Tailoring technologies to the rehabilitational needs of stroke survivors

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Abstract

Stroke is a major cause of physical disability. Recovery is possible, and can continue indefinitely. As such, much of it will take place at home, often with minimal support from professional therapists. As computing becomes more pervasive and familiar, opportunities exist to design technology to support rehabilitation in the home environment. However, given the varied nature of disabilities caused by stroke, there is a need for a greater understanding of how to design technology that is sufficiently tailored to the needs of individuals and which is appropriate for usage in their homes. This thesis offers an exploration of these issues, through a series of research activities constructed around the direct participation of stroke survivors and their families.

The core of this thesis begins with a consideration of a focus group which was attended by survivors of stroke and their partners. Recorded discussions provide a rich insight into their collective experience of living with stroke, and the implications of these findings for the design of effective rehabilitation technologies are considered. The design of bespoke technologies which were directly tailored to the rehabilitational needs and personal motivations of four stroke survivors is then described. Prototypes of these technologies were deployed for periods ranging from one to seven months. Data recorded throughout this entire process provides a detailed understanding of the factors that have influenced their design, use and impact.

Through an analysis of material collected during all of these engagements, this thesis presents a set of contributions which can support the design of better home-based rehabilitation technologies in the future. These contributions support a more general understanding of the interactional needs of individuals who have experienced a dramatic and potentially traumatic change in their life, and of mechanisms for tailoring persuasive computing technologies to the specific motivations of those who use them.

Acknowledgements

To date, my entire research career has been situated in either the Mixed Reality Laboratory [1] or the Horizon Digital Economy Research Institute [2]. These organisations have developed a unique perspective on Human Computer Interaction research, and the traditions of this research have had a significant impact on the structure and presentation of this thesis. In particular, both of these organisations have a focus on research "in the wild", which involves the generation of knowledge through the design, deployment and evaluation of interactive computer systems into realistic settings, rather than their study in the controlled conditions of the laboratory. This approach is reflected in the participatory nature of the design process described in this thesis, and in its emphasis on deploying and evaluating prototype rehabilitation systems with real users for an extended period of time. Research in the wild can be complex to conduct, and experience on a variety of prior research projects has provided me with the skills and experience necessary to engage with this topic sufficiently to allow for the construction of a thesis. I would like to acknowledge the opportunities for learning that have been provided by these projects, and the opportunity for engaging in thesis work that was provided by my participation in Motivating Mobility.

Within these organisations, I would particularly like to thank Tom Rodden, who encouraged me to register over a long period. I would also like to thank Steve Benford, for support both during and after the registration process, and in the workplace in general. There are also many people in the Mixed Reality Laboratory who have allowed me to talk through my ideas, and whose support has made a major difference. The same is certainly true for members of the Motivating Mobility team.

Outside of work, my parents have made a big difference, by providing a home environment that encouraged learning, and for helping out with the many difficulties along the way. I am lucky to have shared it with them, and my two

wonderful brothers, Shaun and Corin. My grandparents played a major role in my life, and are sadly missed. Most importantly of all, however, I wanted to acknowledge the contribution that Helen Thomas, my wife, has made to this thesis, and to my life in general. "My friend and my companion" [3], she is a constant inspiration, and has helped me in so many ways. I am very lucky to have such an amazing person to share my life and all of my future adventures with.

I would also like to thank everyone that has read and commented on this thesis, for the time that they have invested in it, and for the contributions that they have made to its contents.

Organisational context

Most doctorates awarded by the University of Nottingham are to candidates who have been registered as full- or part-time students, and who are required to submit a thesis which has been constructed around novel research work carried out primarily during their period of registration. However, for employees that have been contracted to the University of Nottingham for a minimum of four years, an alternative is to submit a thesis as a staff candidate. Staff candidates are required to demonstrate that their thesis can be constructed around sets of data that have been collected during their own prior research, and are not allocated a supervisor. They must also defend their work at a viva attended by two external examiners, rather than an internal examiner and an external examiner.

This thesis has been submitted through the staff candidate mechanism, based on an original application for permission which was made in March 2010, and which is included in Appendix A. It builds on a substantial corpus of data that was collected by the author during the Motivating Mobility project [4, 5]. For the purposes of transparency, Chapter 4 provides a detailed summary of research conducted during this project, highlighting the contribution that the author made to it, and identifying analyses that have been performed by the author solely for the purposes of this thesis.

Reflexive statement

After leaving school, I studied Computer Science at the University of Cambridge, and then began my post-graduate career as a database developer at the Bank of England. In 2003, I then took on a relatively technical role in the Mixed Reality Laboratory (MRL) in the University of Nottingham, developing code and interfaces to support a variety of research projects that were taking place at the time. In 2006, I spent a year studying a Psychology module with the Open University in my spare time. This module provided me with a grounding in a variety of qualitative analysis skills, which have been applied across a variety of research projects, and also in the construction of this thesis. In parallel to this, I became involved in the *Curious Home* [6], a sub-project that had been established by the Equator Interdisciplinary Research Consortium [7], and whose focus was on the design of novel interactive artefacts for the domestic environment. Through working on this project, I developed an appreciation of the contribution that design practice could make to research, and gained experience in the use of a variety of design and evaluation approaches, such as *cultural probes* [8]. Since then, I have gained further experience in the use of design practice in research in a variety of contexts. Examples have included conducting and analysing participatory design sessions for a variety of MRL projects, including *inScape*, *C-Aware* and *CHESS*, and direct involvement in auteur-led design [9] in the *A Day in the Park*, a project organised by the Horizon Digital Economy Research Institute [2]. Prior to the submission of this thesis, I developed a number of publications that draw directly on my experiences of design practice to make an academic contribution (for example, [10, 11]).

More recently, I have begun to develop a specific research interest in the design of interactive systems to promote health and well-being. This interest primarily arose through my participation in the Motivating Mobility project, which was introduced in the previous section. It was also influenced by

a year-long period of psychotherapy training at the Sherwood Institute in Nottingham [12]. Participation in these activities helped to convince me that there can never be sufficient human resources to employ therapists to treat all medical problems effectively, but that, in some cases, computing can provide a cost-effective alternative which could benefit certain individuals.

The design of interactive systems to support health is then a field of research with a long and complex history, and is an area that I want to make a research contribution to. I am particularly interested in the use of participatory design methods to allow for the integration of the perspective of service users, rather than medical experts, into the design of such systems. The Motivating Mobility project gave me a first opportunity to pursue this interest, and I am currently in the process of searching for other opportunities in this space.

The *Staff Candidate* mechanism, which was introduced earlier in this thesis, would have allowed me to obtain a doctorate by submitting publications. However, I have been motivated to write a thesis by the desire to practice writing at the scale of a small book, having previously only written papers, which have all been much smaller. I have also been motivated by the possibility of producing an output which provides further credibility within research that is orientated around design practice, and which makes a useful contribution to this practice. Finally, a successful thesis has the potential to lead to further opportunities within academia, such as fellowships or the submission of project proposals. As such, I have been keen to write a thesis around a topic of work that I care about, and would like to pursue in the future.

Dedication

This thesis is dedicated to the memory of the people who have made a big difference to my life, but who are no longer around to read it: James Rennick, Hilda and John Egglestone, Pamela Thomas and Joan Page. Also to Gladys Rennick, still with us, but only partly.

