aug 2016, IRAS 207584

University of East Anglia

disability research @ UEA

Equal Lives

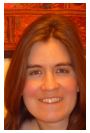
Funded by NHS National Institute for Health Research

Take part in research into Rights-based Rehabilitation!

Are you a disabled person who has experienced rehabilitation?

Your views and experiences could help shape future rehabilitation policy and practice.

Appendix 6: Easy-read project leaflet – inside pages of A5 folded leaflet



Hello. I'm Harriet Cooper and I'm doing **research** at the University of East Anglia into **disabled people's experiences of rehabilitation.**

What is the research for?

I want to find out about disabled people's experiences of the process of rehabilitation, to understand **how disabled people can be involved in shaping rehabilitation services**.

What do you mean by rehabilitation?

Rehabilitation includes:

- physiotherapy, occupational therapy, speech and language therapy
- rehabilitation medicine and nursing
- rehabilitation counselling and psychology
- using wheelchair services
- training for use of other assistive devices
- experience of using orthotics and prosthetics
- another type of rehabilitation for a physical or sensory impairment.

Rehabilitation may have taken place at **any stage of your life**.

You may have been an **inpatient** or an **outpatient**.

How can people participate?

I want to **talk to** disabled people who would like to share their views on, and experiences of, rehabilitation.

I will **talk to people on a one-to-one basis and in small groups.**

If you are interested, I am also holding a **creative writing workshop** on the theme of rehabilitation.

How will the information I gather be used?

I will **write about what people say** in my PhD thesis and in publications, but I will **not use anyone's real name** and will remove any information that could be used to identify people.

How could your contribution be important?

Your views could help to **shape rehabilitation policies** and practices to make sure that they take account of what disabled people think.

Appendix 7: Schedules for interview, focus group, creative writing group

Rights-based Rehabilitation - Interview Schedule
V1, 5 Aug 2016
IRAS: 207584

This is a draft, to be refined with input from the patient group and from creative writing tutors (in relation to the creative writing group programme)

Interview Schedule

Discussion of how the individual came to be disabled, when, where…

Discussion of the individual's experience of rehabilitation, and what it involved.

What went well about rehabilitation?

Which aspects went less well, and why?

What would you change about the experience – what suggestions do you have for how it could be improved? (possible themes: relationships with staff and others, planning, decision-making, goals, equipment, referrals, communication, any other issues?)

To what extent did you feel in control of the process?

Whose priorities were taken into account in making decisions (Yours? Your doctor's? / Member of healthcare staff? / Your relatives?)

Focus Group Schedule

What are your views on the following themes relating to rehabilitation experience?

- What went well, what went less well
- Decision-making and control
- Goal-setting
- Communication among staff
- Relationships
- Access to relevant support, information, funding, equipment
- Transitions

Appendix 7: Schedules for interview, focus group, creative writing group

Rights-based Rehabilitation - Interview Schedule
V1, 5 Aug 2016
IRAS: 207584

Creative Writing Meeting

Possible tasks:

- Write an acrostic poem about rehabilitation, i.e. placing the word REHABILITATION (or another word of your choice) vertically on the page and writing a line starting with each letter of the word.

- Write a haiku / sonnet about rehabilitation (explain rhyme / meter form)

- Write a fictionalised account of rehabilitation – as though you are writing about someone else's experience, not your own. Include references to the following (to provide structure) – e.g. the hospital, your sibling, a member of staff, a colour.

Creative Writing Sharing Group

Attendees will be invited to read their poem or short fictional piece aloud. If they prefer they can read something by a published author which speaks to the theme of rehabilitation. Attendees will be asked to respond to each other's work, to ask questions, offer feedback. The discussion will be relatively unstructured but the aim is to explore rehabilitation narratives – rehabilitation as a lived experience that may provoke different emotions for different individuals.

Appendix 8: Participant information sheet – interview

Harriet Cooper
PhD Researcher
Norwich Medical School
University of East Anglia
Norwich Research Park
Norwich, NR4 7TJ

Telephone
TBC

Email
h.cooper@uea.ac.uk

Participant Information Sheet – Interview

Rights-based Rehabilitation Study

This is information to help you decide if you would like to take part in a research project. Please take time to read it carefully and feel free to ask me if there is anything that is not clear or if you would like more information about the study.

Purpose of the study

The purpose of this study is to find out about disabled people’s experiences of rehabilitation. We are therefore contacting you because you are a disabled person who has experienced rehabilitation. The data collected in this research will be used to help develop recommendations for improving rehabilitation services, and to show how disabled people can be at the centre of their own rehabilitation. The information you provide will be essential to this.

We are interested in your experience of rehabilitation which may have taken place at any stage of your life, whether as an inpatient or an outpatient. Rehabilitation can include:

- physiotherapy, occupational therapy, speech and language therapy
- rehabilitation medicine and nursing
- rehabilitation counselling and psychology
- using wheelchair services
- training for use of other assistive devices
- experience of using orthotics and prosthetics
- another type of rehabilitation for a physical or sensory impairment.

You are being invited to take part in an interview.

Funded by NHS National Institute for Health Research

Appendix 8: Participant information sheet – interview

What will happen during the interview?

The interview will be a one to one discussion with the researcher. It will last no more than 90 minutes, and will take place at a location which is convenient and comfortable for you, such as your home, or in a room at UEA.

The interview is designed to support you to speak about the issues that seem important to you about rehabilitation in ways that you will feel comfortable with. There will be no right or wrong answers. Key themes are likely to include: what went well, and what went less well about rehabilitation and how you felt about it; whose priorities were considered in decision-making processes.

The interview will be recorded on a digital voice recorder, if you agree to this. You will be able to pause or stop taking part in the interview at any time.

After the interview, you will be offered a £10 shopping voucher as a gift to thank you for your time.

How will my information be used?

All the information I gather will be anonymised during transcription. This means that any information which could identify you (address, personal details) or anyone else you refer to will be removed and any names replaced with a pseudonym. If necessary, information may be fictionalised to ensure that you are anonymous.

I will analyse, quote from and discuss the anonymised transcripts in any written reports including my thesis, articles and presentations. Only anonymised quotations will be used in anything I publish. My PhD supervisors may also read anonymised versions of the full transcripts. Short sections of the anonymised transcripts may also be read by members of a small workshop attended by disabled people who are helping to direct the analysis.

Anonymised transcripts will be stored securely for 10 years, after which time they will be destroyed. All audio-recordings will be destroyed at the end of the project.

If you change your mind about taking part, or if you lose decision-making capacity during the interview, I will stop the interview. You can tell me on the consent form whether or not I can keep any data I have collected from you.

Relevant sections of your data collected during the study may be looked at by responsible individuals from the NHS Trust or from regulatory authorities, as part of their audit procedures. This is a standard procedure and these individuals will keep your data confidential.

Appendix 8: Participant information sheet – interview

Rights-based Rehabilitation Participant Information Sheet - Interview
V4, 25 Aug 2016, IRAS: 207584

Benefits of taking part in this study

It is hoped that the study will provide an opportunity for you to reflect on your experiences of rehabilitation.

The information you provide will help me to understand how a rights-based rehabilitation policy and practice can be developed, which gives disabled people a stronger voice in determining their own rehabilitation. We plan to use the research to raise awareness of the need for a rights-based approach among rehabilitation professionals.

Risks of taking part in this study

This study has minimal risks. You may recall aspects of your rehabilitation experience which were distressing. There will be a chance to discuss any concerns or queries you have at any stage of the interview. The interview can be paused at any time, and if necessary we can continue another time.

If you experience further distress as a result of this interview, I will provide you with contact details for appropriate support services.

If during the interview I become aware of actions which pose a significant risk of physical or mental harm to you or other people, I will take action to minimise this risk. This may include informing senior colleagues and relevant authorities. I will discuss these issues with you, and inform you about any action I take.

What if I don’t want to take part?

You do not have to take part in this study. You can withdraw from the study at any time if you change your mind, and I will destroy any data you may have provided if you do not want the study to use it. Your decision will have no consequences for your rehabilitation or for any healthcare you receive.

Who can I contact if I am unhappy about taking part in this research?

If you have any concerns or are unhappy about your participation in this research project, you can contact Andrea Stöckl, who is independent of the study.

Contact details: Dr Andrea Stöckl, Lecturer in Medical Sociology, Norwich Medical School, University of East Anglia, Norwich, NR4 7TJ. Email: _________, telephone: __________.

Funded by NHS National Institute for Health Research

Appendix 8: Participant information sheet – interview

More information about the study

'Rights-based Rehabilitation: A qualitative research project co-produced with disabled people' is a PhD project funded by the National Institute for Health Research's Collaboration for Leadership in Applied Health Research and Care (CLAHRC) East of England. It is being undertaken at the University of East Anglia by Harriet Cooper, under the supervision of Tom Shakespeare, Fiona Poland and Swati Kale. The project is funded within the CLAHRC's Public and Patient Involvement Theme, which means that members of the public (in this case disabled people with an experience of rehabilitation) will have an advisory role in the project.

The study has been reviewed by Newcastle and North Tyneside 1 Research Ethics Committee which on behalf of the Health Research Authority, and it received ethical approval on [insert date].

If you would like to take part in the study, please contact me:

Harriet Cooper, PhD Researcher, Norwich Medical School, University of East Anglia, Norwich Research Park, Norwich, NR4 7TJ. Tel: _____________. Email: h.cooper@uea.ac.uk.

Appendix 9: Easy-read participant information sheet – interview[6]

Easy-read Rights-based Rehabilitation Participant Information Sheet – Interview
V4, 25 Aug 2016, IRAS: 207584

University of East Anglia
NORWICH
MEDICAL
SCHOOL

Harriet Cooper
PhD Researcher
Norwich Medical School
University of East Anglia
Norwich Research Park
Norwich, NR4 7TJ

Telephone
TBC

Email
h.cooper@uea.ac.uk

Rights-based Rehabilitation Research Project

Interview

Who is doing the research?

Harriet Cooper is the **researcher.** She is based at the **University of East Anglia** and is working with several organisations.	

disability research @ UEA

Equal Lives Free from disabling barriers

University of East Anglia

Funded by NHS National Institute for Health Research

---

[6] I would like to acknowledge the NIHR’s Clinical Research Network for Stroke, whose template illustrations for supporting people with aphasia to take part in research are used in all of the easy-read participant information (see NIHR, no date).

Appendix 9: Easy-read participant information sheet – interview

What is the research?

In this research you will **talk** about your **experiences of rehabilitation.**

You will **have a conversation** with the researcher, Harriet, about your experiences.

I want to find out what was **good**

and what could be **improved.**

Rehabilitation includes:

- physiotherapy, occupational therapy, speech and language therapy
- rehabilitation medicine and nursing
- rehabilitation counselling and psychology
- using wheelchair services
- training for use of other assistive devices
- experience of using orthotics and prosthetics
- another type of rehabilitation for a physical or sensory impairment.

Rehabilitation may have taken place at **any stage of your life**.

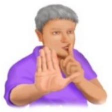
You may have been an **inpatient** or an **outpatient**.

Appendix 9: Easy-read participant information sheet – interview

Easy-read Rights-based Rehabilitation Participant Information Sheet – Interview
V4, 25 Aug 2016, IRAS: 207584

I will take **sound recordings**.	
This helps me to **remember** what you said.	
The sound recordings will be kept **safe.** I will keep the **information** about you **safe and secure.**	

Do I have to take part?

You can decide. You **don't have to** take part. If you don't take part you will **still get your normal help.**	
If you change your mind, **you can stop** at any time.	
You **don't** have to **give a reason**. **If you stop** you will still get your **normal help.**	

disability research @ UEA
Equal Lives Free from disabling barriers
UEA University of East Anglia
Funded by NHS National Institute for Health Research

Appendix 9: Easy-read participant information sheet – interview

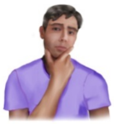
Easy-read Rights-based Rehabilitation Participant Information Sheet – Interview
V4, 25 Aug 2016, IRAS: 207584

If you **lose the capacity to decide** whether you want to take part, I will **stop the interview.** Please tell me on **the consent form** if you want me to **delete your recording** or if I can **keep your recording** in the event that you **change your mind**, or **lose capacity**.	
You don't have to decide now, you can **think about it.** You can **take your time.**	
You can **read** the information **again.**	
If you want, we can meet to talk about the project. You can **talk to your family** to **help you decide.**	

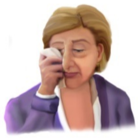
Funded by NHS National Institute for Health Research

Appendix 9: Easy-read participant information sheet – interview

What might be good about taking part?

You may find it **interesting.**	
The research may **help** people in the **future who use rehabilitation services.**	

What might be difficult about taking part?

The risks are low. You may find it **distressing to remember your rehabilitation.**	
You can **take a break at any time.**	
If I become aware of **significant risks** to **you** or to **someone else,** I may have a **duty** to tell a **senior member of staff or relevant authorities.**	
I will talk to you first about this.	

Funded by NHS National Institute for Health Research

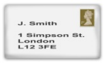
Appendix 9: Easy-read participant information sheet – interview

Easy-read Rights-based Rehabilitation Participant Information Sheet – Interview
V4, 25 Aug 2016, IRAS: 207584

Is the research safe?

An ethics committee has decided that **this research can happen.**	
They say that it has been **planned properly.** Newcastle and North Tyneside 1 Research Ethics Committee **approved this research** on behalf of the **Health Research Authority** on [insert date].	

What if something goes wrong?

This is very unlikely. If you **want to talk to someone who is independent of the research, you can contact**	
Dr Andrea Stöckl, Lecturer in Medical Sociology, Norwich Medical School, University of East Anglia, Norwich, NR4 7TJ. Email:_______________. Telephone: __________.	 

disability research @ UEA
Equal Lives Free from disabling barriers
UEA University of East Anglia
Funded by NHS National Institute for Health Research

Appendix 9: Easy-read participant information sheet – interview

What will happen to the results?

I will **give you the results** of the research.	
I will share the **results** ○ with **other researchers** ○ at **conferences** and **meetings** ○ through **newsletters** and **magazines** ○ in **academic journals** ○ on **websites** ○ with **other people** who have **experienced rehabilitation**	  
No one will be able to identify you.	
The results will **not use your name.**	
Transcripts will be **stored securely** for 10 years, and then destroyed. All **audio-recordings** will be **destroyed** at the end of the project.	
Your data may be looked at **by responsible individuals from the NHS Trust** or from regulatory authorities, as part of their audit procedures. They will keep your data **confidential.**	

disability research @ UEA
Equal Lives Free from disabling barriers
UEA University of East Anglia
Funded by NHS National Institute for Health Research

Appendix 9: Easy-read participant information sheet – interview

Will I get paid?

We will give you a **£10 voucher** if you take part. This is to **thank you.**	

What next?

Do you **want** to **take part?** **You need to decide**.	
You may want **more information** Contact **me, Harriet Cooper:** h.cooper@uea.ac.uk Tel: _______________ PhD Researcher - Rights-based Rehabilitation Norwich Medical School, University of East Anglia Norwich Research Park, Norwich, NR4 7TJ	
If you decide to take part you will need to **sign a consent form.** This says that **you understand** the research and **you agree** to take part.	 

Funded by NHS National Institute for Health Research

Appendix 9: Easy-read Participant Information Sheet – Interview

I will **contact you**. I will ask for **your decision.** **Yes** I want to **No** I don't want to	   

Appendix 10: Consent form - interview

Rights-based Rehabilitation Consent Form
V2, 15 Aug 2016, IRAS: 207584

Rights-based Rehabilitation: Interview - Consent Form

Please initial box

I confirm that I have read the information sheet dated.................. (version...........) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
I understand that my participation is voluntary and that I am free to take a break or withdraw at any time, without giving any reason, without my medical care or legal rights being affected.	
I understand that my anonymised interview may be quoted and discussed in the PhD thesis, in publications and in presentations at workshops and events, but that my real name will not be used and that any information that could be used to identify me will be removed.	
I understand that a sound recording of the interview will be made.	
I understand that relevant sections of my data collected during the study may be looked at by responsible individuals from the NHS Trust or from regulatory authorities, where it is relevant to my taking part in this research. I give permission for these individuals to have access to these data.	
I agree to take part in this study.	

Please circle YES or NO:

If I change my mind about taking part, or if I lose the capacity to decide about taking part, the researcher can keep my contributions and use these in the study.	YES	NO
I would like to receive a transcript of my interview to check.	YES	NO

____________________	____________________	____________________
Name of Participant	Date	Signature
____________________	____________________	____________________
Name of Person taking consent	Date	Signature

Appendix 11: Easy-read consent form - interview

Rights-based Rehabilitation - Easy-read consent form, Interview
V2, 15 Aug 2016, IRAS: 207584

Easy-read Consent Form for Rights-based Rehabilitation Interview

Please initial box:

I **have read the information sheet** dated.................... (version............) for the above study. I have had the opportunity to think about the information, **ask questions** and have **received satisfactory answers.**		

I understand that I can **take a break** at any time.		

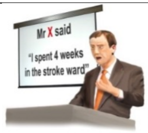
I understand that I can leave the project at any time if I **change my mind.** If I do, this **won't affect** my medical **care** or my legal **rights.**		

disability research @ UEA
Equal Lives Free from disabling barriers
UEA University of East Anglia
Funded by NHS National Institute for Health Research

Appendix 11: Easy-read consent form - interview

Rights-based Rehabilitation - Easy-read consent form, Interview
V2, 15 Aug 2016, IRAS: 207584

Please initial box:

What I say may be **quoted (without my real name) and discussed** in the PhD thesis, in publications and in presentations at events and workshops. **I know that my real name will not be used** and that any information that could be used to **identify me will be removed.**	 	

I understand that **sections of my data** collected during the study **may be looked at by responsible individuals from the NHS Trust or from regulatory authorities**, where it is relevant to my taking part in this research. I **give permission** for these individuals to have access to these data.		

I am aware that **a sound recording** of [insert group title] will be made.		

I would **like to take part** in this research project.		

Appendix 11: Easy-read consent form - interview

Rights-based Rehabilitation - Easy-read consent form, Interview
V2, 15 Aug 2016, IRAS: 207584

Please tick YES or NO:

If I **change my mind** about taking part, or if I **lose the capacity** to decide about taking part, the researcher can **keep my contributions and use these in the study.**		
👍 **yes** ☐	👎 **no** ☐	

I would like to receive a **transcript** of the interview to check**.**		
👍 **yes** ☐	👎 **no** ☐	

__________________ __________________ __________________

Name of Participant Date Signature

__________________ __________________ __________________

Name of Person taking consent Date Signature

Page 3 of 3

disability research @ UEA
Equal Lives Free from disabling barriers
UEA University of East Anglia
Funded by NHS National Institute for Health Research

Appendix 12: Participant information sheet – focus group

Rights-based Rehabilitation Participant Information Sheet - Focus Group
V4, 25 Aug 2016, IRAS: 207584

**Harriet Cooper
PhD Researcher
Norwich Medical School
University of East Anglia
Norwich Research Park
Norwich, NR4 7TJ**

Telephone
TBC

Email
h.cooper@uea.ac.uk

Participant Information Sheet – Focus Group

Rights-based Rehabilitation Study

This is information to help you decide if you would like to take part in a research project. Please take time to read it carefully and feel free to ask me if there is anything that is not clear or if you would like more information about the study.

Purpose of the study

The purpose of this study is to find out about disabled people's experiences of rehabilitation. We are therefore contacting you because you are a disabled person who has experienced rehabilitation. The data collected in this research will be used to help develop recommendations for improving rehabilitation services, and to show how disabled people can be at the centre of their own rehabilitation. The information you provide will be essential to this.

We are interested in your experience of rehabilitation which may have taken place at any stage of your life, whether as an inpatient or an outpatient. Rehabilitation can include:

- physiotherapy, occupational therapy, speech and language therapy
- rehabilitation medicine and nursing
- rehabilitation counselling and psychology
- using wheelchair services
- training for use of other assistive devices
- experience of using orthotics and prosthetics
- another type of rehabilitation for a physical or sensory impairment.

You are being invited to take part in a focus group.

Funded by NHS National Institute for Health Research

Appendix 12: Participant information sheet – focus group

What will happen during the focus group?

The focus group will be a discussion facilitated by the researcher and perhaps another of her colleagues. It will involve around 5 or 6 participants, all of whom have **a spinal cord injury [insert alternative impairment]**, will last around 2 hours and will take place at UEA or in a booked room in a public space.

The discussion will support people to share their views about various aspects of rehabilitation, for example:

- relationships with rehabilitation professionals
- decision-making processes (whose priorities were considered important?)
- continuity of care over time / across geographical locations.

We hope the discussion will offer you the chance to raise related issues that are relevant to you.

After the focus group, you will be offered a £10 shopping voucher as a gift to thank you for giving your time.

Information on the identities of other focus group members, and information shared by focus group members, must not be shared with people outside the focus group.

How will my information be used?

All the information I gather will be anonymised during transcription. This means that any information which could identify you (address, personal details) or anyone else you refer to will be removed and any names replaced with a pseudonym. If necessary, information may be fictionalised to ensure that you are anonymous.

I will analyse, quote from and discuss the anonymised transcripts in any written reports including my thesis, articles and presentations. Only anonymised quotations will be used in anything I publish. My PhD supervisors may also read anonymised versions of the full transcripts. Short sections of the anonymised transcripts may also be read by members of a small workshop attended by disabled people who are helping to direct the analysis.

Anonymised transcripts will be stored securely for 10 years, after which time they will be destroyed. All audio-recordings will be destroyed at the end of the project.

If you change your mind about taking part, or if you lose decision-making capacity during the group, I won't collect any further data from you. You can tell me on the consent form whether or not I can keep any data I have collected from you.

Relevant sections of your data collected during the study may be looked at by responsible individuals from the NHS Trust or from regulatory authorities, as part of their audit procedures. This is a standard procedure and these individuals will keep your data confidential.

Appendix 12: Participant information sheet – focus group

Benefits of taking part in this study

It is hoped that the study will provide an opportunity for you to reflect on your experiences of rehabilitation.

The information you provide will help me to understand how a rights-based rehabilitation policy and practice can be developed, which gives disabled people a stronger voice in determining their own rehabilitation. We plan to use the research to raise awareness of the need for a rights-based approach among rehabilitation professionals.

Risks of taking part in this study

This study has minimal risks. You may recall aspects of your rehabilitation experience which were distressing. The discussion can be paused at any stage to discuss concerns or queries.

If you wish, I can provide you with contact details for appropriate support services.

If, during the discussion, I become aware of actions which pose a significant risk of physical or mental harm to you or other people, I will take action to minimise this risk. This may include informing senior colleagues and relevant authorities. I will discuss these issues with you, and inform you about any action I take.

What if I don’t want to take part?

You do not have to take part in this study. You can withdraw from the study at any time if you change your mind, and I will destroy any data you may have provided if you do not want the study to use it. Your decision will have no consequences for your rehabilitation or for any healthcare you receive.

Who can I contact if I am unhappy about taking part in this research?

If you have any concerns or are unhappy about your participation in this research project, you can contact Andrea Stöckl, who is independent of the study.

Contact details: Dr Andrea Stöckl, Lecturer in Medical Sociology, Norwich Medical School, University of East Anglia, Norwich, NR4 7TJ. Email:___________, telephone:______________.

Appendix 12: Participant information sheet – focus group

More information about the study

'Rights-based Rehabilitation: A qualitative research project co-produced with disabled people' is a PhD project funded by the National Institute for Health Research's Collaboration for Leadership in Applied Health Research and Care (CLAHRC) East of England. It is being undertaken at the University of East Anglia by Harriet Cooper, under the supervision of Tom Shakespeare, Fiona Poland and Swati Kale. The project is funded within the CLAHRC's Public and Patient Involvement Theme, which means that members of the public (in this case disabled people with an experience of rehabilitation) will have an advisory role in the project.

This study has been reviewed by Newcastle and North Tyneside 1 Research Ethics Committee on behalf of the Health Research Authority, and it received ethical approval on [insert date].

If you would like to take part in the study, please contact me:

Harriet Cooper, PhD Researcher, Norwich Medical School, University of East Anglia, Norwich Research Park, Norwich, NR4 7TJ. Tel: ______________. Email: h.cooper@uea.ac.uk.

Appendix 13: Easy-read participant information sheet – focus group

Harriet Cooper
PhD Researcher
Norwich Medical School
University of East Anglia
Norwich Research Park
Norwich, NR4 7TJ

Telephone
TBC

Email
h.cooper@uea.ac.uk

Rights-based Rehabilitation Research Project

Focus Group

Who is doing the research?

Harriet Cooper is the **researcher.** She is based at the **University of East Anglia** and is working with several organisations.	

Funded by NHS National Institute for Health Research

Appendix 13: Easy-read participant information sheet – focus group

Easy-read Rights-based Rehabilitation Participant Information Sheet - Focus Group
V4, 25 Aug 2016 IRAS: 207584

What is the research?

In this research you will **talk** about your **views of rehabilitation.**

You will **have a conversation** with a **group of people** who have an experience of rehabilitation.

I want to find out what was **good**

and what could be **improved.**

Rehabilitation includes:

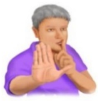
- physiotherapy, occupational therapy, speech and language therapy
- rehabilitation medicine and nursing
- rehabilitation counselling and psychology
- using wheelchair services
- training for use of other assistive devices
- experience of using orthotics and prosthetics
- another type of rehabilitation for a physical or sensory impairment.

Rehabilitation may have taken place at **any stage of your life**.

You may have been an **inpatient** or an **outpatient**.

Funded by NHS National Institute for Health Research

Appendix 13: Easy-read participant information sheet – focus group

I will take **sound recordings**. This helps me to **remember** what you said. The sound recordings will be kept **safe.** I will keep the **information** about you **safe and secure.** Information on the **identities of other focus group members**, and **information shared by focus group members, must not be shared with people outside the focus group.**	   

Do I have to take part?

You can decide. You **don't have to** take part. If you don't take part you will **still get your normal help.** If you change your mind, **you can stop** at any time. You **don't** have to **give a reason**. **If you stop** you will still get your **normal help.**	 

Funded by NHS National Institute for Health Research

Appendix 13: Easy-read participant information sheet – focus group

Easy-read Rights-based Rehabilitation Participant Information Sheet - Focus Group
V4, 25 Aug 2016 IRAS: 207584

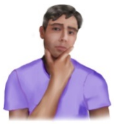
If you **lose the capacity to decide** whether you want to take part, I will **stop the interview.** Please tell me on **the consent form** if you want me to **delete your recording** or if I can **keep your recording** in the event that you **change your mind**, or **lose capacity**.	
You don't have to decide now, you can **think about it.** You can **take your time.**	
You can **read** the information **again.**	
If you want, we can meet to talk about the project. You can **talk to your family** to **help you decide.**	

disability research @ UEA
Equal Lives Free from disabling barriers
UEA University of East Anglia
Funded by NHS National Institute for Health Research

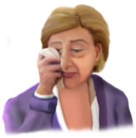
Appendix 13: Easy-read participant information sheet – focus group

Easy-read Rights-based Rehabilitation Participant Information Sheet - Focus Group
V4, 25 Aug 2016 IRAS: 207584

What might be good about taking part?

You may find it **interesting.**	
The research may **help** people in the **future who use rehabilitation services.**	

What might be difficult about taking part?

The risks are low. You may find it **distressing to remember your rehabilitation.**	
You can **take a break at any time.**	
If I become aware of **significant risks** to **you** or to **someone else,** I may have a **duty** to tell a **senior member of staff or relevant authorities.**	
I will talk to you first about this.	

disability research @ UEA

Equal Lives Free from disabling barriers

UEA University of East Anglia

Funded by NHS National Institute for Health Research

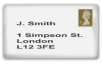
Appendix 13: Easy-read participant information sheet – focus group

Easy-read Rights-based Rehabilitation Participant Information Sheet - Focus Group
V4, 25 Aug 2016 IRAS: 207584

Is the research safe?

An ethics committee has decided that **this research can happen.** They say that it has been **planned properly.** Newcastle and North Tyneside 1 Research Ethics Committee **approved this research** on behalf of the **Health Research Authority** on [insert date].	 

What if something goes wrong?

This is very unlikely. If you **want to talk to someone who is independent of the research, you can contact** Dr Andrea Stöckl, Lecturer in Medical Sociology, Norwich Medical School, University of East Anglia, Norwich, NR4 7TJ. Email: _____________. Telephone: ____________.	  

disability research @ UEA
Equal Lives Free from disabling barriers
UEA University of East Anglia
Funded by NHS National Institute for Health Research

Appendix 13: Easy-read participant information sheet – focus group

What will happen to the results?

I will **give you the results** of the research.	
I will share the **results** ○ with **other researchers** ○ at **conferences** and **meetings** ○ through **newsletters** and **magazines** ○ in **academic journals** ○ on **websites** ○ with **other people** who have **experienced rehabilitation**	  
No one will be able to identify you.	
The results will **not use your name.**	
Transcripts will be **stored securely** for 10 years, and then destroyed. All **audio-recordings** will be **destroyed** at the end of the project.	
Your data may be looked at **by responsible individuals from the NHS Trust** or from **regulatory authorities**, as part of their audit procedures. They will keep your data **confidential.**	

Appendix 13: Easy-read participant information sheet – focus group

Easy-read Rights-based Rehabilitation Participant Information Sheet - Focus Group
V4, 25 Aug 2016 IRAS: 207584

Will I get paid?

We will give you a **£10 voucher** if you take part. This is to **thank you.**	

What next?

Do you **want** to **take part?** **You need to decide**.	
You may want **more information** Contact **me, Harriet Cooper:** **h.cooper@uea.ac.uk** Tel: _______________ PhD Researcher - Rights-based Rehabilitation Norwich Medical School, University of East Anglia Norwich Research Park, Norwich, NR4 7TJ	
If you decide to take part you will need to **sign a consent form.** This says that **you understand** the research and **you agree** to take part.	 

disability research @ UEA

Equal Lives
Free from disabling barriers

UEA
University of East Anglia

Funded by NHS
National Institute for Health Research

Appendix 13: Easy-read participant information sheet – focus group

I will **contact you**. I will ask for **your decision.** **Yes** I want to. **No** I don't want to.	   

Appendix 14: Consent form – focus group

Rights-based Rehabilitation – FG/CWG Consent Form
V3, 25 Aug 2016, IRAS: 207584

Rights-based Rehabilitation: Focus Group Consent Form

Please initial box

I confirm that I have read the information sheet dated................... (version...........) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
I understand that my participation is voluntary and that I am free to take a break or withdraw at any time, without giving any reason, without my medical care or legal rights being affected.	
I understand that what I say in the discussion may be quoted and discussed in the PhD thesis, in publications and in presentations at workshops and events, but that my real name will not be used and that any information that could be used to identify me will be removed.	
I understand that a sound recording of the focus group will be made.	
I understand that information on the **identities of other focus group members**, and **information shared by focus group members, must not be shared with people outside the group.**	
I understand that relevant sections of my data collected during the study may be looked at by responsible individuals from the NHS Trust or from regulatory authorities, where it is relevant to my taking part in this research. I give permission for these individuals to have access to these data.	
I agree to take part in this study.	

Please circle YES or NO:

If I change my mind about taking part, or if I lose the capacity to decide about taking part, the researcher can keep my contributions and use these in the study.	YES NO

___________________ ___________________ ___________________

Name of Participant Date Signature

___________________ ___________________ ___________________

Name of Person taking consent Date Signature

Appendix 15: Easy-read consent form – focus group

Rights-based Rehabilitation - Easy-read consent form, FG/CWG
V3, 25 Aug 2016, IRAS: 207584

Easy-read Consent Form for Rights-based Rehabilitation Focus Group / Creative Writing Group

Please initial box:

I **have read the information sheet** dated.................... (version............) for the above study. I have had the opportunity to think about the information, **ask questions** and have **received satisfactory answers.**		

I understand that I can **take a break** at any time.		