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Chapter 1

Introduction

1.1 Stroke, rehabilitation and technology research

Stroke, a form of cerebro-vascular disease [13], is one of the leading causes of death and disability in the world. A World Health Organisation report [14] provides some illustrative statistics for 2004, which estimates that, during this year, 9 million new cases of stroke occurred, that stroke was the second highest cause of death, and that it was the eighteenth highest cause of moderate or severe disability. The report also estimates that 30.7 million individuals were living with the after-effects of stroke during this period, and that, compared to other types of disease, stroke was the sixth highest cause of economic burden in the world, and the third highest in high-income countries. Given that stroke is a disease which disproportionately affects the older population [14], and given that, demographically, the population of the world is ageing, stroke is predicted to rise to be the fourth highest burden of disease in the world by 2030, and the second highest in high-income countries [14]. In the UK, a major report [15], published in 2007, estimated the economic cost of stroke to be £7 billion per year, consisting of £2.8 billion direct costs to the National Health Service (NHS), £2.4 billion in informal care, and £1.8 billion in lost productivity.

Recovery from disability acquired through stroke is possible, can continue for many years, and would ideally be assisted through a team of professionals, which might include speech and language therapists, dietitians, clinical psychologists, physiotherapists and occupational therapists [16, 17]. Unfor-

tunately, however, in the UK at least, there is very often insufficient support for this type of rehabilitation. This is evidenced by a 2005 Department of Health report [18], which estimated that "only half of individuals who have experienced a stroke receive rehabilitation to meet their needs in the first 6 months following discharge from hospital". The report also estimates that only 20% then obtain sufficient support for rehabilitation in the following 6 months. This then implies a substantial population of survivors of stroke who have been discharged from hospital, but who are living with disabilities from which they might have recovered if more support was provided.

Stroke is a condition which has been of interest to researchers interested in interactive systems since at least 1991. An early system [19] was constructed around a robotic arm, which had been programmed to lead a stroke survivor through a series of reaching exercises, under the supervision of a professional therapist. Other examples include the design of novel robotic [20] and virtual reality [21] technologies, and the re-purposing of commodity gaming technologies such as the Nintendo EyeToy [22]. Much of this research has focused on usage in clinical environments such as hospitals, although the home is increasingly becoming a distinctive target for research. There also seems to have been a wide variety of motivations to develop such systems, including reducing the cost of therapy [19], providing motivation for rehabilitation exercise when therapists are not available [23] and providing training for skills which might be hard to support in the traditional clinical environment [24]. The efficacy of many of the technologies that have been developed has been established through significant clinical trials (for example, [20]). However, despite the range of systems that have been developed, and the weight of evidence that has been collected in relation to their efficacy, the design of rehabilitation systems is very much an area of research which is open to progress, with a range of open questions to address.

1.2 Tailoring technologies to the needs of stroke survivors

Within the community of HCI researchers who are interested in interactive systems to support rehabilitation from stroke, a current question, which is subject to ongoing research, is how to design interactive rehabilitation sys-

tems which can be sufficiently *tailored* to the needs of individual stroke survivors [25]. A key motivation for this research relates to the nature of stroke, which is often associated with long-term damage to the brain [13]. Because different regions of the brain have specialised functions [26], this means that the patterns of disability that are caused by a particular stroke will be unique for each individual, thereby creating a need for a tailored rehabilitation program. Although the issue of systems that can be tailored has been discussed in a number of recent publications [25, 27], it is certainly not one which has been solved. A particularly important question to address is how to support the deployment of rehabilitation technologies that are tailored to individuals, but which are sufficiently cost-effective to be utilised on a large scale.

Given that many survivors of stroke will be discharged into their homes (or may never be hospitalised in the first place), the question of how to design rehabilitation technologies that are appropriate for use in the home is also an important one, and a topic that has only been partially addressed by the research community. Although there are a variety of rehabilitation technologies which are intended for use in the home, including a significant number of case-studies constructed around the Nintendo Wii [28], there is little research that explicitly focuses on the home as a distinctive environment for technology deployment, and which considers it as a daily place of living. Prior research in disciplines such as Computer Supported Co-operative Work (CSCW) or Ubiquitous Computing (e.g. see [29]) has highlighted the unique nature of the home, and motivated design that draws on a rich understanding of its nature. This then raises the question of how to integrate a rich understanding of the nature of the home into the design of rehabilitation systems that are targeted at this environment.

1.3   Summary of approach

In seeking to engage with these topics, work presented in this thesis draws on the qualitative analysis of a variety of interactions with survivors of stroke and their families, which took place through a series of workshops, participatory design sessions and prototype deployments organised during the Motivating Mobility project. Stroke survivors and their families are key stakeholders to consider when establishing effective designs rehabilitation technologies, and yet in a detailed review of the literature, presented in Chapter 3, the au-

thor found very little documented evidence of engagement with these groups during the process of design. Instead, where there is participation in this process, it is often on the part of professional therapists. This then carries the risk of producing designs that are implicitly structured around the perspectives of such professionals, which may not speak to the unique nature of the home and the needs of those that live in it. In contrast, this thesis focuses on documenting knowledge developed in relation to the perspective of stroke survivors and their families. By presenting this knowledge to the research community, the intention is to support the design of more effective rehabilitation technologies in the future, as well as making a novel contribution that can support further research. Work presented in this thesis has been structured around a number of ineractions with stroke survivors and others in their social context. A brief summary of structure of this process, and the knowledge that has been generated through it, is provided at the end of this chapter.

More broadly, work presented in this thesis is has been guided by the longer-term goal of constructing a specialised toolkit of hardware and software components which might be used by a future rehabilitation specialist to rapidly deploy tailored systems that were suited for use in the home. Toolkit design is a long-standing topic of research in computing, and examples of specialised toolkits includes offerings which support the rapid assembly of Ubiquitous Computing systems [30] or context aware systems [31]. The possibility of constructing a toolkit to support rehabilitation work is then a very recent topic of discussion in research [27], and is a concept which could be broadly applicable to a range of health problems. Such a toolkit might monitor physical movement through a set of standardised physical input devices, and movement might then be used to drive interaction with motivational content such as games [27]. By motivating significant amounts of carefully-selected movements which have been affected by an acquired disability, we might then expect to support long-term recovery in these patterns of movement [32]. Motivating movement in this way is core to the approach presented by a broad variety of rehabilitation technologies, and further examples of the application of this approach are given in Chapter 3.

Work presented within this thesis is situated in Research through Design, an approach to the generation of knowledge which is well-accepted within research [33], and which uses the process of design to explore complex problems

which are not suited to reductionist enquiry. Participatory Design, which emphasises the importance of integrating potential users of technologies directly into the design process, is also an important influence. The thesis concludes with a detailed reflection on the utility of these concepts in relation to the research that has been presented, which supports an understanding of their relevance in relation to rehabilitation technology research.

1.4   Thesis structure

This thesis is structured into nine chapters, including this introduction. Brief summaries of the succeeding eight chapters are included below.

Chapter 2

This chapter defines stroke as a medical condition, and discusses its treatment, with specific reference to the UK medical system. It describes typical patterns of disability post-stroke, and explores aspects of the professional practice of movement therapists that are relevant to the design of rehabilitation technologies. It also considers a number of relatively basic technologies that are already in common use by movement therapists during this process. The chapter concludes with a commentary which draws on this material to highlight five key topics for consideration by technology designers. These are intended to establish a broad framework within which the more specific contributions that this thesis makes can be placed.

Chapter 3

This chapter provides a detailed review of prior research relevant to the design of rehabilitation technologies. It begins with a review of existing technologies, to support an understanding of the approaches that have been taken and the opportunities for the development of knowledge. It then presents a broader review of relevant HCI and CSCW literature, focusing on exertion interfaces, exergames, persuasive computing and the home as a target for technology research. It concludes with a statement of the contributions to research that have been made in this thesis, which has been informed by the literature that has been presented.

Chapter 4

This chapter provides an outline of the approaches and methods that have influenced work presented in this thesis. It begins with an introduction to Research through Design (RtD), the approach within research presented in this thesis is situated. RtD is particularly relevant in complex settings in which reductionist approaches to research are not relevant, and is often associated with contributions structured as sensitizing concepts, guidelines for design or conceptual frameworks, all of which are present in this thesis.

This chapter also documents the methods adopted during the Motivating Mobility project, during which the corpus of data on which this thesis depends was collected. A substantial amount of analysis has been conducted by the author specifically for the purposes of constructing this thesis, and a summary of analytical work is provided. For the purposes of transparency, this chapter documents the contribution of the author to Motivating Mobility, and highlights project work that was carried out solely by the author, project work that was carried out in collaborative manner with a contribution from the author, and project work that has informed this thesis but which the author was not directly involved in. Details of the implementation of relevant pieces of research are then provided in succeeding chapters.

Chapter 5

This chapter presents a set of seven concepts which are intended to sensitise designers to key aspects of the experience of living with a stroke that have not been considered sufficiently in the literature. These concepts are grounded in a corpus of data collected through a workshop organised by the Motivating Mobility project. This workshop was constructed around a number of focus groups with survivors of stroke and their partners, and concepts are therefore intended to represent the perspectives of those individuals that attended this workshop. The proceedings of this workshop were recorded through a number of mechanisms, and a qualitative analysis has been performed by the author. Concepts developed through this approach focus on the experience of living with stroke as described and discussed by the participants, and have been chosen for their relevance to the design of rehabilitation technologies for the home. As well as presenting these concepts, a discussion of their collective implications for design is provided.

Chapter 6

This chapter describes design work that was conducted with the participation of four survivors of stroke, alongside partners and family members. For each individual, this work was focused on designing a bespoke rehabilitation system that was tailored to their individual motivations and needs, and to the broader social and domestic context in which they lived. Design work took place in the home, and three or four sessions were conducted with each participant. A detailed record of this process has been maintained, consisting of photographs, field notes and design notes. For each participant, a detailed case study of the design process is provided in this chapter. The process of constructing these case studies is also described in detail.

The chapter concludes with a discussion of the nature of tailoring in each of these case studies, providing a five-factor model which is of broader relevance to researchers interested in the concept of tailoring. This discussion also explores the various ways in which individual motivations for recovery were integrated into the design of tailored technologies, thereby making a contribution which is relevant to research into persuasive computing technologies.

Chapter 7

This chapter describes a set of prototype implementations of designs described in the previous chapter, and the deployment of these prototypes into the homes of participants. During the deployment process, a corpus of data consisting of both system logs and regular interviews was collected. Analysis of this material has provided some insights into the implications of integrating personal motivations into the design of rehabilitation technologies, the impact of the social nature of the home on usage of these technologies, and the necessity of providing external professional support for deployments, even if on an occasional or periodic basis. A discussion of these insights is provided, which considers them in relation to both the existing literature and the open questions for research that they raise.

Chapter 8

This chapter integrates across material presented in all previous chapters to present a series of abstractions. These consist of:

- A set of guidelines intended to inform the design of rehabilitation technologies that are sensitive to the unique nature of the home as a place of living

- A discussion which presents two ways in which existing rehabilitation research needs to be reconceptualised in light of work presented in this thesis

- A conceptual model intended to inform the design of a future rehabilitation toolkit

These abstractions are discussed in the context of existing literature.

Chapter 9

This thesis concludes with a chapter that provides a reflection on the process of research, and which considers its broader implications for HCI and CSCW research. Beginning with a summary of the key contributions to knowledge that have been made, this chapter also presents a discussion of the concept of tailoring as it has been presented in this thesis, and a reflection on the strengths and limitations of the chosen research method.

1.5 Related works

A summary of key elements of the literature review work presented in Chapters 1, 2 and 3 has been published at the Interactive Technologies and Games: Education, Health and Disability conference in 2012 [34], which was written after the initial submission of this thesis.

> Rennick-Egglestone, S. *Approaches to movement therapy and their relevance to the design of interactive systems to support rehabilitation.* Proceedings of ITAG, 2012.

During the Motivating Mobility project, the author published an initial analysis of collected workshop material at the IEEE Pervasive Technologies for Healthcare conference in 2009 [35]. Chapter 5 then substantially extends and re-purposes this initial analysis.

> Rennick-Egglestone, S., Axelrod, L., Nind, T., Wilkinson, A., Robertson, Z., Ricketts, I., Turk, R., Burridge, J., Mawson, S., Rodden, T., Smith, P. and Shublaq, N. *A design framework for a home-based rehabilitation system.* Proceedings of Pervasive Technologies for Healthcare, 2009.

Case-study material written specifically for Chapters 6 and 7 has been included in a paper published at CHI in 2011 [27].

> Balaam, M., Rennick-Egglestone, S., Fitzpatrick, G., Rodden, T., Hughes, A.M., Wilkinson, A., Nind, T., Axelrod, L., Harris, E., Ricketts, I., Mawson, S. and Burridge, J. *Motivating Mobility: Designing for lived motivation in stroke rehabilitation.* Proceedings of the ACM conference on Computer-Human Interaction, 2011.

Chapter 2

Recovering from a stroke: Essential knowledge

This chapter provides background knowledge about stroke as a medical condition. It is structured around topics that are relevant to the challenge of designing rehabilitational technologies, and which support an understanding of the interactional needs of stroke survivors. It begins by defining what a stroke is, and then considers typical patterns of disability post-stroke. To support an understanding of how stroke is treated, it then presents a case study of organisational support for recovery in the UK, and discusses elements of the professional practice of movement therapists that are important to understand in the context of an exploration of rehabilitation technology design. This chapter concludes with a commentary, which highlights five key issues to consider when designing and evaluating technologies. These then provide a context for understanding work presented in succeeding chapters.

2.1 What is a stroke?

The human Central Nervous System (CNS) consists of the brain and spinal cord, which together provide much of the information processing functionality of the body. A stroke, otherwise known as a cerebro-vascular accident [13], occurs when the blood supply to a region of the CNS is interrupted or reduced, either permanently, or temporarily [13]. This situation is extremely dangerous as neurons, the cells that are primarily responsible for processing information, have a high demand for energy, but no significant fuel or

oxygen stores, so can be damaged, permanently, even if blood supply is lost completely for just a few minutes [36, 13]. Damaged neurons can then leak water into brain cavities through breaches in their cell membrane, leading to a condition called oedema. This involves released water placing pressure on major arteries, and therefore leading to further reductions in blood flow to damaged areas [37]. In addition, if blood flow to the damaged area is not restored within several days, then the blood-brain barrier can start to break down in that area [37]. Since the blood-brain barrier is a structure whose function is to maintain a healthy environment for the brain [36], then such an occurrence can be very serious for the person experiencing a stroke, leading to further medical complications.

There are two principal causes of stroke, and, in the short-term, both require different medical treatments, and imply different patterns of survival and recovery. Ischemic stroke involves a blockage in part of the network of vessels that carry blood to the various regions of the brain, and is caused by either a blood clot, an air bubble or a fat globule [38]. If symptoms of ischemic stroke last less than 24 hours, then the stroke is classed as a transient ischemic attack (TIA), whilst if they last longer than 24 hours, it is classed as a full stroke [37]. Hemorrhagic stroke occurs when a blood vessel in the brain bursts [38]. Systematic reviews of stroke incidences suggest that around 80% of strokes are ischemic, 15% are hemorrhagic, and 5% are unidentifiable [37]. Survival rates are high for ischemic stroke, with around 80% of patients who have had their first full (i.e. non-transient) stroke surviving for at least 1 year [37]. In comparison, only 40% of patients who have suffered a hemorrhagic stroke survive for a year [37]. In all patients, recurrence rates for stroke are high, with an average annual risk of 4-5% for ischemic stroke [37]. Recurrence rates for hemorrhagic stroke are far higher, and this is the primary reason why far fewer individuals who have suffered a hemorrhagic stroke survive for more than a year [37].