I understand that I can leave the project at any time if I **change my mind.** If I do, this **won't affect** my medical **care** or my legal **rights.**		

disability research @ UEA
Equal Lives Free from disabling barriers
UEA University of East Anglia
Funded by NHS National Institute for Health Research

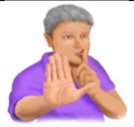
Appendix 15: Easy-read consent form – focus group

Rights-based Rehabilitation - Easy-read consent form, FG/CWG
V3, 25 Aug 2016, IRAS: 207584

Please initial box:

What I say may be **quoted (without my real name) and discussed** in the PhD thesis, in publications and in presentations at events and workshops. **I know that my real name will not be used** and that any information that could be used to **identify me will be removed.**		

I understand that **sections of my data** collected during the study **may be looked at by responsible individuals from the NHS Trust or from regulatory authorities**, where it is relevant to my taking part in this research. I **give permission** for these individuals to have access to these data.		

I understand that information on the **identities of other focus group members**, and **information shared by focus group members, must not be shared with people outside the group.**		

Appendix 15: Easy-read consent form – focus group

Rights-based Rehabilitation - Easy-read consent form, FG/CWG
V3, 25 Aug 2016, IRAS: 207584

Please tick YES or NO:

I am aware that **a sound recording** of [insert group title] will be made.		

I would **like to take part** in this research project.		

If I **change my mind** about taking part, or if I **lose the capacity** to decide about taking part, the researcher can **keep my contributions and use these in the study.**		
👍 **yes** ☐	👎 **no** ☐	

______________________ ______________________ ______________________

Name of Participant Date Signature

______________________ ______________________ ______________________

Name of Person taking consent Date Signature

Appendix 16: Participant information sheet – creative writing group (final version, agreed as part of the substantial amendment)

Rights-based Rehabilitation Participant Information Sheet – Creative Writing Group
V5, 29 Aug 2018, IRAS: 207584

Harriet Cooper
PhD Researcher
Norwich Medical School
University of East Anglia
Norwich Research Park
Norwich, NR4 7TJ

Telephone
TBC

Email
h.cooper@uea.ac.uk

Participant Information Sheet – Creative Writing Group

Rights-based Rehabilitation Study

This is information to help you decide if you would like to take part in a research project. Please take time to read it carefully and feel free to ask me if there is anything that is not clear or if you would like more information about the study.

Purpose of the study

The purpose of this study is to find out about disabled people's experiences of rehabilitation. We are therefore contacting you because you are a disabled person who has experienced rehabilitation. The data collected in this research will be used to help develop recommendations for improving rehabilitation services, and to show how disabled people can be at the centre of their own rehabilitation. The information you provide will be essential to this.

We are interested in your experience of rehabilitation which may have taken place at any stage of your life, whether as an inpatient or an outpatient. Rehabilitation can include:

- physiotherapy, occupational therapy, speech and language therapy
- rehabilitation medicine and nursing
- rehabilitation counselling and psychology
- using wheelchair services
- training for use of other assistive devices
- experience of using orthotics and prosthetics
- another type of rehabilitation for a physical or sensory impairment.

You are being invited to take part in the creative writing group.

disability research@UEA
Equal Lives Free from disabling barriers
University of East Anglia
Funded by NHS National Institute for Health Research

Appendix 16: Participant information sheet – creative writing group

Rights-based Rehabilitation Participant Information Sheet – Creative Writing Group
V5, 29 Aug 2018, IRAS: 207584

What will happen during the creative writing group?

There will be two writing activity sessions (with up to 10 people overall), facilitated by 2 people. Many people find it helpful to express their views on their experiences through creative writing activities which use their imagination and different ways of writing. There would be no expectations of "right and wrong ways" to write.

There will be two meetings of the creative writing group, a writing group and a sharing group. Prior to the groups, I will explore with potential participants whether they need any adjustments in order to be able to take part. Potential adjustments might include, for example, the option to dictate writing to a facilitator in a separate room, to use a voice recorder, or to work in pairs to write.

The first (writing) group: The purpose of the writing group would be for you to write about rehabilitation in a creative and/or fictionalised form. There will be themed writing exercises which will act as prompts for you to reflect on and write about your experiences of rehabilitation. We won't be recording the session and we won't expect you to read out your writing. You will keep any writing you produce, and take it writing away with you. You would be free to attend only this session and not to attend the second (sharing) session.I will send you details of the writing tasks before the first session.

Between the two meetings, perhaps you will feel inspired to develop your writing further.

The second (sharing) group: Attendees may choose to read out or perform their creative writing, or to read something else by a published author. Alternatively they may choose for their writing to be read out anonymously by another participant, or by one of the facilitators, or they may put up their writing on the wall for others to read during the session. This will hopefully lead to in-depth discussions about the experience of rehabilitation. This session will be audio-recorded and transcripts of the discussion will be written up which will be used in my research. I would like to collect a paper copy or email copy of your writing, if you are happy for me to do this. These documents will be kept safe and anonymised in discussions in my research, as will discussion transcripts. I am requesting this because it will help me with my research, but it is optional.

After the second session, you will be offered a £10 shopping voucher as a gift to thank you for your time. As resources are limited, those who attend only the first session will not receive a voucher.

Information on the identities of other members of the creative writing group, and information shared by members of the creative writing group, must not be shared with people outside the group.

How will my information be used?

Appendix 16: Participant information sheet – creative writing group

All the information I gather will be anonymised during transcription. This means that any information which could identify you (address, personal details) or anyone else you refer to will be removed and any names replaced with a pseudonym. If necessary, information may be fictionalised to ensure that you are anonymous.

I will analyse, quote from and discuss the anonymised transcripts and creative writing documents (if supplied) in any written reports including my thesis, articles and presentations. Only anonymised quotations will be used in anything I publish. My PhD supervisors may also read anonymised versions of the full transcripts. Short sections of the anonymised transcripts may also be read by members of a small workshop attended by disabled people who are helping to direct the analysis.

Anonymised transcripts will be stored securely for 10 years, after which time they will be destroyed. All audio-recordings will be destroyed at the end of the project.

If you change your mind about taking part, or if you lose decision-making capacity during the group, I won't collect any further data from you. You can tell me on the consent form whether or not I can keep any data I have collected from you.

Relevant sections of your data collected during the study may be looked at by responsible individuals from the NHS Trust or from regulatory authorities, as part of their audit procedures. This is a standard procedure and these individuals will keep your data confidential.

Benefits of taking part in this study

It is hoped that the study will provide an opportunity for you to reflect on your experiences of rehabilitation.

The information you provide will help me to understand how a rights-based rehabilitation policy and practice can be developed, which gives disabled people a stronger voice in determining their own rehabilitation. We plan to use the research to raise awareness of the need for a rights-based approach among rehabilitation professionals.

Risks of taking part in this study

This study has minimal risks. You may recall aspects of your rehabilitation experience which were distressing. The discussion can be paused at any stage to discuss concerns or queries.

If you wish, I can provide you with contact details for appropriate support services.

Appendix 16: Participant information sheet – creative writing group

If, during the discussion, I become aware of actions which pose a significant risk of physical or mental harm to you or other people, I will take action to minimise this risk. This may include informing senior colleagues and relevant authorities. I will discuss these issues with you, and inform you about any action I take.

What if I don't want to take part?

You do not have to take part in this study. You can withdraw from the study at any time if you change your mind, and I will destroy any data you may have provided if you do not want the study to use it. Your decision will have no consequences for your rehabilitation or for any healthcare you receive.

Who can I contact if I am unhappy about taking part in this research?

If you have any concerns or are unhappy about your participation in this research project, you can contact Andrea Stöckl, who is independent of the study.

Contact details: Dr Andrea Stöckl, Lecturer in Medical Sociology, Norwich Medical School, University of East Anglia, Norwich, NR4 7TJ. Email: __________ telephone: _________.

More information about the study

'Rights-based Rehabilitation: A qualitative research project co-produced with disabled people' is a PhD project funded by the National Institute for Health Research's Collaboration for Leadership in Applied Health Research and Care (CLAHRC) East of England. It is being undertaken at the University of East Anglia by Harriet Cooper, under the supervision of Tom Shakespeare, Fiona Poland and Swati Kale. The project is funded within the CLAHRC's Public and Patient Involvement Theme, which means that members of the public (in this case disabled people with an experience of rehabilitation) will have an advisory role in the project.

This study has been reviewed by Newcastle and North Tyneside 1 Research Ethics Committee on behalf of the Health Research Authority, and it received ethical approval on 30th August 2016.

If you would like to take part in the study, please contact me:

Harriet Cooper, PhD Researcher, Norwich Medical School, University of East Anglia, Norwich Research Park, Norwich, NR4 7TJ. Tel: __________________. Email: h.cooper@uea.ac.uk.

Appendix 17: Easy-read participant information sheet – creative writing group (final version, agreed as part of the substantial amendment)

Easy-read Rights-based Rehabilitation Participant Information Sheet - Creative Writing Group
V5, 29 Aug 2018, IRAS: 207584

Harriet Cooper
PhD Researcher
Norwich Medical School
University of East Anglia
Norwich Research Park
Norwich, NR4 7TJ

Telephone
TBC

Email
h.cooper@uea.ac.uk

Rights-based Rehabilitation Research Project

Creative Writing Group

Who is doing the research?

Harriet Cooper is the **researcher.** She is based at the **University of East Anglia** and is working with several organisations.	

Appendix 17: Easy-read participant information sheet – creative writing group

Easy-read Rights-based Rehabilitation Participant Information Sheet - Creative Writing Group
V5, 29 Aug 2018, IRAS: 207584

What is the research?

This information sheet is about a **discussion meeting** on [date] in which **participants will talk about the writing they did in the creative writing workshop** on [date].

Hopefully this will lead to a conversation about…

👍 what was **good….**

👎 and what could be **improved….**

about rehabilitation.

The creative writing workshop on [date] will **not be recorded** and **no information will be gathered** for my research in that workshop. **Only the discussion meeting on [date] will be recorded.**

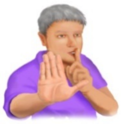
Rehabilitation includes:

- physiotherapy, occupational therapy, speech and language therapy
- rehabilitation medicine and nursing
- rehabilitation counselling and psychology
- using wheelchair services
- training for use of other assistive devices
- experience of using orthotics and prosthetics
- another type of rehabilitation for a physical or sensory impairment.

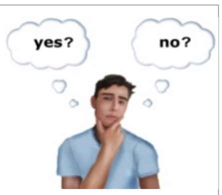
Rehabilitation may have taken place at **any stage of your life**.

You may have been an **inpatient** or an **outpatient**.

Appendix 17: Easy-read participant information sheet – creative writing group

I will take **sound recordings**. This helps me to **remember** what you said. I would like to have a **paper copy or email copy of your writing** if you are happy to give it to me. **This is optional** but it will **help me** with the research. **No one will be able to identify you** if I discuss your writing in my research. The sound recordings and paper copies will be kept **safe.** I will keep the **information** about you **safe and secure.** Information on the **identities** of other **members of the creative writing group**, and **information shared by members of the creative writing group**, must **not be shared with people outside the group**.	   

Do I have to take part?

You can decide. You **don't have to** take part. If you don't take part you will **still get your normal help.**	

disability research @ UEA
Equal Lives Free from disabling barriers
UEA University of East Anglia
Funded by NHS National Institute for Health Research

Appendix 17: Easy-read participant information sheet – creative writing group

Easy-read Rights-based Rehabilitation Participant Information Sheet - Creative Writing Group
V5, 29 Aug 2018, IRAS: 207584

If you change your mind, **you can stop** at any time. You **don't** have to **give a reason**. **If you stop** you will still get your **normal help.**	
If you **lose the capacity to decide** whether you want to take part, I will **stop the interview.** Please tell me on **the consent form** if you want me to **delete your recording** or if I can **keep your recording** in the event that you **change your mind**, or **lose capacity**.	
You don't have to decide now, you can **think about it.** You can **take your time.**	
You can **read** the information **again.**	
If you want, we can meet to talk about the project. You can **talk to your family** to **help you decide.**	

disability research @ UEA
Equal Lives Free from disabling barriers
UEA University of East Anglia
Funded by NHS National Institute for Health Research

Appendix 17: Easy-read participant information sheet – creative writing group

Easy-read Rights-based Rehabilitation Participant Information Sheet - Creative Writing Group
V5, 29 Aug 2018, IRAS: 207584

Do you need any adjustments to be able to take part?

Please talk to me in advance if there are **things I can do to make it easier** for you to take part.	
For example, you could **use a voice recorder** rather than writing by hand, you could **work with someone else**, or you could **dictate your writing to a facilitator.**	
I will **send you details** of the tasks **before** the group.	
If you **prefer not to read** your writing aloud, you can **display it on the wall** or **someone else can read** it.	

disability research @ UEA

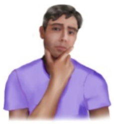
Equal Lives
Free from disabling barriers

UEA
University of East Anglia

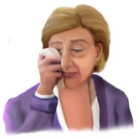
Funded by
NHS
National Institute for
Health Research

Appendix 17: Easy-read participant information sheet – creative writing group

What might be good about taking part?

You may find it **interesting.**	
The research may **help** people in the **future who use rehabilitation services.**	

What might be difficult about taking part?

The risks are low. You may find it **distressing to remember your rehabilitation.**	
You can **take a break at any time.**	
If I become aware of **significant risks** to **you** or to **someone else,** I may have a **duty** to tell a **senior member of staff or relevant authorities.**	
I will talk to you first about this.	

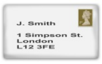
disability research @ UEA
Equal Lives Free from disabling barriers
UEA University of East Anglia
Funded by NHS National Institute for Health Research

Appendix 17: Easy-read participant information sheet – creative writing group

Is the research safe?

An ethics committee has decided that **this research can happen.** They say that it has been **planned properly.** Newcastle and North Tyneside 1 Research Ethics Committee **approved this research** on behalf of the **Health Research Authority** on 30th August 2016.	 

What if something goes wrong?

This is very unlikely. If you **want to talk to someone who is independent of the research, you can contact:** Dr Andrea Stöckl, Lecturer in Medical Sociology, Norwich Medical School, University of East Anglia, Norwich, NR4 7TJ. Email: A.Stockl@uea.ac.uk. Telephone: 01603 591879.	  

disability research @ UEA
Equal Lives Free from disabling barriers
UEA University of East Anglia
Funded by NHS National Institute for Health Research

Appendix 17: Easy-read participant information sheet – creative writing group

Easy-read Rights-based Rehabilitation Participant Information Sheet - Creative Writing Group
V5, 29 Aug 2018, IRAS: 207584

What will happen to the results?

I will **give you the results** of the research.	
I will share the **results** ○ with **other researchers** ○ at **conferences** and **meetings** ○ through **newsletters** and **magazines** ○ in **academic journals** ○ on **websites** ○ with **other people** who have **experienced rehabilitation**	  
No one will be able to identify you.	
The results will **not use your name.**	
Transcripts will be **stored securely** for 10 years, and then destroyed. All **audio-recordings** will be **destroyed** at the end of the project.	
Your data may be looked at **by responsible individuals from the NHS Trust** or from **regulatory authorities**, as part of their audit procedures. They will keep your data **confidential.**	

Funded by NHS National Institute for Health Research

Appendix 17: Easy-read participant information sheet – creative writing group

Will I get paid?

We will give you a **£10 voucher** if you take part. This is to **thank you.**	

What next?

Do you **want** to **take part?** **You need to decide**.	
You may want **more information** Contact **me, Harriet Cooper:** h.cooper@uea.ac.uk Tel: _______________ PhD Researcher - Rights-based Rehabilitation Norwich Medical School, University of East Anglia Norwich Research Park, Norwich, NR4 7TJ	
If you decide to take part you will need to **sign a consent form.** This says that **you understand** the research and **you agree** to take part.	

Appendix 17: Easy-read participant information sheet – creative writing group

I will **contact you**.	
I will ask for **your decision.**	
Yes I want to.	
No I don't want to.	