For those individuals who do survive a major stroke, the process of recovery can generally be divided into three phases [37], although the exact nature of the process of recovery can vary dramatically between individuals. During the first phase, which may last for 2-4 weeks, recovery is linked with the brain returning, in some way, towards normal operation. Such recovery may involve an increase in blood supply to neurons in the vicinity of the stroke that were not completely starved, and which therefore survived [37]. It may also involve

the reduction of cerebral oedemas [37]. Recovery in these situations can be aided by a wide variety of medical interventions, which can aid natural bodily processes [37, 13]. During this phase, technological interventions may not be appropriate at all.

Natural recovery in the second phase, which typically last 6 months is often rapid, and is linked to a phenomenon called neuroplastic change, involving undamaged parts of the brain taking on the function of damaged parts [37]. Beyond 6 months, recovery becomes much slower, but can continue for many years. Recovery in this third phase can be aided through various types of therapy, many of which are focused on stimulating neuroplastic mechanisms [15]. Different styles of technological interventions may be appropriate in each phase, and this issue is discussed in more detail at the end of this chapter.

2.2   Patterns of disability post-stroke

Because neurons die rapidly if starved of blood supply through stroke, and because the brain is the information processing centre of the body, disability in stroke survivors is very likely, but the precise nature of this disability will vary between individuals. The location of the stroke in the brain is a very important influence on the nature of any resulting disability; this is because different physical regions of the brain have specialised processing functions [39], so damage in a specific area can often be related to a specific set of functional impairments in the individual. As such, observations of developing disabilities, just a few hours post-stroke, can help in a diagnosis of the location of the ischemia or hemorrhage, and can suggest medical intervention [37]. In addition, because there are certain areas of the network of cerebral blood vessels that are particularly susceptible to stroke, then there are certain common patterns of ongoing disability that can be recognised in a significant number of the surviving stroke population.

One common example, seen in strokes caused by blockages or hemorrhages in either of the two middle cerebral arteries [13], is hemiplegia [37]; this involves functional impairments of the whole of one side of the body, which is known as the ipsilateral side. This pattern is caused by the division of much of the human brain into two hemispheres, with neural systems in the left hemisphere being related to functionality in the right side of the body,

and vice-versa [13]. Each middle cerebral artery feeds into one hemisphere, so a disruption in one of these vessels can cause a substantial damage across a wide variety of neural systems. Since, in addition, each hemisphere contains some specialised functions that are not purely related to one side of the body, then hemiplegia can be associated with further cognitive disabilities, such as those impacting on speech and language production[1].

Of course, strokes do not always lead to hemiplegia, and in general, strokes that occur in smaller blood vessels tend to cause much more specific patterns of disability, as these vessels feed a smaller region of the brain. Occasionally, a small stroke may affect an area of the brain that purely relates to cognition, in which case there may be no physical disabilities whatsoever. In contrast, strokes that affect the lower brain-stem and, in particular, a region called the myelencephalon [36], tend to be fatal, as this is a part of the brain that controls functions that are essential for survival, such as regulation of the cardiovascular system. A stroke affecting the upper brain stem can lead to an unusual situation called locked-in syndrome [37].This involves a complete paralysis of the limbs, neck, jaw and face, with often only eye movement being available to the survivor, who may, otherwise, be completely conscious. Locked-in syndrome was the topic of a recent book [40], Le Scaphandre et le Papillon (the Diving Bell and the Butterfly). The author communicated the text of this book, letter by letter, to a therapist, over a series of months, purely through the mechanism of blinking his left eyelid. This example provides further evidence for the massive range of disability that can be caused by a stroke.

2.3   Organisational support for stroke treatment and recovery

Any proposed technological support for rehabilitation will need to co-exist with, and potentially be supplied by, a broader organisational system. Understanding how to design effective rehabilitational technologies then requires an understanding of the nature of support provided by these systems. There is, however, a very significant variation in both the incidence and the treat-

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[1]These functions are associated with a very specific region of the brain called Broca's area [13]

ment of stroke across the world [41], and a survey of organisational support would be the work of an entire PhD thesis or greater. Given that work presented in this thesis took place in the UK, and given that the UK has a relatively developed organisational structure to support stroke recovery, this chapter now provides a summary of the structure of treatment and support as provided by the UK. This description then establishes a context in which research presented later in this thesis has taken place, thereby supporting an understanding of the choices that have been made during this process.

The UK has a health system that directly controlled by the UK government, through the work of the Department of Health, who are responsible for strategic planning and delivery. Stroke treatment and rehabilitation is then strongly influenced by a major document, published in 2007, and known as the National Stroke Strategy (NSS) [15]. Although it is clear that organisational support does not yet fully conform to the vision presented in this document (as an example, see statistics presented on p.14 of the NSS), the document also provides a statistical analysis of existing services, and it is therefore a valuable guide to organisational support for stroke at present, and how it is likely to progress in the future. A brief summary of this document is then valuable in understanding the direction of travel for stroke support in the UK, and is provided below.

The central focus of the document is on preventing stroke from occurring, treating stroke as an emergency when it does occur, and on providing appropriate support for survivors, relatives and carers throughout the survivors lifetime. The document outlines various settings in which stroke support needs to be provided. These include hospitals, the homes of stroke survivors, and residential homes, for those unable to live at home after discharge. As a stroke occurs, the document advises rapid assessment and treatment, in order to minimise the long-term damage that can be caused. Transient Ischemic Attacks (TIAs) are seen as a possible indicator of major stroke, with a 20% chance of stroke within 4 weeks of the TIA. The emphasis here is therefore on identifying those individuals who are most at risk, and on reducing risk factors that can lead to major stroke. This might include treatments to thin the blood, along with advice on healthy living. It might also include scans of various bodily functions, searching for anomalies.

Where a stroke is classed as major, or where the diagnosis is uncertain, the document advocates immediate transfer, by ambulance, to a hospital

with the facilities to offer acute stroke services. Various short-term medical interventions may then be used to try and reduce the long-term impact of the stroke, such as thrombolysis, which involves the administration of clot-busting drugs. Patients who have been admitted to a hospital are then likely to stay there for a period of time, as their needs are assessed, and as a care plan is devised for them [16]. The National Stroke Strategy presents evidence that, where possible, early discharge, to a home environment, can be the best option, as long as a community care team, which has a specialism in stroke, is available. Some survivors may need to be discharged into a care home. However, the document makes it clear that recovery can continue for many years post-stroke, and that support should be provided for the recovery process for all, regardless of setting.

Unfortunately, as noted in Chapter 1, at present, only half of individuals who have experienced a stroke receive the rehabilitation to meet their needs in the first six months following discharge from hospital [18, 15]. This situation gets worse as the individual gets further in time from their discharge, and only a fifth get sufficient rehabilitation in the following six months [18, 15]. Given that the population of the UK is ageing, and given the likely increase in levels of stroke that this implies, this is a situation that seems likely to deteriorate in the future, suggesting the need for an alternative mechanism that supports more cost-effective rehabilitation at home. There is then an argument for the development of cost-effective rehabilitation technologies for use in the homes of survivors of stroke who have been discharged.

Support for rehabilitation early in the process of recovery tends to require a team of individuals with different skills. Many stroke survivors have immediate difficulties in swallowing food and water, so an assessment by a speech and language therapist is likely to take place relatively quickly post-stroke, to identify what types of food can be eaten, and to provide instruction to the patient about how to eat safely [16]. Such an assessment might involve a dietitian, who can work out how to provide sufficient nutrients through easily-swallowed foods, if problems in swallowing persist for more than a few days [16]. In particularly serious cases, nutrition may also need to be provided intravenously, by doctors or nursing staff [16]. Later in the recovery process, speech and language therapists can help in ongoing difficulties in talking, reading and writing, which may include time spent with relatives, family and friends, who can be advised about how to deal with any com-

munication difficulties that the patient has [16]. Support for psychological re-orientation can be provided by clinical psychologists [16].

Help with movement difficulties, which are very common post-stroke, can be provided by physiotherapists and occupational therapists [16], either in a clinical environment, or at home. These two groups of professionals are collectively referred to in this thesis as movement therapists. Various items of literature differentiate between the roles of these two groups of professionals, and suggest that physiotherapists provide exercises to address difficulties with balance, weakness, or paralysis, and to avoid pain caused by stiff and painful limbs [16], whilst occupational therapists tend to focus more on regaining functional abilities, such as dressing, using the toilet, or washing [16]. However, throughout hospital visits conducted as part of the Motivating Mobility project, the author has observed that, in reality, these roles are less distinct in relation to stroke, and that movement therapists will tend to select an approach which is most suited to their patient, potentially picking and choosing from the variety of interventions that are available to either occupational therapists or physiotherapists.

In general, regardless of the specific type of intervention, there is good evidence that interventions to improve movement and mobility can provide substantial benefits for survivors in the long-term, including long-term reductions in mortality and disability [42]. Professional practice in the movement therapies has influenced much of the existing research into novel interactive rehabilitation systems for stroke, and a review of this influence is provided throughout Chapter 3. Firstly, however, the remainder of this chapter focuses on providing a more detailed overview of the role of the movement therapist in traditional stroke rehabilitation. This is presented through a discussion of different approaches to therapy, through a consideration of issues such as how movement therapists motivate their patients, and through a discussion of the tools and technologies which are already in use in everyday professional practice.

2.4 Understanding the professional practice of movement therapists

In the UK at least, physiotherapy and occupational therapy are both professions, in that they are regulated by a professional body (the Health and Care Professions Council [43]), require professional qualifications for entry, and provide a variety of forums for discussion and debate (e.g. see conferences organised by the Chartered Society of Physiotherapists [44]). Given that professional movement therapists are frequently involved in the long-term treatment of stroke, and given that there are established patterns of practice within these professions, then understanding the nature of this practice is then important in the context of designing appropriate technologies. Much of the work of movement therapists is conducted through a series of sessional engagements with clients [45]. Understanding professional practice then requires an understanding of both the work that is done within these sessions, and the longer-term relationship between these sessions and the process of recovery.

Movement therapy is a practical profession, and a substantial part of the training of therapists is orientated around the development of knowledge and experience through practical work with clients [42]. At the same time, although there is good evidence that such therapies provide beneficial outcomes, there is a lack of scientific evidence to guide the specific details of treatments that are given [42]. As such, there is a substantial variation in the practice of therapy across the profession, with each therapist being influenced by their interpretation of the literature, their accumulated clinical experience, and their continuing education [46].

Due to this substantial variation, it is impossible, within the space available in this literature review, to consider the full spectrum of orientations to the process of treatment that are present in the movement therapies today, as to do so would be a major piece of research in its own right. Given the interest of HCI researchers in engaging with the design and evaluation of health technologies, this then raises a broader question of how to incorporate the knowledge present within a variety of health professions into these technologies, with movement therapies being just one example. How to address this question is an open topic for research, and a detailed discussion of it has been provided by the author in a paper written in parallel to this thesis [34].

Given this challenging issue, the orientation of work presented within this chapter is to consider a significant and tractable subset of professional practice, and to provide summary details of this subset. The structure of this work then draws on an observation by Marsden and Greenwood [47] that training and practice in the movement therapies tends to be constructed around a number of recognized *approaches*, with these approaches then providing a window that can be used to partially understand professional practice in the movement therapies. In this context, approaches are theoretical constructs that encompass a series of ideas and hypotheses about how therapy works, and how therapy sessions should be structured [47]. Although these approaches may be unproven (in a strict scientific sense), and do not provide a fully precise definition of the work of those therapists that engage with them, research shows that they have influenced a large proportion of its practitioners [48]. They therefore provide a useful source of information for application developers, and, in particular, can provide an interesting framework around which design discussions can be constructed [34]. Understanding the nature of practice as prescribed by these specific approaches is then one route into understanding part of the professional practice of movement therapists, especially given that approaches are often defined by referenceable publications providing descriptions of how to conduct this practice.

A significant number of different approaches to the treatment of disabilities acquired through stroke have been defined - Davidson and Waters [48] list 7, and hint that there are more - but research work indicates that the Bobath approach [49] is by far the most influential in the UK. A variety of studies suggest that between 80% and 90% of physiotherapists feel that they work within it, or were strongly influenced by it [48]. Furthermore, the experience of the author is that the vast majority of movement therapists who have been consulted during the construction of this thesis have at least been aware of Bobath, and have adopted aspects of this approach into their work. An understanding of Bobath can then provide some insights into the professional practice of movement therapists. The following section then provides a summary, drawing on "Adult Hemiplegia: Evaluation and Treatment" [49], arguably the defining text for this approach.

2.4.1 Understanding the professional practice of a Bobath therapist

The Bobath approach to stroke rehabilitation is based on a number of hypotheses, the structure of which was developed through the professional practice of Berta Bobath, who has then authored the reflective works that present this approach. In common with many approaches to treatment, a core hypothesis is that therapists should focus on directing patients to regain abilities that they have lost, rather than on assisting them in learning other methods of performing functions. Bobath then places a particularly strong emphasis on preparing patients to perform high-quality movement, on the assumption that normal function will follow, and that learning low-quality movements will ultimately hinder recovery. As such, regaining quality of movement (for example, not rotating the core of the body when extending an arm to pick up an object), is seen as far more important than regaining speed or strength of movement, which are important aspects of function. In fact, a belief expressed within the Bobath approach is that an emphasis, too early in a treatment programme, of regaining speed or strength, can be damaging, as, in the long term, this may lead patients to learn patterns of movement which are sub-optimal.

A strong recommendation of the Bobath approach is that treatment begins with an assessment of the general physical abilities of the client. The table presented in Figure 2.1 summarises elements of ability that might be assessed by a Bobath therapist. Assessments might take place in early therapy sessions, and can be carried out by ancillary staff. They have a general role of guiding a therapist to the most important elements of disability to consider, supporting them in the process of designing a programme of treatment.

This kind of assessment can then provide a general understanding of the types of disability that have been acquired through stroke. A more detailed understanding can then be developed through more specific assessments of the quality of damaged movements, which can then guide the selection of specific exercises. Here, Bobath provides practical systematic assessment material that can be used, and which has been developed through her own professional practice, with an example included in Figure 2.2, which also includes two images of an assessment being conducted. In her book [49], Bobath has provided systematic material that can be used assess the quality

Joint range	Limitations in the available range of movement around specific joints are commonly found post-stroke.
Muscle power	Stroke can have an impact on the power that can be generated by particular groups of muscles.
Postural tone	"Tone" in this context means the level of tension present in muscles that should be at rest. Postural tone then refers to levels of tension found in the posture of the whole body at rest. For normally-abled humans, some tension is needed when standing, to oppose gravity. Stroke often leads to unusual patterns of postural tone that can be physically stressful, such as the body leaning to one side.
Sensory deficits	An inability to sense the position of the body or to sense the external world are often present in stroke, and is important to consider in treatment.
Reactions to external movement of joints	Movement of a joint by a therapist can lead to unusual and uncontrollable reactions.