Funded by NHS National Institute for Health Research

Appendix 18: Consent form – creative writing group

Rights-based Rehabilitation – CWG Consent Form
V4, 29 Aug 2018, IRAS: 207584

Rights-based Rehabilitation: Creative Writing Group

Consent Form

	Please initial box
I confirm that I have read the information sheet dated................... (version............) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
I understand that my participation is voluntary and that I am free to take a break or withdraw at any time, without giving any reason, without my medical care or legal rights being affected.	
I understand that what I say in the discussion, including my writing, if it is read aloud or displayed for discussion, may be quoted and discussed in the PhD thesis, in publications and in presentations at workshops and events, but that my real name will not be used and that any information that could be used to identify me will be removed.	
I understand that a sound recording of the second writing group will be made.	
I understand that information on the identities of other creative writing group members, and information shared by creative writing group members, must not be shared with people outside the group.	
I understand that relevant sections of my data collected during the study may be looked at by responsible individuals from the NHS Trust or from regulatory authorities, where it is relevant to my taking part in this research. I give permission for these individuals to have access to these data.	
I agree to take part in this study.	

disability research @ UEA
Equal Lives Free from disabling barriers
UEA University of East Anglia
Funded by NHS National Institute for Health Research

Appendix 18: Consent form – creative writing group

Rights-based Rehabilitation – CWG Consent Form
V4, 29 Aug 2018, IRAS: 207584

Please circle YES or NO:

If I change my mind about taking part, or if I lose the capacity to decide about taking part, the researcher can keep my contributions and use these in the study.	YES	NO
I am happy for a hard copy of my writing to be displayed on the wall during the discussion, for others to read.	YES	NO
I am happy for the researcher to keep a hard copy or electronic copy of my writing, and to use this version of my writing in her analysis, as well as the version in the audio-recording.	YES	NO

__________________ __________________ __________________

Name of Participant Date Signature

__________________ __________________ __________________

Name of Person
taking consent Date Signature

Appendix 19: Easy-read consent form – creative writing group

Rights-based Rehabilitation - Easy-read consent form, CWG
V4, 29 August 2018, IRAS: 207584

Easy-read Consent Form for Rights-based Rehabilitation Creative Writing Group

Please initial box:

I **have read the information sheet** dated.................... (version............) for the above study. I have had the opportunity to think about the information, **ask questions** and have **received satisfactory answers.**	  	

I understand that I can **take a break** at any time.		

I understand that I can leave the project at any time if I **change my mind.** If I do, this **won't affect** my medical **care** or my legal **rights.**	 	

disability research @ UEA
Equal Lives Free from disabling barriers
UEA University of East Anglia
Funded by NHS National Institute for Health Research

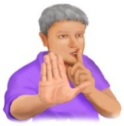
Appendix 19: Easy-read consent form – creative writing group

Rights-based Rehabilitation - Easy-read consent form, CWG
V4, 29 August 2018, IRAS: 207584

Please initial box:

What I say, including my writing, may be **quoted (without my real name) and discussed** in the PhD thesis, in publications and in presentations at events and workshops. **I know that my real name will not be used** and that any information that could be used to **identify me will be removed.**	 	

I understand that **sections of my data** collected during the study **may be looked at by responsible individuals from the NHS Trust or from regulatory authorities**, where it is relevant to my taking part in this research. I **give permission** for these individuals to have access to these data.		

I understand that information on the **identities of other creative writing group members**, and **information shared by creative writing group members, must not be shared with people outside the group.**		

disability research @ UEA

Equal Lives Free from disabling barriers

UEA University of East Anglia

Funded by NHS National Institute for Health Research

Appendix 19: Easy-read consent form – creative writing group

Rights-based Rehabilitation - Easy-read consent form, CWG
V4, 29 August 2018, IRAS: 207584

I am aware that **a sound recording** of [insert group title] will be made.		

I would **like to take part** in this research project.		

Please tick YES or NO:

If I **change my mind** about taking part, or if I **lose the capacity** to decide about taking part, the researcher can **keep my contributions and use these in the study.**		
👍 yes ☐	👎 no ☐	

I am happy for a hard copy of my **writing to be displayed on the wall** during the discussion, **for others to read.**		
👍 **yes** ☐	👎 **no** ☐	

disability research@UEA

Equal Lives Free from disabling barriers

UEA University of East Anglia

Funded by NHS National Institute for Health Research

Appendix 19: Easy-read consent form – creative writing group

Rights-based Rehabilitation - Easy-read consent form, CWG
V4, 29 August 2018, IRAS: 207584

The **researcher can keep a hard copy or electronic copy of my writing** to use in her research, **in addition to the audio-recording** of my writing.		
👍 **yes** ☐	👎 **no** ☐	

__________________ __________________ __________________

Name of Participant Date Signature

__________________ __________________ __________________

Name of Person taking consent Date Signature

Page 4 of 4

disability research @ UEA
Equal Lives Free from disabling barriers
UEA University of East Anglia
Funded by NHS National Institute for Health Research

Appendix 20: Consent to contact table

Rights-based Rehabilitation - Consent to Contact table
V1, 10 Aug 2016
IRAS: 207584

Rights-based Rehabilitation Research Study, Consent to Contact Table

Lead Researcher: Harriet Cooper, PhD Researcher, UEA

Consent to contact table completed by ____________________ (name), ___________________ (job title)

This form will be returned to Harriet Cooper who will keep it in a locked cupboard in a lockable office at the University of East Anglia. Only Harriet Cooper will have access to the form.

Name	Date that individual was informed about project	Date that individual gave consent to be contacted	Name of member of staff to whom they formally gave consent	Patient telephone number	Patient email address	Best time of day to phone

Appendix 21: Introduction letter

Rights-based Rehabilitation – Introduction letter
V4, 25 Aug 2016, IRAS: 207584

NORWICH MEDICAL SCHOOL

Harriet Cooper
PhD Researcher
Norwich Medical School
University of East Anglia
Norwich Research Park
Norwich, NR4 7TJ

Telephone
TBC

Email
h.cooper@uea.ac.uk

Date

Dear [insert name],

My name is Harriet Cooper and I am conducting a research study at UEA entitled Rights-based Rehabilitation.

You are being contacted because your healthcare professional, [insert name], at the Colman Centre for Specialist Rehabilitation Services has identified you as someone who would be eligible to take part in this research, and who might be interested in doing so. I am researching disabled people's experiences of rehabilitation.

I enclose a leaflet containing more information about the research.

If you would like to find out more about the project, or have any queries, please contact me directly, using the contact details above. You are welcome to contact me for an initial discussion without any further obligation to become involved.

Yours sincerely,

Harriet Cooper

PhD Researcher – Rights-based Rehabilitation

Funded by NHS National Institute for Health Research

Appendix 22: Over-recruitment letter

Rights-based Rehabilitation - Over-recruitment Letter
V4, 25 Aug 2016, IRAS: 207584

University of East Anglia
NORWICH MEDICAL SCHOOL

Harriet Cooper
PhD Researcher
Norwich Medical School
University of East Anglia
Norwich Research Park
Norwich, NR4 7TJ

Telephone
TBC

Email
h.cooper@uea.ac.uk

Date

Dear [insert name],

Thank you for your interest taking part in the Rights-based Rehabilitation study. Unfortunately the research project has now recruited all the participants needed and so I will not be asking you to take part further. I will, however keep your name on a waiting list to contact you if further opportunities to take part arise. Please let me know if you do not want your name to be held on the waiting list.

There are other ways that you can become involved in the project. For example, you may wish to attend an upcoming data analysis roundtable event, on [insert full details]. I will also be holding a dissemination event to inform people about the results of the research, and will send you an invitation to this event when I have more details.

Thank you again for your interest in my research.

Yours sincerely,

Harriet Cooper

PhD Researcher – Rights-based Rehabilitation

disability research@UEA
Equal Lives Free from disabling barriers
University of East Anglia
Funded by NHS National Institute for Health Research

Appendix 23: Tasks for creative writing group (agreed via substantial amendment)

Rights-based Rehabilitation – Tasks for creative writing group
V1, 29 Aug 2018, IRAS: 207584

Creative Writing Group Tasks:

1) Write a **poem about rehabilitation**, placing the word **REHABILITATION / REHAB / THERAPY or another word of your choice vertically** on the page and writing a line using each letter of the word. The letter can occur at the beginning of a line, or in the middle.

   In the session, you can look at the example poem for inspiration if you need to.

   I will provide blank versions of this task on coloured paper during the group.

   E.g.

R…

E…

H…

A…

B…

I …

L…

I…

T…

A…

T…

I…

O…

N…

Appendix 23: Tasks for creative writing group (agreed via substantial amendment)

Or

R…

E…

H…

A…

B…

Or

T…

H…

E…

R…

A…

P…

Y…

2) Choose a **part of your body**, and write about your **rehabilitation** from the **point of view of that body part**. Alternatively, you might choose to write about your rehabilitation from the **point of view of your wheelchair, guide dog, or an assistive device**.

   In the session, I will provide a sample piece of writing for you to look at.

Appendix 24: Debrief contacts

Rights-based Rehabilitation - Debrief contacts

V1 5 Aug 2016

IRAS 207584

List of organisations you may wish to contact

The Samaritans: 116 123

Equal Lives: 01508 491210

The Stroke Association: 0303 3033 100

Scope: 0808 800 3333

Headway: 0808 800 2244

Spinal Injuries Association: 0800 980 0501

Multiple Sclerosis Society: 0808 800 8000

Shine (spina bifida and hydrocephalus charity): 01733 555988

Age UK: 0800 169 2081

Carers UK: 0808 808 7777

Norfolk Social Services, Adult care: 0344 800 8020

Appendix 25: Example interview transcript excerpt

P18 I will continue to wear [type of support] simply because it's safer for me and my health. I should wear [type of support] but at the moment I'm waiting for my new [type of support] from the orthotics department. I have received physiotherapy. Currently I'm under a lady physiotherapist who has [a similar condition] and has given a lecture to her fellow physiotherapists on the condition and that was in December/January. She's a very good physiotherapist to talk to about [my condition].

HC How do you find working with a physio who's got a similar condition?

P18 It's been amazing because it's not traditional physiotherapy of get you well after you've been sick. It's trying to help you when there's no recovery in sight so it's not as goal led as 'in eight weeks' time we'll have you jogging again.' This has got to be slow, considered and what we do is Pilates. We do beginner level Pilates with some adjustments. [description of activities removed to protect anonymity] So even some of the Pilates stuff is difficult to get on with. So, she has worked with me for a while now but instead of getting my NHS six appointments and you do it over six weeks, we've been meeting once every two or three months, so I've [been] given a set of physiotherapy Pilates to go and do and then I come back to her and we see what my progress is like. [She refers to an operation - details removed to protect anonymity] [At another point] we did hydrotherapy – the same person. The problem is, once again you can only get hydrotherapy six sessions and it's not done by location. My condition gets six appointments. Somebody who's had knee surgery gets six appointments. Whereas I could do with six appointments per location, so that I can get benefit from the hydrotherapy.

HC So as an ongoing thing you could benefit from something that would just continue and then it would work… when you say location you mean different parts of your body…

P18 … yeah, [refers to specific parts of body]. I do understand the NHS is stressed. I do understand what the political landscape is like at the moment and I do understand that. It's frustrating.

Appendix 26: Example focus group transcript excerpt

P1 ‘Oh, we can’t have any of that. We can’t have your computer desk in.’ My husband said, ‘Where is she going to work? – because I was doing the magazine then and some other writing stuff. ‘She’s got to be able to work,’ because I was doing a magazine then and some other writing. They said, ‘She can’t have it there,’ and there wasn’t any room, because I couldn’t access any other rooms except the kitchen. That was an OT in [city]. We moved to [area] and it was a different ball game, completely.

P2 It’s an interesting thing you’re saying, which is that people will tell you what you can and can’t do, what you can and can’t have, telling you what you can have in your living room. But I’m afraid I’m the sort of person who will say, ‘Sorry, that’s my living room,’ and nobody can actually *tell* you. You can just say no to all of it, if you want, because it’s *your* condition.

P1 Yes, but the other problem is, if you don’t have the equipment you’ve got to buy it and [*talking over each other*]…

P3 … in the past there was room for negotiation within the services, but now there isn’t. It’s either, ‘You have this or you don’t have this.’ There’s nothing in the middle.

P1 I have [pieces of equipment]. I like them, they keep me safe [brief section removed to protect anonymity]. I needed replacement [related piece of equipment], but they aren’t supplied by the normal services. I had to get in an OT who then decided [to change the related equipment, citing a health reason; the new equipment presented a lot of problems]. I rang up on Monday morning and said, to the OT, ‘If you don’t take this [equipment] away, I’m taking this up to a higher level.’ She went back to her boss who said, ‘We will give her back [the old type of equipment].’ Then I got a message saying, ‘You can have the same brand of [equipment], but you can’t have the acute one, which is the next one up,’ so I’m slightly lower. [Brief clause about the dispute removed to protect anonymity] they really fought me, and I wasn’t having any of it [Brief passage about the dispute removed to protect anonymity]. So, I insisted and they said they would give them to me for six months and then review it. I will fight them tooth and nail.

P2(?) Just don’t phone them back.

P1 I will not give in. But that’s the same thing as you saying, where is this OT when we moved – she left, unfortunately; she listened to me and said that I knew what I needed […].

Appendix 27: Example creative writing group transcript excerpt

This excerpt comes after the group have introduced themselves and briefly discussed their experiences of writing (discussed in Chapter Seven). They then turn to sharing their writing and responding to each other's work. The section opens with P1 reading a poem and the others then respond. The poem is in blue text and the responses in black.

P1:

Meeting Management – I'm Fine

We used to be consulted about how services would be run, tailored to help us.
Now, team meetings consult one another about how *I* will be run, manoeuvred to fit
Past comments morph like Chinese whispers in the records
Subtle changes since then mean nothing
'Don't worry, you will always be consulted'
'Shouldn't I be consulting you, you responding to me, not me responding to you?
Hang on a minute, when did I change from a member of the public to a case to be managed?
Person in need for advice and assistance, to a bed-blocker, burden on my carers, person who shouts loudest to get more than their fair share.
What is fair in life and death?'

Sometimes we meet in the street; 'How are you?', you say
'I'm fine, how are you?'
'I am a person. I have had a hard and [tenuous (?)] life, but well worth living. I react the same as you, but I'm not really fine. I'm afraid of you, and your rules, the records you make, the things they make you do: things done to me, not for me'.

Group: Mmmm!

P2: That's amazing.

P3: [inaudible]

P2: That feeling of being fitted into the system…is very strong isn't it [P1: yeah]… the system is up there and running at its own pace and you've got to fit in with it.

P1: it's getting…..

P2: …more like that

P1: yes, and I don't know whether it's getting worse, well I think it probably is getting worse for everyone, but it certainly feels like it's getting worse as I get more disabled.

P3: [inaudible]…. You're just a commodity, to be managed along with all other commodities, and you've got to fit in with the system, not the system that fits in around you.

P2: I've got the opinion, that the health service is first and foremost an educational and research organisation. I think the actual care, has been shelved onto other agencies, the NHS is steaming forward with research and…life-saving if you like, but the everyday care of people has been put out to tender all the way along the line.

[some sounds of agreement]

[some text removed for preservation of anonymity, ending with a remark about the fact that it is patients teaching students about illness/disability experience]

P2: It's a good contribution to make in life, though, teach them [i.e. student] how to do it

P4: And how not to do it!

P2: And how not to do it, yeah!

P1: It's all the wrong way round.

P2: [some text removed to preserve anonymity] now I think it's all down to targets and tasks and education [in the NHS] and the poor patient has to fit in with that, that's my feeling.

HC: [returning to the poem] I was really interested in this thing about being consulted, in what you wrote [P1 name], and that you used to be consulted more. And also the question marks you had about who was consulting whom – and the confusion.