Figure 2.1: Elements of physical ability that are assessed early in the process of treatment

of movement in the *arm, shouldergirdle, pelvis, leg, foot*, and to assess a specific set of *balancing* and *reflex* activities. Therapists might deploy this kind of material repeatedly during the process of recovery, to aid the process of designing suitable interventions.

Having identified deficits in the quality of particular movements, a programme can be designed to address these; the design of this programme will be updated as abilities progress. Early in the process of treatment, this may involve a therapist manipulating the client's body directly, and hence this work can only take place during the time allocated to a therapy session. As a client regains the ability to voluntarily initiate and conclude movements, then sessions make become more focussed on assessing current deficits in movement, devising and teaching exercises intended to address these (which can then be repeated outside of the session), and checking the quality with which prescribed exercises can be performed. Towards the end of a treatment programme, sessions may focus on educating clients about how to continue progress without the support of a therapist, to provide them with the ability to continue self-rehabilitation. Throughout the programme of treatment, there is a progression from exercises constructed around static postures (such as holding an arm parallel to the ground for a pre-determined amount of time) towards exercises constructed around movements, with required movements increasing in range and level of integration over time. Bobath also discusses the need for therapists to train ancillary staff in the principles of therapy, so that they can also encourage high quality movements through their daily interactions with clients.

In general, and in common with other approaches to therapy, how exactly how to carry out some of the processes above, and how to devise programmes of exercises that are relevant and appropriate for particular clients, is more akin to a craft than a science, developed through practical experience with patients and a detailed knowledge of physiology and anatomy. Bobath provides a broad range of specific techniques to draw from in her book, including "Shunting" - in which the manual manipulation of a defective element of posture by a therapist (such as a client continuously leaning to the right) suddenly allows for much more natural movement of a variety of muscle groups involved in maintaining that posture. An eventual aim would then be for the client to correct the defective postural element themselves, without the support of a therapist.

Tests for Balance Reactions—*contd.*

Patient sitting on the plinth, his feet unsupported.

	Yes?	No?
a. He is pushed towards the affected side. Does he stay upright?		
Does he laterally flex his head towards the sound side?		
Does he abduct his sound leg?		
Does he use the affected forearm for support?		
Does he use the affected hand for support? (Fig. 4.4) . . .		
b. He is pushed forward. Does he bend affected hip and knee?		
Does he extend his spine?		
Does he lift his head? (Fig. 4.5)		
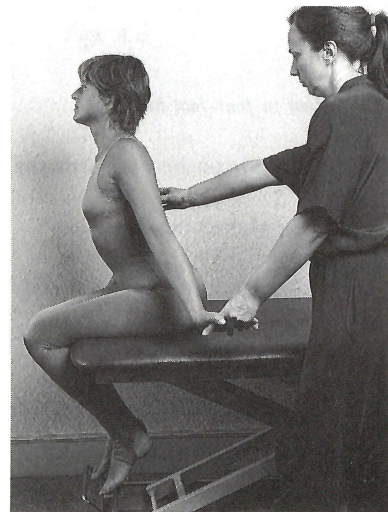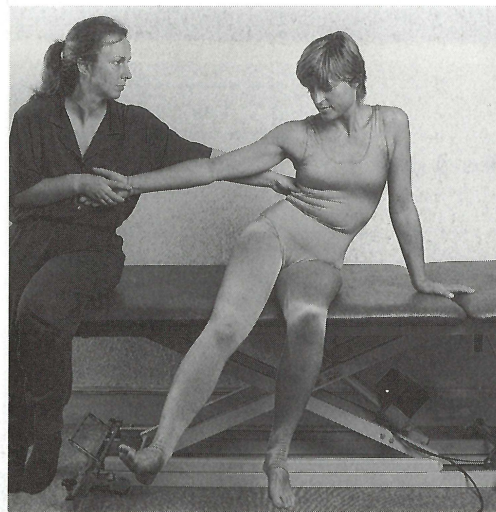
Figure 2.2: Systematic material used to assess balance and photographs of assessments in progress. Both sourced from [49].

Much of this work then involves a very detailed understanding of the dynamics of particular healthy integrated movements, and experience in addressing difficulties in component movements, as part of the process of recreating a healthy integrated version. As an example, Bobath breaks down the process of walking into two phases ("stance" and "swing"), and a number of components, such as the heel-toe strike pattern found in the foot. She then describes a broad variety of difficulties that can be experienced (such as the foot rotating left or right rather than remaining central) and a variety of tactics for addressing these issues (such as relaxing the knee to take the pressure off the foot). Helping a client to reassemble the complex movement of walking is then the responsibility of the therapist, who may identify a series of exercises intended to lead to this eventual goal, some of which can be down outside of a therapy session.

As well as knowledge and experience gained through initial training courses, there are then a broad variety of opportunities and structures for therapists to develop their practice, much of which are applicable across a range of approaches, including *clinical supervision*[50], in which practical experience is shared and analysed with a more experienced colleague, often in a group, and also through the publication and discussion of case-studies of practice at conferences. These opportunities are generally not limited to particular therapeutic approaches, and instead promote discussion and debate across multiple approaches. They are often organised by professional bodies who are interested in movement therapies, such as the Chartered Society of Physiotherapy [44] or the British Association of Occupational Therapists [51].

2.4.2 Contrasting Bobath to other approaches to therapy

As noted above, *approaches* to movement therapy should be thought of as a detailed framework to support professional practice, with each therapist drawing on their own experience to make decisions about how to design each session of engagement and any exercises that are prescribed to clients. The Bobath approach also has much in common with other approaches to movement therapy - for example, an ongoing assessment of abilities seems to be a key feature of most approaches. However, whereas Bobath places a significant emphasis on high-quality movement from an early stage, other

Bobath	Aims to prevent abnormal movements and adverse plastic adaptation and facilitate normal movement and subsequent plastic change
Brunnström	Makes use of abnormal synergies and incorporates them into functional activities
Conductive education	Patients encouraged to verbalise the activities as they perform them. Focused on function
Johnstone	Follows developmental patterns focusing on proximal stability. Use of orally inflated pressure splints a significant characteristic
Motor re-learning programme	Training of motor control based on an understanding of kinematics and kinetics of normal movement, motor control processes and motor learning
Proprioceptive neuromuscular facilitation	To maximise sensory stimulation on the pool of anterior horn cells in order to stimulate purposeful muscular contraction
Rood	To achieve purposeful muscular contractions by stimulating the skin through facilitatory strokes

Figure 2.3: Key features of seven approaches to movement therapies. Sourced from [48].

approaches have different emphases. The table presented in Figure 2.3, which is drawn from [48], provides a summary of the key foci of seven commonly-encountered approaches to rehabilitation. The purpose of providing this table is to illustrate the wide range of approaches that are in common practice.