P1: Yes, it's halfway between social services and health, which also confuses it, because social services had a good phase when they were really changing to consult people and we were actually co-producing the work with them, which is quite different, it is where people receiving the services actually help to construct how things are going to develop and that was actually beginning to work. But now, of course now I've become more disabled, and far more involved with health, and I suddenly found that health was completely the opposite, they do not understand about co-production, they decide what they're going to do, and then they have a consultation, to 'tick' it, and so all you may ever hope, is to make a little adjustment, because it's just going to be done that way, whether it's the right way, for the public, or not! So, I mean, it's gets a bit far removed from the poor clinicians, who are trying to … but it's getting to the point where the clinicians are just not allowed to use their judgement. The doctors, the physios, are being told that they've got to fit into the boxes, instead of using their judgement.

Appendix 28: Example of coding work – interview

Selected quotations	**Notes on themes**
'I should wear [type of support] but at the moment I'm waiting for my new [type of support] from the orthotics department.'	Waiting (literal reading) Obligations around rehabilitation – to do/wear something – links with the theme of expertise by experience, or maybe expertise developed over time/in the course of rehabilitation experience (interpretive reading)
'Currently I'm under a lady physiotherapist who has [a similar condition] and has given a lecture to her fellow physiotherapists on the condition and that was in December/ January. She's a very good physiotherapist to talk to about [my condition].'	Shared experience - working with a therapist who shares a lived experience of disability Relational aspects of rehabilitation
It's been amazing because it's not traditional physiotherapy of get you well after you've been sick. It's trying to help you when there's no recovery in sight so it's not as goal-led as 'in eight weeks' time we'll have you jogging again.'	Maintenance not cure (interpretive) Dissimilar from illness experience – where it is implied that one gets better (literal) Less goal-led than a standard treatment regimen, in her view (literal)
This has got to be slow, considered.	
So, she has worked with me for a while now but instead of getting my NHS six appointments and you do it over six weeks, we've been meeting once every two or three months, so I've been given a set of physiotherapy Pilates to go and do and then I come back to her and we see what my progress is like.	Temporality of rehabilitation – it takes time; It requires thought and attention Temporality Timing of appointments suits her, suits the maintenance approach, contrasts with her sense of what other NHS treatments regimens are like Rehabilitation as labour that the person with the condition has to do in their own time
The problem is, once again you can only get hydrotherapy six sessions and it's not done	Progress is seen as important

Appendix 28: Example of coding work – interview

by location. My condition gets six appointments. Somebody who's had knee surgery gets six appointments. Whereas I could do with six appointments per location, so that I can get benefit from the hydrotherapy.	Rigidity of structure of services Whatever the condition, the entitlement is the same; this is problematic Stating her sense of her own needs; expertise by experience
I do understand the NHS is stressed. I do understand what the political landscape is like at the moment and I do understand that. It's frustrating.	Make allowances for things not being perfect with the NHS Placing her experience in its broader social and political context

Appendix 30: Example of Coding Work – Focus Group

Selected quotations	**Notes on themes**
P1 'Oh, we can't have any of that. We can't have your computer desk in.' My husband said, 'Where is she going to work? – because I was doing the magazine then and some other writing stuff. 'She's got to be able to work,' because I was doing a magazine then and some other writing. They said, 'She can't have it there,' and there wasn't any room, because I couldn't access any other rooms except the kitchen.	Rigidity of structure of services; doesn't take account of needs of individual (interpretive reading) Role of others in advocating for the participant Highlighting her work / vocation Rigid rules are experienced as problematic here Lack of participant's own voice in this excerpt (interpretive reading)
P2 It's an interesting thing you're saying, which is that people will tell you what you can and can't do, what you can and can't have, telling you what you can have in your living room. But I'm afraid I'm the sort of person who will say, 'Sorry, that's my living room,' and nobody can actually *tell* you. You can just say no to all of it, if you want, because it's *your* condition.	Voice – who gets to speak, who gets to make the rules? Different approach on display from that offered by P1 Experiences of being 'told' what to do – lack of involvement in decision-making (literal reading) Self-assertion – linked to her own personality (implies that not everyone is this 'sort of person) Ownership of condition gives you certain rights and entitlements
P1 Yes, but the other problem is, if you don't have the equipment you've got to buy it and [*talking over each other*]…	Potential to become dis-entitled; implies need to comply with rules in order to get the equipment; Implies that not everyone may be able to buy equipment
P3 … in the past there was room for negotiation within the services, but now there isn't. It's either, 'You have this or you don't have this.' There's nothing in the middle.	Temporality Discussing how relationships with services have changed over time No room for negotiation; implies no room for patient-voice; no middle ground. Seems to be broadly agreeing with the position of P1

Appendix 29: Example of coding work – focus group

P1 I rang up on Monday morning and said, to the OT, 'If you don't take this [equipment] away, I'm taking this up to a higher level.' She went back to her boss who said, 'We will give her back [the old type of equipment].' Then I got a message saying, 'You can have the same brand of [equipment], but you can't have the acute one, which is the next one up,' so I'm slightly lower.	Need for voice and self-assertion in order to make something happen in the way one needs it Demonstrates administrative time spent on rehabilitation (interpretive reading) Rigidity of services Even when pressure is applied, it is still difficult to get what one needs
They really fought me, and I wasn't having any of it	Fight/battle to be involved in decision-making Fight to reject being put in a particular position by services
So, I insisted and they said they would give them to me for six months and then review it. I will fight them tooth and nail.	Temporality – precarity of offer from services – implies things may change Shows determination, and anger at situation

Appendix 30: Example of how I would work with creative writing group transcript

Transcript text	**Preliminary thoughts on how I would go about analysing this material**
P1: **Meeting Management – I'm Fine** We used to be consulted about how services would be run, tailored to help us. Now, team meetings consult one another about how *I* will be run, manoeuvred to fit Past comments morph like Chinese whispers in the records Subtle changes since then mean nothing 'Don't worry, you will always be consulted' 'Shouldn't I be consulting you, you responding to me, not me responding to you?	I would explore the effects of the poem, drawing on my training in literary studies. Particularly striking here is the mobilisation of the voices of different figures in her narrative, often without context, so that the reader has to work to understand which figure is speaking. This creates confusion about who is speaking, which is a seemingly deliberate effect to underline the sense that it is not very clear who is doing the consulting and who is being consulted. This literary effect develops a sense that 'consultation' is lip service here. This effect is consolidated by the 'Chinese whispers' image, again suggesting that things get confused as they are reported, and that there is a lack of clarity for the patient.
Hang on a minute, when did I change from a member of the public to a case to be managed? Person in need for advice and assistance, to a bed-blocker, burden on my carers, person who shouts loudest to get more than their fair share. What is fair in life and death?'	Here there is an accumulation of images of around the theme of being dehumanised as a 'case' or a 'burden'. There is an emphasis on the double bind of needing support and yet needing to 'shout the loudest' in order to get attention, which perhaps gives the speaker a reputation as difficult.
Sometimes we meet in the street; 'How are you?', you say 'I'm fine, how are you?' 'I am a person. I have had a hard and [tenuous (?)] life, but well worth living. I react the same as you, but I'm not really fine. I'm afraid of you, and your rules, the records you make, the things they make you do: things done to me, not for me'.	The lack of context for the 'we' here again leaves us hanging, but also draws us in, so that we really focus on what is being said. The refusal of the narrator to simply accede to convention and say she is 'fine' generates curiosity and pulls the reader in, compelling the reader to reflect on what the narrator's experience of not being fine is really like. In this sense, this part of the poem offers insight into the physical and social experience of living with a disability.
Group: Mmmm! P2: That's amazing. P3: [inaudible] P2: That feeling of being fitted into the system…is very strong isn't it [P1: yeah]… the system is up there and running at its own pace and you've got to fit in with it. P1: it's getting….. P2: …more like that P1: yes, and I don't know whether it's getting worse, well I think it probably is getting worse for everyone, but it certainly feels like it's getting worse as I get more disabled. P3: [inaudible]…. You're just a commodity, to be managed along with all other commodities, and you've got to fit in with the system, not the system that fits in around you.	Here I would seek to analyse both the thematic points that participants are making, and to explore whether and how their interactions are shaped by the fact that they are responding to someone else's writing, rather than to topic headings, which is what I used in the focus groups. To begin with, for example, we see that there is a real sense of appreciation for what the first participant has given the group. The participants do not immediately say whether or not they share the experience narrated in the poem, but instead reflect back what they hear in, or take from, the poem. For example, P2 talks about the 'feeling of being fitted into the system' and P3 talks about the idea that 'you are just a commodity'. We could speculate that these

Appendix 30: Example of how I would work with creative writing group transcript

P2: I've got the opinion, that the health service is first and foremost an educational and research organisation. I think the actual care, has been shelved onto other agencies, the NHS is steaming forward with research and…life-saving if you like, but the everyday care of people has been put out to tender all the way along the line.
[some sounds of agreement]
[some text removed for preservation of anonymity, ending with a remark about the fact that it is patients teaching students about illness/disability experience]
P2: It's a good contribution to make in life, though, teach them [i.e. student] how to do it
P4: And how not to do it!
P2: And how not to do it, yeah!
P1: It's all the wrong way round.
P2: [some text removed to preserve anonymity] now I think it's all down to targets and tasks and education [in the NHS] and the poor patient has to fit in with that, that's my feeling.
HC: [returning to the poem] I was really interested in this thing about being consulted, in what you wrote [P1 name], and that you used to be consulted more. And also the question marks you had about who was consulting whom – and the confusion.
P1: Yes, it's halfway between social services and health, which also confuses it, because social services had a good phase when they were really changing to consult people and we were actually co-producing the work with them, which is quite different, it is where people receiving the services actually help to construct how things are going to develop and that was actually beginning to work. But now, of course now I've become more disabled, and far more involved with health, and I suddenly found that health was completely the opposite, they do not understand about co-production, they decide what they're going to do, and then they have a consultation, to 'tick' it, and so all you may ever hope, is to make a little adjustment, because it's just going to be done that way, whether it's the right way, for the public, or not! So, I mean, it's gets a bit far removed from the poor clinicians, who are trying to … but it's getting to the point where the clinicians are just not allowed to use their judgement. The doctors, the physios, are being told that they've got to fit into the boxes, instead of using their judgement.

individuals might be referring to these ideas because they resonate with their own experience, but perhaps more importantly, the sharing of the creative writing has opened up a space in which participants can explore an idea without necessarily claiming it as their own.

Here they talk about patient involvement in the training of healthcare professionals, which they concur is a good thing.

Here it is suggested that the climate of 'targets' creates a situation where the patient has to 'fit in', rather than being consulted.

Here the participant gives us more context for understanding her poem, highlighting what she experiences as a decline of co-production in social services, and also remarking on the way co-production is sometimes undertaken in superficial ways in health research. This material, and this entire section of transcript, offers further evidence to support my analysis of how involvement in rehabilitation is understood and experienced by disabled people who have been through the process (Chapter Six). The material here could also be used to develop the work undertaken on PPI across the thesis. Further work on the creative writing transcript will feed into the publications I develop from my thesis.

Appendix 31: Transcript extracts for data analysis meeting with PPI members

Female interviewee, speaking about her rehabilitation experience:
It’s trying to help you when there’s no recovery in sight so it’s not as goal-led as ‘in eight weeks’ time we’ll have you jogging again’. This has got to be slow, considered, and what we do is Pilates. We do beginner level Pilates with some adjustments. Last time I saw her, five or six weeks ago, I was lying on my back with my knees bent and my feet on the bed and we were taking the knee and opening it out to the side and as we reached a certain point [my body responded in a way that a non-disabled body would not]. So even some of the Pilates stuff is difficult to get on with. So, she has worked with me for a while now but instead of getting my NHS six appointments and you do it over six weeks, we’ve been meeting once every two or three months, so I’ve [been] given a set of physiotherapy Pilates to go and do and then I come back to her and we see what my progress is like.

Male focus group participant, speaking about wheelchair services:
After many, many months of arguing about it, they eventually said they’d give me the next one up, but that it wouldn’t be made for me but would come off the shelf. I was willing to try anything. But they didn’t look at me from [the] point of view [of my specific impairment]. They looked at me as somebody who needed to use a wheelchair, so they gave me one that was built for somebody with a spinal injury, which was terrible. It was light in its way that it tilted and lifted, but it was slow in its pushing. So, I was given an inappropriate piece of equipment, which I kept falling out the back of.

Male interview participant, discussing feelings about rehabilitation:

…there have been times when I've thought, 'Why are they telling me that? I'm a grown adult. I don't need that!' – a little bit, I have resented it, but then I've thought about it and I've realised that although I'm in control of referring myself for more help to learn a new route, I've had to accept that it's a bit of a pupil/teacher relationship where you do have to accept that sometimes you have to accept constructive criticism…

Female focus group participant, responding to someone's story about an occupational therapist: It's an interesting thing you're saying, which is that people will tell you what you can and can't do, what you can and can't have, telling you what you can have in your living room. But I'm afraid I'm the sort of person who will say, 'Sorry, that's my living room,' and nobody can actually tell you. You can just say no to all of it, if you want, because it's your condition.

Appendix 32: Example mind map of emerging themes

Appendix 33: Co-authored article for *Social Inclusion*, which drew on data collected as part of this project, and analysis that I later developed for chapters of this thesis

I am grateful to *Social Inclusion* and to my co-authors for granting permission to reproduce this article here.

COGITATIO

Social Inclusion (ISSN: 2183–2803)
2018, Volume 6, Issue 1, Pages 61–72
DOI: 10.17645/si.v6i1.1175

Article

Rehabilitation as a Disability Equality Issue: A Conceptual Shift for Disability Studies?

Tom Shakespeare [1,*], Harriet Cooper [1], Dikmen Bezmez [2] and Fiona Poland [1]

[1] Norwich Medical School, University of East Anglia, Norwich, NR4 7TJ, UK; E-Mails: tom.shakespeare@uea.ac.uk (T.S.), h.cooper@uea.ac.uk (H.C.), f.poland@uea.ac.uk (F.P.)
[2] College of Social Sciences and Humanities, Koç University, 34450 Istanbul, Turkey; E-Mail: dbezmez@ku.edu.tr

* Corresponding author

Submitted: 29 September 2017 | Accepted: 14 February 2018 | Published: 26 March 2018

Abstract
Rehabilitation is a controversial subject in disability studies, often discussed in terms of oppression, normalisation, and unwanted intrusion. While there may be good reasons for positioning rehabilitation in this way, this has also meant that, as a lived experience, it is under-researched and neglected in disabilities literature, as we show by surveying leading disability studies journals. With some notable exceptions, rehabilitation research has remained the preserve of the rehabilitation sciences, and such studies have rarely included the voices of disabled people themselves, as we also demonstrate by surveying a cross-section of rehabilitation science literature. Next, drawing on new research, we argue for reframing access to rehabilitation as a disability equality issue. Through in-depth discussion of two case studies, we demonstrate that rehabilitation can be a tool for inclusion and for supporting an equal life. Indeed, we contend that rehabilitation merits disability researchers' sustained engagement, precisely to ensure that a 'right-based rehabilitation' policy and practice can be developed, which is *not* oppressive, but reflects the views and experiences of the disabled people who rehabilitation should serve.

Keywords
concept; disability; equality; rehabilitation; rights

Issue
This article is part of the issue "Disability Equality: In Theory and Practice", edited by Mark Priestley (University of Leeds, UK) and Lisa Waddington (Maastricht University, The Netherlands).

1. Introduction

Definitions of rehabilitation are contested. For example, outside clinical care, the term has been used in social contexts, which include vocational rehabilitation helping people access employment, and in rehabilitating ex-offenders. The focus of this article is health-related rehabilitation. The World Health Organisation (WHO) defines rehabilitation based on the *International Classification of Functioning, Disability and Health*:

> As set of measures that assist individuals who experience, or are likely to experience, disability to achieve and maintain optimal functioning in interaction with their environments. (WHO, 2011, p. 96)

In this approach, disability is defined as a decrement in functioning, which rehabilitation can help reduce. In the WHO approach, as expressed in the *World Report on Disability* (2011), rehabilitation comprises rehabilitation medicine; physical, occupational and other therapies; and assistive devices. However, in the Convention on the Rights of Persons with Disabilities (CRPD; UN, 2006), rehabilitation is conceptualised as a broader process of social transformation which may not have been explicitly realised in rehabilitative practices to date.