2.4.3 Orientations to the concept of motivation within the movement therapies

Even with therapeutic intervention, the process of recovering from a stroke can be lengthy, and can be frustrating for all involved [17]. Bobath [49], for example, presents a case-study in which a patient required 11 months of therapy before regaining the spontaneous use of an immobile arm and fingers, of which 7 months of which was carried out at home, following a treatment plan devised by a therapist. For many patients, returning home

from hospital post-stroke can be a challenge, potentially due to difficulties in communicating wishes or feelings, to a continuing poor state of mental health, or simply caused by a need for help with even everyday tasks [17]. Motivating patients to engage in therapy is therefore an important, but difficult aspect of the job of a therapist [52], and is an area which has become a topic of research within the movement therapy community. Such research has included a variety of studies which suggest that motivated patients have better therapeutic outcomes [53, 54], and a variety of attempts to define the term *motivation*, both from the points of view of the therapist and the patient (for example, see [55, 56]). Most relevant to this thesis, however, is research which attempts to identify the various ways in which therapists motivate their clients as part of their professional practice, and this section now introduces a short review in this area.

In relation to motivation, one of the most important concepts within movement therapy practice seems to be that of goal-setting. This is often presented as a cyclical process, in which a patient agrees to work towards a specified goal over a certain time period, at the end of which their progress is assessed, and new goals are set [57]. Young, Manmathan and Ward [58] argue that goal-setting is effective as a motivational tool because it encourages patients to focus on short-term, achievable goals, rather than dwelling on unrealistic and unachievable targets, though this does require the setting of goals which are achievable, but still sufficiently challenging. Maclean et al [56] highlight the importance of choosing goals which are relevant to the life of patient, which places an emphasis on the therapist to learn about the life of the patient, both pre- and post-stroke, and to design goals accordingly. In general, including the patient in the process of identifying their own goals seems to be thought of as beneficial, and Young, Manmathan and Ward [58] argue against practices that exclude patients from this, such as a therapist who arrive at a goal-setting meeting with a pre-determined list of goals, rather than agreeing them with their patient, or who fail to adequately explain the goals that they have devised, as being de-motivational.

Beyond goal-setting, there seems to be a recognition that the relationship between a therapist and a patient will change over time, with different approaches to motivation being needed in different phases. Pomeroy [59] identifies a common pattern, in which a therapist has to provide a substantial level of control and motivation early in the rehabilitation process, but then has to

step back, and to focus on helping a patient in becoming independent, in anticipation of the therapeutic process ending. In addition, Maclean et al [56] argues that the therapy process can be supported by practices that encourage therapists to transmit information about rehabilitation to patients, with examples including therapists observations about progress that has been made over time, their rationale for choosing particular exercises, and the reasons why those exercises had to be performed in a certain way.

Finally, an important role of therapy seems to be in identifying psychological barriers to engagement with rehabilitation activity, and in finding approaches that reduce those barriers, thereby increasing the chance of achieving success [60]. Such efforts are often related to the concept of self-efficacy, which has been defined as the belief that one can organise and execute courses of action required to produce a given outcome [61]. Self-efficacy for exercises has proven to be the strongest predictor of exercise success in a review of studies [62] and hence low self-efficacy for particular exercises is an important factor for physiotherapists to consider. Unfortunately, there are suggestions that serious disease can reduce self-efficacy for exercise [63], thereby raising difficulties for patients wishing to recover from stroke.

2.5 Existing uses of technologies to support rehabilitation

Undoubtedly, one of the primary roles of the therapist is to motivate their patients to engage in rehabilitative exercise, potentially through use of some of the techniques described above, but even within the hospital system, therapist contact hours are likely to be small in number, and a patient is likely to spend the vast majority of their time without a professional to provide motivation. In addition, contact hours decrease even further on discharge, unless the patient has the financial means to employ a private therapist. This, of course, is one reason why the procedure of goal-setting and evaluation, introduced above, is so important. When done well, it can provide a patient with a framework around which to organise their own rehabilitation, in the periods between therapeutic interventions, thereby acting as a positive influence on their ability to rehabilitate themselves. However, there are certain problems which are commonly experienced by stroke patients once outside
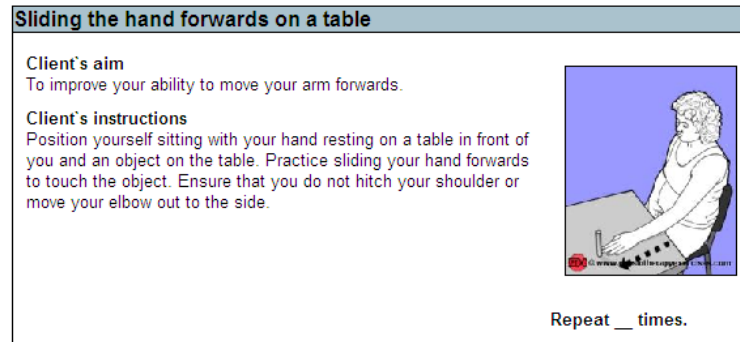
Figure 2.4: A simple example of a physiotherapy exercise sheet. Image sourced from [67].

of contact time with a therapist for which tools and technologies have been developed. This section now provides a brief review of three examples which currently used in practice. Chapter 3 then provides a more detailed review of many more speculative computational tools and technologies which are currently being developed, and which may influence physiotherapy practice over the next few decades.

2.5.1 Exercise sheets

Exercise sheets [64] are a very simple tool, which form a very common part of practice, especially within physiotherapy, and which are designed to address issues such as the need to perform exercises with a sufficient quality of movement [65], and memory deficits, which are common post-stroke [66]. Exercise sheets are commonly printed or hand-drawn, and often contain text and a set of illustrative images. The purpose of this content is to describe an exercise or a set of exercises to perform, and to illustrate how to perform these effectively. A physiotherapist may choose to hand-craft an exercise sheet for a particular patient, and resources are available to allow the automatic generation of a set of an exercise sheet from a database of exercises, given a set of parameters [67]. Figure 2.4 shows an example of an exercise which was generated by such a site, and which might be appropriate for an individual at the beginning of the rehabilitation process. In addition to printed material such as this, studies have also examined the provision of audio and video equivalents to exercise sheets [65].

2.5.2 The Saebo family of devices

In addition to memory deficits, patients may have significant difficulties in performing particular movements without the aid of a therapist, especially if they are still in the earlier stages of a rehabilitation program. Such a situation may well be caused by deficits in the control of very specific muscle groups, meaning that a patient may be able to start an exercise (such as closing their hand to grasp an object), but not complete it (by releasing the hand and dropping the exercise). In this example, a patient may then under use that hand, and even the whole limb to which it is attached [68], thereby slowing, and potentially reversing, recovery. Conversely, improving the ability of a patient to complete such an exercise, and therefore to engage in normal tasks may increase their motivation to use the damaged limb, and speed recovery [68]. A mechanical approach to addressing this situation is provided by the SaeboFlex, part of the Saebo family of devices [69], an image of which is shown in Figure 2.5. This consists of a set of springs, which are placed under tension when the hand is closed. When the hand is released, then this tension is sufficient to open the hand, possibly under the assistance of any muscle strength available to the user. In addition, the strength of support provided can be adjusted, by the patient or therapist, so as to allow the patient to progressively improve [69].