Tensions in both definitions of, and attitudes to, rehabilitation run through this article. Two of the authors have an insider status (Corbin Dwyer & Buckle, 2009), one having experienced childhood habilitation for hemiplegia, the other having experienced in-patient rehabilitation after spinal cord injury as an adult. The former experienced physiotherapy as a profoundly intrusive experience, impinging much more on her life than the direct effects of her relatively mild impairment. It was partly through reflecting on her experience of habilitation that she came to disability studies, finding it to be an emancipatory academic (and activist) space. Conversely, the latter experienced physiotherapy as empowering, enabling him to regain functioning and thus maximise his social participation. These divergent attitudes to rehabilitation reflect a wider ambivalence within the disability rights community.

Authors within the materialist disability studies tradition have re-defined disability in terms of social barriers and oppression, rather than deficits in personal functioning (Oliver, 1990), otherwise known as the 'social model'. The goal of this disability rights approach is to remove environmental barriers and discrimination, whereas rehabilitation may be considered suspect because it attempts to fix the origins of limitations within individuals (Finkelstein, 1980). Disability studies academics have written of their personal experience of rehabilitation as oppressive, because they see it as emphasising "normalisation" (Abberley, 1995; Finkelstein, 2004; Oliver, 1990, 1993). For example, in his professorial inaugural lecture, Michael Oliver (1993) posed the question 'what's so wonderful about walking?', and thereby querying the very desirability of 'optimal functioning'. Later, Michael Oliver and Colin Barnes asserted that:

> Clearly the concept of rehabilitation is laden with normative assumptions clustered around an able-bodied/mind ideal. And, despite its limitations in terms of returning people with acquired impairments such as spinal cord injury, for example, to their former status, it has little or no relevance or meaning for people born with congenital conditions such as blindness or deafness other than to enforce their sense of inadequacy and difference. (Oliver & Barnes, 2012, p. 42)

That some disabled people hold ambivalent views about rehabilitation may be understandable, especially when seeing the development of rehabilitation within a historical context where the statistical norm became an increasingly influential referent for medical practice (Davis, 1995; Gibson, 2016). Furthermore, within this branch of disability studies, rehabilitation is understood as a practice that is 'done to' rather than 'done with' the collaboration of the patient. Within this context, rehabilitation professionals may understandably be experienced as suspect, because representing a mode of acting towards disabled people that privileges the professional's voice over that of the patient (Finkelstein, 1980).

While there may be good reasons for positioning rehabilitation in this way, this has also meant that, as a lived experience, it is under-researched and neglected (Shakespeare, 2014). With some notable exceptions (e.g., Bevan, 2014; Bezmez, 2016; Crisp, 2000; Hammell, 2006; Swart & Horton, 2015), rehabilitation research has therefore, by default remained the preserve of the rehabilitation sciences. This is reflected in our analysis of recent papers (January 2011 to December 2015) published in the four leading disability studies journals (*Disability and Society, Alter, Scandinavian Journal of Disability Research, Disability Studies Quarterly*). Of 954 articles published, only 41 (~4%), focused on rehabilitation. This might indicate relatively low research interest, especially given the relevance of rehabilitation in many disabled people's lives. Some research does prioritise the lived experience of disability in rehabilitation, with research studies focusing on participatory, inclusive and patient-centred rehabilitation (e.g., Byrnes et al., 2012; Lund, Tamm, & Bränholm, 2001) and in health settings (Cook & Inglis, 2012). Additionally, there is other research based on first-person perspectives of individuals going through rehabilitation (e.g., Arntzen, Hamran, & Borg, 2015; Chun & Lee, 2013).

Nonetheless the critique remains that, firstly, most of this work comes from rehabilitation sciences scholarship which remains separated from disability studies and, secondly, that both fields of study would benefit from mutual contributions. For instance, Chun and Lee (2013) identify feelings of gratitude when comparing levels of injury with individuals whose impairments are more severe, following traumatic spinal cord injury. Disability scholars might be critical of this comparison. On the other hand, if disability scholars engaged with rehabilitation sciences this might facilitate more nuanced approaches to rehabilitation.

From the rehabilitation sciences perspective, the scope of the materialist disability research critique of rehabilitation, as highlighted in Oliver's previous quotation, could itself be criticised. For example, spinal cord injury rehabilitation measures for muscles, bowels, bladder, skin are all about living healthily in the new, paralysed, status, not regaining the former status of being "a walker" (WHO, 2014). Second, there is a danger in traducing the whole field of rehabilitation when challenging the cure obsession of some charity campaigns. Finally, contradicting Oliver and Barnes (2012), people who are born with or who acquire sight or hearing loss, do experience habilitation and rehabilitation interventions and assistive technologies, such as magnifiers, white canes, cochlear implants and other corrective surgery. Some papers by 'founding fathers' in materialist disability studies are more nuanced, such as Finkelstein (1984), who concludes that, where patients are actively involved, medicine and rehabilitation can and should prevent and mitigate impairment.

To balance the emphasis on disability studies, three multi-disciplinary rehabilitation journals were also se-

Appendix 33: Co-authored article for *Social Inclusion*

lected for review: *The International Journal of Therapy and Rehabilitation*; *Disability and Rehabilitation* and; *Clinical Rehabilitation* for the same search dates, but this time studies were included where the voices of patients were heard in rehabilitation processes, particularly focusing on two conditions: one congenital (cerebral palsy) and one acquired (spinal cord injury). The 164 rehabilitation science articles reviewed produced no substantial evidence of public and patient involvement—in contrast to the more developed practices of participatory and emancipatory research in the disability studies literature (Oliver & Hasler, 1987). Fewer than 10% of articles indicated that research participants were involved in some way, such as data analysis, interview piloting or checking transcripts (Bourke, Hay-Smith, Snell, & Dejong, 2015; Byrnes et al., 2012; Chun & Lee, 2013; Dew, Llewellyn, & Balandin, 2014; Guilcher et al., 2013; Huang, Wang, & Chan, 2013; Kim & Shin, 2012; Moll & Cott, 2013; Papadimitriou & Stone, 2011; Shikako-Thomas, Bogossian, Lach, Shevell, & Majnemer, 2013; Smith, Papathomas, Martin Ginis, & Latimer-Cheung, 2013; Goodridge et al., 2015; Van de Velde et al., 2012).

Moll and Cott (2013) present insights yielded by qualitative research with adults with cerebral palsy, who reported on the problems of a 'rehabilitation' wholly conceived as 'normalisation'. Such an approach to interventions did not offer people with cerebral palsy what they needed to be able to manage their bodies as they age (Moll & Cott, 2013). However, this article appears unique within the cerebral palsy literature in questioning received ideas about rehabilitation. Other important insights in this literature include: an emphasis on agency rather than autonomy, which might help rehabilitation patients to adjust to their new situation and to be more comfortable with themselves (Van de Velde et al., 2012; see also Bezmez, 2016; Papadimitriou, 2008). The experience of psychological loss associated with acquired impairment should not be underestimated (Clifton, 2014). For congenital and lifelong impairments, an emphasis on nourishing bodily self-awareness and on learning how to manage the ageing body may be more appropriate than an emphasis on normalisation (Brunton & Bartlett, 2013; Moll & Cott, 2013). Despite these positive insights, our reviews of literature suggest that rehabilitation is marginal within disability studies, and the voices of disabled people are marginal within rehabilitation sciences. The lack of emphasis on the voices of disabled people might in part reflect the professional focus of the rehabilitation science journals searched, and their preference for methodologies with measurable outcomes over qualitative methodologies which privilege the opinions and experiences of participants.

Health-related rehabilitation comprises a very broad and diverse set of interventions, and rehabilitation professionals vary in their outlook and behaviour. Not all rehabilitation interventions are experienced as appropriate, let alone effective; some professionals act in oppressive ways (Oliver, 1993). The disability community itself has a range of views and experiences regarding rehabilitation. Many disabled people derive considerable benefit from habilitation and rehabilitation: some regain the ability to walk (as with 10% of people with spinal cord injury including one of the current authors); others regain functional speech; many manage to use artificial limbs successfully. The danger surely lies in a blanket dismissal of a whole area of healthcare and human experience. A more nuanced approach is required.

Shakespeare (2014) has argued that the materialist disability studies commitment to a 'strong' social model has hampered the development of disciplinary alliances (for example, with medical sociology) that could lead to research promoting the human rights of all disabled people. He and others reject the dualist social model understanding of disability as over-simplified and reductionist. Rather than reducing disability to either impairment, or barriers or oppression, they call for a relational approach to disability, which conceptualises disability as the outcome of the interactions between the person with the impairment, and the wider context. Critical realists set out a "laminated" approach (Danermark & Gellerstedt, 2004), referring to different levels of reality. From this perspective, the range of appropriate responses to disability could include: healthcare to prevent or treat the health condition; rehabilitation to maximise functioning; psychological interventions; removal of barriers in environments; social provision of independent living supports; legal protections to combat discrimination.

The ambiguous position of rehabilitation within progressive responses to disability is also evidenced in human rights law. Within the CRPD, rehabilitation is covered under Article 25, Health, and Article 26, Rehabilitation. Article 25 explicitly states 'States parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation'. This suggests that there is a right to health-related rehabilitation, within an overall right to health. Article 26 calls on all States to:

> Take effective and appropriate measures…to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life. To that end, States Parties shall organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes.

Yet, significantly, Article 26 does not conceptualise any distinct right to rehabilitation. This appears to be because Convention was negotiated under a somewhat contradictory UN General Assembly mandate to draft a treaty that paralleled existing human rights instruments, rather than one which created new rights (Kayess & French, 2008, p. 20). Because there had been no explicit right to rehabilitation in the existing human rights architecture, it was not expressed as a stand-alone right

Appendix 33: Co-authored article for *Social Inclusion*

in the CRPD. Equality in the CRPD is often phrased in terms of disabled people achieving access to, for example, services, "on an equal basis to others". Yet when it comes to a specific service such as rehabilitation, which may be particularly relevant to people with long-term conditions, it is not then a matter of equality with non-disabled people. It is a matter of meeting needs associated with impairments. Without appropriate rehabilitation, people cannot enjoy equality of opportunity in education and employment. Drawing on new research taking place at the University of East Anglia, we argue in this article that rehabilitation and access to rehabilitation is therefore a disability equality issue. We call for a dialogue between disability studies/disability rights and rehabilitation sciences (see also Bevan, 2014; Hammell, 2006; Gibson, 2015).

Through an in-depth discussion of two case studies, which examine in detail the meaning of rehabilitation as a social experience in the lives of disabled people, we demonstrate that rehabilitation can be a tool for inclusion and for an equal life. Indeed, we contend that rehabilitation merits a sustained engagement from disability researchers precisely to help ensure a 'right-based rehabilitation' policy and practice can be developed which is *not* oppressive, but which instead reflects the views and experiences of the disabled people it should serve.

2. Methods

Our qualitative research explores the importance and meaning of health-related rehabilitation seen as a social process in disabled people's lives. This article draws on primarily two research studies. The first explored disabled people's experiences of, and views about, rehabilitation in England: this study included people with differing congenital and acquired impairments and was based on semi-structured interviews, focus groups and a creative writing group (Case study 1). The second study looked at disabled people who had experienced acquired brain injury or who had undergone amputations, on two wards of a rehabilitation hospital in England, and entailed in-depth interviews, focus group discussions and participant observations (Case study 2). Although the main findings of this research are drawn from these two research studies, at times the article draws on comparable findings from an ethnographic research project conducted previously in Turkey by one of the authors. For the purposes of this article, the various forms of data have been used to generate rich case studies, which reflect the wider data, but specific experiences with analytic resonance and relevance are presented for discussion here (Crowe et al., 2011).

The first case study is drawn from Harriet Cooper's ongoing research project, 'Rights-based Rehabilitation: A qualitative research project co-produced with disabled people'. This project is being supported by an advisory group of disabled individuals which meets to discuss aspects of research design, implementation, analysis and dissemination. While the data has now largely been collected, a comprehensive phenomenological analysis of themes in the data is yet to be completed. The emergent themes to be discussed here are indicative rather than comprehensive or definitively situated within the broader data set. This particular case study was therefore selected for inclusion in this article as it offers a wide-ranging critical illustration of ways in which rehabilitation can be understood as a disability equality issue. The richness of the case study was facilitated by the rapport developed between Mary (not her real name) and Harriet during the course of the interview, and through their shared interest in disability rights.

The second case study is drawn from fieldwork undertaken from October 2016 to February 2017, including interviews with 10 patients and 8 family members and focus group discussions with doctors (4), nurses (5), physiotherapists and occupational therapists (6). Additionally, participant observation was undertaken with 5 families as they were visiting the patients; finally, 5 in-depth interviews were conducted with academic experts in rehabilitation. All the interviewees staying in the neurological services were patients with mental capacity, who could consent and talk. Our first contact with interested participants was initiated by a member of the staff and we were then invited to meet with the patients and their families. The particular case study was selected because it introduces an important social aspect of physical rehabilitation, in providing room for socialisation and peer support. This theme was not examined in the first case study. The study has several limitations: first, the original focus of the second research study lies in examining the role of the family in in-patient rehabilitation in the UK. Thus, interview questions primarily focused on family roles with information on rights-based rehabilitation to promote disability equality being derived from the responses to these questions, to set the framework for the case study. In consequence, some data on rehabilitation services and dynamics specific to rehabilitation such as rehabilitation techniques were not available. However, the emphasis on the importance of having a communal rehabilitation experience remained essential. Second and relatedly, the focus on family roles made it necessary to draw on the fieldwork conducted in the amputee service to ensure the depth and soundness of the analysis in Case study 2.

The studies received ethical permission from the UEA Faculty of Medicine and Health Sciences Research Ethics Committee and the South East Coast Brighton & Sussex NHS Research Ethics Committee, respectively. All the names in the case studies have been changed.

3. Results and Discussion

The two case studies analysed in this section emphasise different aspects of rights-based rehabilitation. Thus, even though they have themes that overlap, they are in fact more complementary in terms of initiating a discus-

Appendix 33: Co-authored article for *Social Inclusion*

sion on rights-based rehabilitation, which can promote disability equality. The first case foregrounds the issues of maintaining access to services, i.e. the question of whether rehabilitation is withheld or restricted, and the appropriateness of the treatments on offer. This raises the central question of whether rehabilitation offered is relevant to the patient's needs. The second case discusses an issue often neglected in health-related rehabilitation, namely the importance of making room for socialisation and peer support while receiving health-related treatment. This case provides information which broadens existing conceptions of rehabilitation. The first-person accounts in both case studies demonstrate how all three issues have significance for developing rights-based rehabilitation to promote disability equality.

3.1. Case Study 1: Mary

3.1.1. Mary's 'Battle' for Access

Mary is a woman in late middle age, who has been living with multiple sclerosis for thirty-five years. In her interview, she described her different struggles as she sought to access rehabilitation services. Mary deployed a battle metaphor (including the 'big battle' and the 'constant battle') when she identified where rehabilitation was withheld, or restricted, and when she believed it was not relevant to her needs:

> Later on, to me rehabilitation wasn't actually responding to me, it was, um, it had put me in a category, a person with MS, er…who therefore would have…set treatments….Um, and everything turned into a battle because, it wasn't actually what I was wanting…or what I needed.

The concept of the battle was used frequently by Mary to characterise her experience; as a result it appears several times in the case study, even when the data is being discussed in terms of another theme. It is a relevant detail because it highlights the amount of energy that was expended by Mary to obtain and maintain access to the rehabilitation services she needed.

3.1.2. Obtaining Appropriate Treatment: The Importance of User Involvement

Mary described her struggle to obtain the immune-suppressing treatment beta-interferon, and her experience of being categorised as someone who would not benefit from it. She appealed to the Health Secretary, and eventually won the right to receive the treatment, which she found had a profoundly positive effect on her relapsing-remitting MS.

Mary also described her efforts to receive the right treatment for continence control as 'a struggle' and as something which 'again turned into a battle':

> People wanted to catheterise me. Again, er, because it was easier and cheaper than getting people in to help me get to the toilet. So that again was a struggle because I found a catheter very uncomfortable; my bladder reacts to it and pushes it out.

For Mary, being helped to use the toilet via a toileting sling allowed her to maintain muscle strength and lung capacity; she regarded it as part of her rehabilitation. Moreover, using a catheter had caused her to suffer severe bladder infections. Yet the care providers restricted the number of continence pads she could have and the frequency of the care-workers' visits to assist her with toileting, which again began a battle of proving need for pads and care-worker visits. These experiences are perceived to have 'turned into' battles, due to 'shrinking availability' of services. When something 'turns into' a battle, there is the implication that energy and resources could have been saved—on all sides—if the 'battle' simply were not necessary.

3.1.3. Resource-Scarcity Creates Access and Equality Issues

Several times, Mary made a connection between a failure to have her needs met and the rationing of state resources. She talked about how she lost her access to assistance with her arm splints, when the relevant health-care professional moved away and was not replaced, meaning that Mary's arm splints have gradually deteriorated. In Mary's experience, decisions have been made on the basis of cost-effectiveness rather than being taken in accordance with need.

At one stage there had been an attempt to remove her continuous physiotherapy and to offer Mary only a limited number of sessions, after which she would have had to return to her GP and request a new referral. According to Mary, this was not because her own need had decreased, but because others were not able to access the physiotherapy they needed. Again, Mary had to appeal to the health authority, and won her case.

3.1.4. Rights-Based Rehabilitation Makes Space for the Voices of Disabled People

As well as depicting her struggle against rationing of scarce NHS resources, Mary's story also illustrates the specific relevance of the concept of 'expert by experience'. Mary found that she needed to contest received ideas about what would be right for her. Her knowledge and understanding were sometimes overlooked, and the views of medical professionals dominated. Sometimes this seemed to be because the NHS had a fixed notion of the needs of a person with MS, rather than a flexible notion relevant to her own experience of disability. Sometimes it seemed to be because of discriminatory assumptions about disabled people. For example, she reported that it was suggested to her that one way to avoid the need for a more expensive wheelchair would be to go to bed during the day, but she felt this would dramatically reduce her quality of life:

> I have a different view on what I want to do, and I want to, I want to live, until I die, and that's the way I want to do it, and so again it's a battle of how I want to do it.

Mary's commitment to self-determination, and to 'follow[ing] her instinct' have contributed to her success in obtaining access to rehabilitation services. A less empowered or supported individual might have conformed and lost control and functioning.

3.1.5. Uncertainty about Access Can Erode One's Sense of Personhood

One of the long-term effects of the uncertainty Mary has experienced in relation to service provision has been to erode her sense of entitlement, and even her sense of personhood. Mary explained that she felt as though she was a 'burden':

> It's like…you've had—you've had your character deconstructed….You lose your right to be the person you were because you're taking resources, and therefore you will do as you're told.

When her physiotherapy was withdrawn, Mary's condition went downhill, and she also experienced considerable distress at the uncertainty of not knowing whether her treatment would continue, affecting her ability to plan or to maintain her health:

> The distress…when you don't know that people are going to agree with you…is quite profound, and stress, is the thing that triggers MS, which makes it worse, so it was actually damaging me.

Mary located the problem in the 'systems' and not in the individuals who were involved in her rehabilitation, whom she held in high regard. With one significant exception, the rehabilitation professionals Mary had encountered were, in her words, 'wonderful'.

In summary, huge amounts of emotional, physical and administrative labour were involved in the process of fighting for what Mary needs to maintain her quality of life. She has had some very positive experiences of rehabilitation but reports that she has had to struggle to obtain the right services for herself on an ongoing basis. Mary joked that while her husband could enjoy retirement, she still had the full time job of arranging her access to care and treatment.

3.2. Case Study 2: Robert

The main themes discussed in Mary's case related to maintaining access to rehabilitation and the appropriateness of treatments on offer. This second case study highlights a different theme, in order to argue that rehabilitation is also a disability equality issue because it can affect opportunities for disabled people to be part of relevant social networks and to take part in social interactions, when going through the rehabilitation process itself. Limited opportunities for socialisation during rehabilitation can lead to feelings of loneliness and despair at a time which can already bring many challenges. We argue that although traditionally and practically it has not always been the case, in-patient rehabilitation is distinctive when compared to other treatment experiences, because it is supposed to facilitate a transition to a new life with a new bodily status. Often this process takes months or even years, which precludes a quick cure for the patient. Rehabilitation is a process for managing liminality (Hammell, 2006), which necessitates the creation of spaces that contain some of the characteristics of the everyday life beyond the hospital walls. Socialisation is one of those characteristic processes. Another is the way that families personalise routines and environments to make them familiar and welcoming to their loved ones. We argue that rehabilitation can promote disability equality if it develops a holistic approach to the complex needs of individuals who experience it. The discussion below illustrates this claim in the light of the experiences in two different hospital wards, neurological and amputee services, in a specialist rehabilitation hospital in England. We identify how the way that rehabilitation is organised may lead to a sense of isolation and loneliness in people. Similar to the case of Mary, we show that this state of affairs is not perceived as a failure of the individual professionals by the patient, for staff are described as doing everything they can. Again, this case demonstrates that when an individual's complex needs are not met, this can erode that individual's sense of personhood, and stir up feelings of being a "burden". At a more general level, both case studies draw attention to the importance of including disabled people within rehabilitation processes through practices which can integrate their complex needs. Both case studies also highlight how people are disabled by society as well as by their bodies. Mary's case demonstrated this in critically discussing fixed ideas about disability which are based on NHS assumptions rather than on patients' needs; the second case study illustrates this by drawing attention to the lack of attention paid to the patients' need to socialise as they go through rehabilitation.

Robert (not his real name) is a 72-year-old man, who in the previous eight months had had one hip replacement operation, two strokes, and two brain operations, eventually leading to him living with the condition of epilepsy. At the time of the interview, he had been an in-patient in the neurological rehabilitation service for about a month. Robert was estranged from most of his family members and the only person who occasionally visited him was his partner, with whom he had been having an on-and-off relationship over recent years. He was staying in a single room, which he associated with feelings of "being stuck in", because he had not been out of his room on his own since he had been in the hospital. Asked about what he disliked about rehabilitation, he responded: "The things I don't like is being stuck to that bed; being stuck in this room".

Throughout the interview, Robert emphasised themes related to feelings of isolation, loneliness, despair and despondence. Asked about his plans for the time after discharge Robert replied:

> I don't know if things are going to get any worse. My eyesight has diminished ever so much since the stroke. I get very despondent. Loneliness I've never felt, I've been lonely before many times in my life but I've never felt lonely, do you understand?….Now I feel it as loneliness, it's despair sometimes. I don't think there is anything else I can tell you. Nobody told me anything about what a stroke entails when I had it….What to expect and that is frightening when you get these things thrown at you umm…..I've lost an awful lot because of the stroke. I've no confidence now, whereas before I was self-confident in everything I did. That's what worries me about getting discharged and going back to the flat. How will I cope?

Robert's feeling of living now with loneliness not only relates to his complicated past, as someone who is estranged from the family, or the dramatic change he had to go through in his life situation, but also to how the rehabilitation process itself is organised. His emphasis on how he had never felt being lonely as "loneliness", before having had the stroke, and "being stuck" in the room, is telling in that respect. Similarly, the experiences of some patients in the amputee service, as explained in subsequent paragraphs, demonstrate that if complementary services such as peer support and provision of space for socialisation were to be integrated into existing rehabilitation schemes, patients' experience of rehabilitation might change significantly. This sense of isolation demonstrates the complex needs of individuals as they go through in-patient rehabilitation, and the importance of being part of relevant social networks as a feature of rights-based rehabilitation that promotes disability equality. In this context Robert seemed to value highly any interaction with staff. Asked about what he liked about rehabilitation, he answered:

> The things I do like are the nurses; they do everything they can for you…they are really nice.

Thus, as seen in the case for Mary, Robert also did not perceive the sources of his distress as deriving from the individual staff members. At the same time, it was hard for Robert to call for the nurses every time he needed them:

> They say all the nurses here are good they get you what you need in the night. You don't realise how much you do need when you can't walk because I get out of bed and walk over to that container with the wipe sheets or the light switch I've got to get someone to come and do it…which I don't like. I think it's wasting their time.

Similarly to Mary's reported experiences of uncertainty about her sense of personhood, when encountering problems in accessing services, Robert's experiences of such feelings of loneliness and despair led him to question his own enacted personality and the relationships he did or did not form over the years:

> In my previous life I wasn't very nice person to anybody…I was a nasty person. I'd hurt people.

Robert's experience of in-patient rehabilitation is telling, in illustrating how, in an already-challenging life episode entailing increased fragility and need for support, experiences of being additionally secluded by the conditions of rehabilitation, engendering feelings of being "stuck" to a bed in a room with few social interactions, can add unhelpful feelings of loneliness and despair. We contend that a rights-based rehabilitation practice promoting disability equality needs to engage with the psychological impact of acquiring impairment as well, and foreground the importance here of forming meaningful social networks.

Within the framework of the same field study, interviews and participant observation were also conducted in the amputee rehabilitation service of the same hospital. The amputee rehabilitation service differed from the neurological service, in that most patients were not individually isolated, but stayed in rooms for three or four people. Furthermore, most patients in the amputee ward did not experience the cognitive difficulties specific to the experience of many patients within the neurological services, such as loss of memory or confusion. As a result, the amputee service emerges as offering a space that may be more conducive than some other rehabilitation services to generating feelings of community and camaraderie.

This specificity in organising and experiencing the amputee service was highlighted in our various casual chats with the staff members, even from setting up arrangements for interviews. At the initial stage of reaching out to interested participants, NHS staff acted as mediators. The first time we were informed about interested patients, a staff member flagged up three people, all of whom wanted to be interviewed. These were all patients staying in the same room, who had been informed about the study at the same time and collectively decided to participate. In addition, when we first went into the ward to make appointments with the respective patients, they were sitting in their wheelchairs in a semi-circle, and socialising. Our initial meeting to arrange the interview dates was also a collective gathering, where patients were having a social welcoming chat with us. Our subsequent meetings in the amputee ward involved similar, more socially-interactive encounters, which felt quite different from our recruitment experience in the neurological service settings. Sometimes, patients spontaneously referred to other patients' experiences with whom they shared their room. For instance, Kate was explaining some problems she was having in her interactions with the staff and suggested that Lisa had similar issues:

> In fact that upset me and that upset Lisa. I may be speaking out of turn, but she probably won't even tell you because she is very, very quiet.

Thus, for Kate this was a collectively-experienced problem, described almost as a "patients versus the staff" polarising discourse, which could be perceived as illustrating the collective character of rehabilitation for amputee patients and the shared sense of community and camaraderie in the amputee ward.

The interviews conducted with the patients in the amputee service did not bring up themes of loneliness. This was not because patients were not stressed about making a transition to a life with an amputated leg. This transition is experienced as stressful; and needs to be planned, especially when it comes to issues of accessibility at home after discharge. Yet, the loneliness and despair mentioned by Robert and several other participants in the neurological services were not mentioned by the participants in the amputee ward. To a certain extent, this might have to do with the particularities of the different impairments. Yet, we contend that a rehabilitation process which enabled patients to share collectively the rehabilitation process in time and space, also plays a significant factor. This is corroborated by findings from a previous study conducted in a Turkish rehabilitation hospital, demonstrating how opportunities for socialisation as patients went through the rehabilitation process, constituted one of the most important aspects of the whole experience:

> The thing we liked most were our meetings in the evening after dinner time…We would get together about 10–12 people….We would not talk about our illness but have general chat (about the government, the economy)….Everyone would be telling their stories about parts of their lives. (Mehmet—not real name)

These more specific insights link contexts with experiences of rehabilitation, showing that rehabilitation can promote disability equality if it makes space for forming social networks within the process, rather than engendering isolation or other life-disruptions or patients, where they are not essential or intrinsic to the treatment process, as, for instance, experiences of pain and nausea within life chemotherapy. We realise the complexities of accomplishing this goal, especially since it requires service providers to develop a patient-focused, comprehensive, holistic understanding of rehabilitation. Yet, if rehabilitation practices are indeed about facilitating a transition into a new life with a new bodily status, this complexity needs to be acknowledged. As such, disability equality can be promoted by facilitating access to rehabilitation services that are based on an adequate assessment of patients' complex needs. The importance of comprehensive rehabilitation programmes has been highlighted by both the aforementioned Article 26 of the CRPD, and a considerable amount of literature (e.g., Byrnes et al., 2012; Dewar & Nolan, 2013; Falkenberg, 2007). Some literature also discussed the specific significance of socialisation and peer support in reducing psychological stress and promoting wellbeing during in-patient and community-based rehabilitation (Jain, McLean, Adler, & Rosen, 2016; Parker et al. 2016; Szalai et al., 2017). One additional factor to highlight here relates to the potential value of developing appropriate inner architectural design to allow more room for socialisation. In this respect, our earlier experience in the Turkish rehabilitation hospital demonstrated the importance of having communal spaces, like inner courtyards, while undergoing rehabilitation. Although sociological studies have often neglected the role of the built environment in medical practice (Martin, Nettleton, Buse, Prior, & Twigg, 2015), we argue for its significance in rehabilitation, and particularly in a rights-based approach.

4. Limitations of This Research

The authors are working towards a conception of rights-based rehabilitation, which undoubtedly requires more evidence, analysis and debate, also drawing on the contributions of others (Siegert & Ward, 2010; Skempes & Bickenbach, 2015). Key features of this approach are that it should:

- Be based on partnership with disabled people, for example through peer support;
- Make space for the voices of disabled people;
- Refer to a comprehensive, holistic understanding of rehabilitation where the complex needs of patients are taken into consideration;
- Be open to diverse ways of functioning, rather than imposing rigid normalisation of impaired bodies;
- See assistive technology as a valid alternative strategy for functioning, rather than a tool for normalisation;
- Understand that people are disabled by society as well as by their bodies, requiring a wider response that challenges social and economic disempowerment;
- Understand that health-related rehabilitation is relevant and important to many but not all people with impairment.

More consultation with wider communities of disabled people is needed before these elements can be validated.

Appendix 33: Co-authored article for *Social Inclusion*

We note that others have stressed freedom, well-being, and dignity as key features of a human rights perspective on rehabilitation, and we would not contest this. However, we would argue for the importance of taking a political as well as a philosophical perspective.

Our literature review was limited by our choice of journals for review and selected time-frame. For example, *Disability and Rehabilitation* published articles on disability rights in the year before our review started (Siegert & Ward, 2010); moreover, there are other journals in the health-related rehabilitation field, some of which are more ready to publish rights-based papers (Skempes & Bickenbach, 2015). The lack of emphasis on the voices of disabled people might in part reflect the professional focus of the rehabilitation science journals searched, and their preference for methodologies with measurable outcomes over qualitative methodologies which privilege the opinions and experiences of participants. A future literature search might include occupational therapy journals, for example, to examine whether voices remain as marginal in this field. It should also be noted that the a small but burgeoning field of critical rehabilitation studies, exemplified by groups such as the Critical Physiotherapy Network (https://criticalphysio.net) is also beginning to challenge prevailing discourses.

Our empirical research was qualitative, and based in one English county, and a few rehabilitation settings, and a few disability organisations, with less than 50 respondents in total. Our interpretations are inevitably interpretative and can be accused of being subjective, like all qualitative research. Using this data, it is impossible to draw broad conclusions about the wider rehabilitation sector, or the total population of individuals experiencing rehabilitation. The original focus of the second research study lies in finding out the role of the family in in-patient rehabilitation in the UK. Thus, interview questions primarily focused on family role and information on rights-based rehabilitation to promote disability equality was derived from the responses to these questions, which set the framework of the case study. As such, some data on rehabilitation services and dynamics specific to rehabilitation like for instance techniques of rehabilitation were not available. Still the emphasis on the importance of having a communal rehabilitation experience is essential. Second and related to the first point, the focus on family role made it necessary to draw upon the fieldwork conducted in the amputee service. Data collected in the amputee service enriched the depth and soundness of the analysis in case study.

5. Concluding Remarks

The premise of this article is that disability is *both* a decrement in functioning, *and* the experience of barriers and discrimination. The disability rights and rehabilitation sciences approaches offer different and equally valid ways of dealing with the loss that often comes with impairment, one which celebrates the resilience of individuals and their capacity to adapt, and the other which calls for society to adapt. We contend that rehabilitation merits sustained engagement from disability researchers as well as rehabilitation scientists, in order to develop rights-based rehabilitation schemes that promote disability equality. For this purpose, based on the first-person accounts and experiences of primarily two disabled people, who go through health-related rehabilitation, Mary and Robert, this article sought to find out the main contours of rights-based rehabilitation. Mary and Robert's experiences foregrounded three important components of rights-based rehabilitation.

First, if rehabilitation is one of the diverse needs faced by many disabled people, then access to rehabilitation is an equality issue. Mary's interview reveals that accessing rehabilitation can be a real 'battle'. Resilience, determination and expertise about one's needs can sometimes be a prerequisite to obtaining access to the right services, and these strengths are not available to all disabled people. Mary struggled to obtain rehabilitation services such as ongoing physiotherapy to keep her muscles in use, and she had to fight for this when she was being encouraged to opt for treatments such as muscle relaxants, which, in her lived experience, reduced her physical capacities and were likely to make her more dependent in the long-term.

Second, beyond the issue of accessing services, there appears to be an equality issue around perceptions of what was right for Mary, which seemed at times to be shaped by others' views about the kind of quality of life she can expect as a disabled person, rather than drawing on Mary's own knowledge of how she can best be supported, via rehabilitation, to determine her own life. Therefore, rights-based rehabilitation must genuinely acknowledge the importance of disabled people's own views and choices regarding their lives and expectations, not as a matter of lip service, through dialogue between professional and patient to form the basis of the service.

Finally, the ways that rehabilitation services are delivered have to be sensitive to the other needs that disabled people also have, beyond the physical (Shakespeare, 2014), to be healed emotionally, to connect with others, to participate, to make sense of their lives. In other words, rights-based rehabilitation would be holistic, rather than reductionist. Robert's sense of isolation and loneliness demonstrated the significance of services that provide room for social networks and peer support, and that they need to be understood as essential aspects of rehabilitation. This point is emphasised also by Skempes and Bickenbach (2015), who argue for an extension of rehabilitation services to ensure that people's needs are properly covered. They call for a rights-based approach to rehabilitation, which considers holistic models of care provision that move beyond a curative approach and "promote alternative means of optimizing functioning such as self-management and peer support". Similarly, Siegert and Ward (2010) refer to a study by Slet-

Appendix 33: Co-authored article for *Social Inclusion*

tebø, Caspari, Lohne, Aasgaard and Nåden (2009), whose qualitative interviews in an in-patient setting for people with traumatic head injuries suggested that support enhanced dignity.

In-patient rehabilitation is not like any other treatment process. It takes often longer and is supposed to aim at facilitating a transition to a new life with a new bodily status. Hence, room should be allowed for some aspects of everyday life that are conventionally associated with life beyond the hospital walls.

The case studies demonstrate that resource constraints in the UK health system appeared to restrict choices, possibly making it harder to achieve rights-based rehabilitation services. This could erode the individual's sense of personhood/entitlement and reinforce feelings of being a "burden". It is exactly for this reason that closer collaboration between disability and rehabilitation scholars and research on rehabilitation as a lived experience is needed.

The UK has better rehabilitation services than most of the world, and a stronger emphasis on patient autonomy than many cultures. In many developing countries, the full implementation of rehabilitation policies has 'lagged' due to a number of 'systemic barriers' (WHO, 2011, p. 104). Among these barriers, the WHO cites 'absence of engagement with people with disabilities' in relation to the design, delivery and evaluation of rehabilitation services (2011, p. 105). So it is not simply a matter of funding services, but also developing and managing services in ways which are empowering and which help people enjoy their rights as disabled people. There is an urgent need to improve understanding and dialogue between the rehabilitation profession and the disability community (Hammel, 2006), in all parts of the world. Rehabilitation sciences need to take on the human rights-based approach which now dominates global and national policy on disability (UN, 2006; WHO 2011). Just as importantly, disability studies and disability policy need to make space for the contribution of health-related rehabilitation, as one element in a multi-disciplinary approach to improving the lives of disabled people (Shakespeare, 2014).

Acknowledgements

Harriet Cooper's project about rights-based rehabilitation received funding from the Collaboration for Leadership in Applied Health Research and Care (CLAHRC) in the East of England. Dikmen Bezmez' project about the role of the family in rehabilitation has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No. 701075. We acknowledge the contribution of Swati Kale and Kate Lee in conducting these two research projects.

Conflict of Interests

The authors declare no conflict of interests.

References

Abberley, P. (1995). Disabling ideology in health and welfare—The case of occupational therapy. *Disability and Society*, *10*(2), 221–232.

Arntzen, C., Hamran, T., & Borg, T. (2015). Body, participation and self-transformations during and after in-patient stroke rehabilitation. *Scandinavian Journal of Disability Research*, *17*(4), 300–320.

Bevan, J. (2014). Disabled occupational therapists: Asset, liability…or 'watering down' the profession? *Disability and Society*, *29*(4), 583–596.

Bezmez, D. (2016). Looking for a 'cure': Negotiating 'walking' in a Turkish rehabilitation hospital. Disability and Society, 31(3), 389-405.

Bourke, J. A., Hay-Smith, E. J. C., Snell, D. L., & Dejong, G. (2015). Attending to biographical disruption: The experience of rehabilitation following tetraplegia due to spinal cord injury. *Disability & Rehabilitation*, *37*(4), 296–303.

Brunton, L. K., & Bartlett, D. J. (2013). The bodily experience of cerebral palsy: A journey to self-awareness. *Disability & Rehabilitation*, *35*(23), 1981–1990.

Byrnes, M., Beilby, J., Ray, P., Mclennan, R., Ker, J., & Schug, S. (2012). Patient-focused goal planning process and outcome after spinal cord injury rehabilitation: Quantitative and qualitative audit. *Clinical Rehabilitation*, *26*(12), 1141–1149.

Chun, S., & Lee, Y. (2013). 'I am just thankful': The experience of gratitude following traumatic spinal cord injury. *Disability & Rehabilitation*, *35*(1), 11–19.

Clifton, S. (2014). Grieving my broken body: An autoethnographic account of spinal cord injury as an experience of grief. *Disability & Rehabilitation*, *36*(21), 1823–1829.

Cook, T., & Inglis, P. (2012). Participatory research with men with learning disability: Informed consent. *Tizard Learning Disability Review*, *17*(2), 92–101.

Corbin Dwyer, S., & Buckle, J. L. (2009). The space between: On being an insider-outsider in qualitative research. *International Journal of Qualitative Methods*, *8*(1), 54–63.

Crisp, R. (2000). A qualitative study of the perceptions of individuals with disabilities concerning health and rehabilitation professionals. *Disability and Society*, *15*(2), 355–367.

Crowe, S., Cresswell, K., Robertson A., Huby, G., Avery, A., & Sheikh, A. (2011). The case study approach. *BMC Medical Research Methodology*, *11*(1), 100–108.

Danermark, B., & Gellerstedt, L. C. (2004). Social justice: Redistribution and recognition. A non-reductionist perspective on disability. *Disability and Society*, *19*(4), 339–353.

Davis, L. (1995). *Enforcing normalcy: Disability, deafness, and the body*. London and New York: Verso.

Dew, A., Llewellyn, G., & Balandin, S. (2014). Exploring the later life relationship between adults with cerebral palsy and their non-disabled siblings. *Disability*

Appendix 33: Co-authored article for *Social Inclusion*

& Rehabilitation, *36*(9), 756–764.

Dewar, B., & Nolan, M. (2013). Caring about caring: Developing a model to implement compassionate relationship centred care in an older people care setting. *International Journal of Nursing Studies*, *50*, 1247–1258.

Falkenberg, E. (2007). Holistic aural rehabilitation: A challenge. *Scandinavian Journal of Disability Research*, *9*(2), 78–90.

Finkelstein, V. (1980). *Attitudes and disabled people*. New York: World Rehabilitation Fund.

Finkelstein, V. (1984). Rehabilitation services. In T. Lobstein & Namibia Support Committee Health Collective (Eds.), *Namibia: Reclaiming the peoples' health*. AON Publications.

Finkelstein, V. (2004). Representing disability. In J. Swain, S. French, C. Barnes, & C. Thomas (Eds.), *Disabling barriers, enabling environments*. London: Sage.

Gibson, B. (2016). *Rehabilitation: A post-critical approach*. Florida: Taylor and Francis.

Goodridge, D., Rogers, M., Klassen, L., Jeffery, B., Knox, K., Rohatinsky, N., & Linassi, G. (2015). Access to health and support services: Perspectives of people living with a long-term traumatic spinal cord injury in rural and urban areas. *Disability & Rehabilitation*, *37*(16), 1401–1410.

Guilcher, S. J. T., Craven, B. C., Mccoll, M. A., Lemieux-Charles, L., Casciaro, T., & Jaglal, S. B. (2012). Application of the Andersen's health care utilization framework to secondary complications of spinal cord injury: A scoping review. *Disability & Rehabilitation*, *34*(7), 531–541.

Hammell, K. W. (2006). *Perspectives on disability & rehabilitation: Contesting assumptions; Challenging practice*. London: Churchill Livingstone.

Huang, I.-C., Wang, Y.-T., & Chan, F. (2013). Employment outcomes of adults with cerebral palsy in Taiwan. *Disability & Rehabilitation*, *35*(3), 228–235.

Jain, S., McLean, C., Adler, E., & Rosen, C. (2016). Peer support and outcome for veterans with posttraumatic stress disorder (PTSD) in a residential rehabilitation program. *Community Mental Health Journal*, *52*(8), 1089–1092.

Kayess, R., & French, P. (2008). Out of darkness into light? Introducing the Convention on the Rights of Persons with Disabilities. *Human Rights Law Review*, *8*(1), 1–34.

Kim, H.-R., & Shin, H. I. (2012). When is it appropriate to deliver a prognosis to Korean persons with acute spinal cord injury? *Disability & Rehabilitation*, *34*(16), 1396–1403.

Lund, M. L., Tamm, M., & Bränholm, I. (2001) Patients' perceptions of their participation in rehabilitation planning and professionals' view of their strategies to encourage it. *Occupational Therapy International*, *8*(33), 151–167.

Martin, D., Nettleton, S., Buse, C., Prior, L., & Twigg, J. (2015). Architecture, embodiment and health care: A place for sociology. *Sociology of Health & Illness*, *37*, 1007–1022.

Moll, L. R., & Cott, C. A. (2013). The paradox of normalization through rehabilitation: Growing up and growing older with cerebral palsy. *Disability & Rehabilitation*, *35*(15), 1276–1283.

Oliver, M. (1990). *The politics of disablement*. Basingstoke: Macmillan.

Oliver, M. (1993). *What's so wonderful about walking?* Inaugural Professorial Lecture, University of Greenwich, February. Retrieved from http://disability-studies.leeds.ac.uk/files/library/Oliver-PROFLEC.pdf

Oliver, M., & Barnes, C. (2012). *The new politics of disablement*. Basingstoke: Palgrave Macmillan.

Oliver, M., & Hasler, F. (1987). Disability and self-help: A case study of the Spinal Injuries Association. *Disability, Handicap and Society*, *2*(2), 113–125.

Papadimitriou, C. (2008). Becoming en-wheeled: The situated accomplishment of re-embodiment as a wheelchair user after spinal cord injury. *Disability & Society*, *23*(7), 691–704.

Papadimitriou, C., & Stone, D. (2011). Addressing existential disruption in traumatic spinal cord injury: A new approach to human temporality in inpatient rehabilitation. *Disability & Rehabilitation*, *33*(21/22), 2121–2133.

Parker, S., Dark, F., Newman, E., Korman, N., Meurk, C., Siskind, D., & Harris, M. (2016). Longitudinal comparative evaluation of the equivalence of an integrated peer-support and clinical staffing model for residential mental health rehabilitation: A mixed methods protocol incorporating multiple stakeholder perspectives. *BMC Psychiatry*, *16*, 1–21.

Shakespeare, T. (2014). *Disability rights and wrongs revisited*. Abingdon: Routledge.

Shikako-Thomas, K., Bogossian, A., Lach, L. M., Shevell, M., & Majnemer, A. (2013). Parents' perspectives on the quality of life of adolescents with cerebral palsy: Trajectory, choices and hope. *Disability & Rehabilitation*, *35*(25), 2113–2122.

Siegert, R. J., & Ward, T. (2010). Dignity, rights and capabilities in clinical rehabilitation. *Disability and Rehabilitation*, *32*, 2138–2146.

Skempes, D., & Bickenbach, J. (2015). Strengthening rehabilitation for people with disabilities: A human rights approach as the essential next step to accelerating global progress. *American Journal of Physical Medicine and Rehabilitation*, *94*, 823–828.

Slettebø, A., Caspari, S., Lohne, V., Aasgaard, T., & Nåden, D. (2009). Dignity in the life of people with head injuries. *Journal of Advanced Nursing*, *65*, 2426–2433.

Smith, B., Papathomas, A., Martin Ginis, K. A., & Latimer-Cheung, A. E. (2013). Understanding physical activity in spinal cord injury rehabilitation: Translating and communicating research through stories. *Disability & Rehabilitation*, *35*(24), 2046–2055.

Swart, J., & Horton, S. (2015). From patients to teachers: The perspectives of trainers with aphasia in a UK

Appendix 33: Co-authored article for *Social Inclusion*

Conversation Partner Scheme. *Aphasiology*, *29*(2), 195–213.

Szalai, M., Szirmai, A., Füge, K., Makai, A., Erdélyi, G., Prémusz, V., & Bódis, J. (2017). Special aspects of social support: Qualitative analysis of oncologic rehabilitation through a belly dancing peer support group. *European Journal of Cancer Care*, *26*(6).

UN. (2006). *Convention on the rights of persons with disabilities*. New York: United Nations.

Van De Velde, D., Bracke, P., Van Hove, G., Josephsson, S., Devisch, I., & Vanderstraeten, G. (2012). The illusion and the paradox of being autonomous, experiences from persons with spinal cord injury in their transition period from hospital to home. *Disability & Rehabilitation*, *34*(6), 491–502.

World Health Organisation. (2001). *International classification of functioning, disability and health*. Geneva: WHO.

World Health Organisation, & World Bank. (2011). *World report on disability*. Geneva: WHO.

World Health Organization, & ISCOS. (2014). *International perspectives on spinal cord injury*. Geneva: WHO.

About the Authors

Tom Shakespeare is Professor of Disability Research at the University of East Anglia. He was formerly in the Disability and Rehabilitation team at WHO for 5 years, where he helped produce the *World Report on Disability* (2011) and *International Perspectives on Spinal Cord Injury* (2014). His publications include *Disability Rights and Wrongs* (2006). He is trustee of Equal Lives, the disabled people's organisation for Norfolk.

Harriet Cooper is working on a qualitative social research project entitled 'Rights-based Rehabilitation' at the University of East Anglia. She holds a PhD in Disability Studies/Medical Humanities from Birkbeck, University of London. Her work has appeared in a range of publications, including most recently in *The Palgrave Handbook of Disabled Children's Childhood Studies* (2018).

Dikmen Bezmez is Assistant Professor of Sociology at Koç University, Istanbul. Her recent research focuses on social experiences of physical rehabilitation. Some of her publications include an article on discourses surrounding the concept of "walking" in in-patient rehabilitation in Turkey, in *Disability & Society* (2016), and another one on the use of medical technology in rehabilitation in the *Scandinavian Journal of Disability Research* (2016). She co-edited a reader in disability studies in Turkish (2011).

Fiona Poland is Professor of Social Research Methodology at the University of East Anglia. She co-leads a Public and Patient Involvement Research theme for the NIHR Collaboration for Leadership in Applied Health Research and Care in the East of England. Her research addresses community wellbeing and promotes cross-sector collaborations. She is Editor-in-Chief of *Quality in Ageing and Older Adults*. She is trustee of the *Association for Research in the Voluntary and Community Sector*.