2.5.3 Functional Electrical Stimulation

Unfortunately, although the SaeboFlex is effective at supporting movement, it is obviously bulky, potentially uncomfortable for use over longer periods, and is visually obtrusive. As such, many patients report choosing not to use it for long periods of time. An alternative technology is Functional Electrical Stimulation (FES), which uses the application of short bursts of electrical activity, either directly to a specific muscle, or to those motor neurons which are connected to it [70]. This is a technique which requires the implantation of subcutaneous electrodes [71], and which can allow for the voluntary control of otherwise uncontrollable muscle activity [70]. At the time of writing, discussions with movement therapists indicate that FES has just begun to make the transition from research to practice.
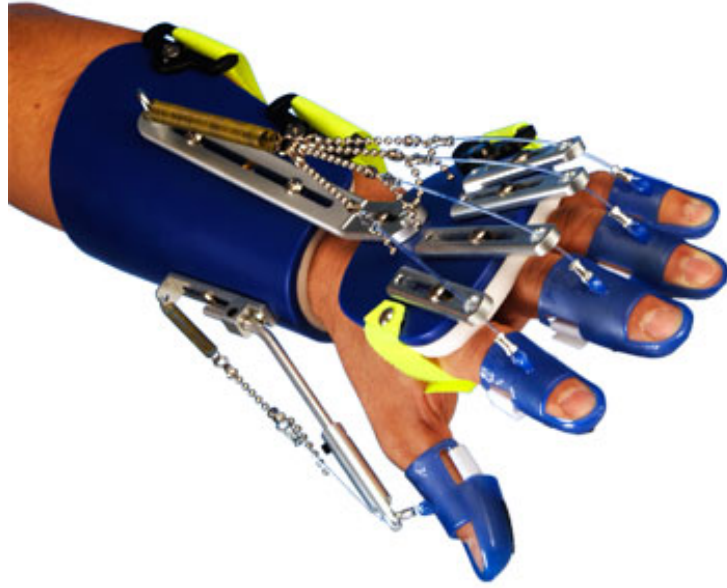
Figure 2.5: The SaeboFlex, a member of the Saebo family of therapeutic prosthetics. Image sourced from [69].

2.6 Chapter commentary

Having defined stroke as a medical condition, and discussed its treatment, primarily in the context of the UK medical system, this chapter now concludes with a discussion of the implications of this knowledge for the design of rehabilitation systems. It presents five key topics to consider, some of which are considered in the remainder of this thesis.

Topic 1: There are multiple phases in the recovery from stroke

A key observation, presented earlier in this review, is that there are often quite distinct phases in the process of recovering from a stroke. Survivors often experience a *critical phase*, in which they are profoundly ill. This critical phase ends as the stroke is resolved, and as the condition of the patient stabilises. During the course of this phase, survivors may have acquired significant levels of sensory, motor and cognitive disability. A second phase can then involve a partial and spontaneous recovery from disability, related to mechanisms such as the reduction in oedema, or recovery of function in

surviving neurons. Recovery can continue through a third phase, in which healthy regions of the brain take on functions previously present in damaged regions, through a process called neuroplastic change. Systems intended to promote rehabilitation are probably irrelevant to the critical phase of a stroke, and may be less relevant during the second phase. They are likely to be more relevant during the third phase, which can continue for many years, and it is this phase which is the focus of this thesis.

Topic 2: There are multiple sources of variability in disability between stroke survivors

There is likely to be an extreme variation in the disabilities acquired through stroke, for survivors who have entered the third phase of recovery. Disabilities may have sensory, motor and cognitive components, and which may be accompanied by secondary disabilities acquired through the process of *neglect*. Although this thesis focuses on systems intended to support physical rehabilitation, sensory and cognitive components cannot be ignored, and may have an impact on the ability of particular individuals to engage with particular designs of rehabilitation system. These components may then be an important consideration in relation to the process of tailoring technologies to individuals.

Topic 3: Understanding the social context is important

Beyond the individual, the social context with which they engage can clearly have an important influence on their rehabilitation, and therefore needs to be understood if effective designs are to be produced. Survivors of stroke might engage with individuals with a broad variety of skills and professions, including doctors, surgeons, clinical psychologists, speech and language therapists, occupational therapists, movement therapists, social workers and care workers. These engagements might take place in a broad variety of locations, including hospitals, the home or a care-home to which the survivor has been discharged. Each of these categories has a very different nature, and systems might require very different designs based upon the category of location for which they are intended. In addition, individuals from any of these professions might need to interact with future rehabilitation systems. Hence, the

design of such systems may need to take into account the roles that these individuals take in recovery, and any of these individuals could be potential users of rehabilitation system, in collaboration with survivors of stroke.

Topic 4: Orientation towards the professional practice of movement therapy needs to be carefully considered

In relation to the movement therapies, evidence presented in this chapter suggests that there are at least seven approaches in current use by movement therapists, and that some of these approaches may contain concepts which are mutually contradictory. For example, whilst the *Bobath* approach aims to prevent abnormal movement, the *Brunnström* approach advocates the incorporation of abnormal synergies into functional activities. Whilst it seems rational to draw on existing practices within the movement therapies as an inspiration for system design, such contradictions must somehow be accounted for in the process of design. Within the Motivating Mobility project, which is the primary source of data for this thesis, the chosen approach was to draw on the experience of a professional therapist during the process of designing technologies, with the therapist acting as a consultative role, and drawing on their own experience of providing therapy to guide particular decisions. Part of this role involved the provision of advice on how to motivate particular individuals to recover.

Topic 5: Some technology is already used in rehabilitation

Many therapists already use particular technologies in their professional practice, with a prominent example being exercise sheets. Existing technology usage might provide inspiration for the design of future rehabilitation systems. New technologies may need to co-exist with existing uses of technologies, and may need to take into account the existing working practices and expertise that have evolved around existing technologies.

Chapter 3

Rehabilitation technologies and other related works

This chapter contributes a detailed review of prior academic research that can be related to challenge of developing interactive technologies to assist physical rehabilitation post-stroke, and concludes with a discussion of the contributions made by this thesis in light of the literature that has been identified.

There is then a very substantial body of prior research that explores technological approaches to this kind of rehabilitation, and the first section of this review focuses on providing a summary of key themes that have emerged from this. So as to consider as much relevant literature as possible, the remit of this first section is slightly broader than that of the thesis, in that it considers research relating to recovery from brain injury associated with a variety of causes, including cerebral palsy and traumatic accidents. This section is structured under the following headings, each of which relates to a distinctive and important strand of research;

- Virtual reality installations

- Large-scale robotic and force-feedback systems

- Use of commodity technologies to support rehabilitation

Technologically-focused research within these strands has remained relatively disjoint, but where there are significant cross-overs, these are noted in the text.

Having considered research which is specifically focussed on rehabilitation from brain injury, a broader exploration of relevant research from the HCI and CSCW literatures is then provided, with a specific focus on research into exertion interfaces and exergames, persuasive technologies and domestic life. The chapter then concludes with a detailed discussion of the position of this thesis relative to the reviewed body of research, and an explication of the contributions that it makes relative to this.

3.1 Technological approaches to rehabilitation

3.1.1 Virtual reality installations

Research into the use of Virtual Reality (VR) and Virtual Environments (VEs) in rehabilitation from traumatic brain injury is a theme which has been studied since at least 1997. Since then, a number of approaches for the use of VR in rehabilitation have been investigated, and these are summarised in this section. Due to the expense and bulk of VR systems, most of this research has been directed towards future deployments in clinical environments such as hospitals. However, the increasing power and decreasing cost of home computers has allowed for some research to take place which is directed towards deployments in the home [21]. Many of the examples below seem to make use of the ability of VR to generate content that is hyper-real, with augmentations that are not available in the real-world [72].

An approach which emerged early within this field of research was the use of VR in the assessment of ongoing disabilities caused by brain injuries, and in the planning, and sometimes in the execution, of a treatment programme designed to address these disabilities. An example is provided by the use of VR simulators to assess driving ability, and to provide training to improve driving skills, in preparation for a return to the road. Early examples of this kind of work have been provided by Schultheis and Mourant [73], who describe work on a virtual reality driving assessment system, and provide examples of its use in training drivers. Rizzo and Kim [74] identify the use of such systems as being highly motivational for survivors of traumatic injury, who are often strongly motivated to regain the ability to use a car. A significant advantage of the use of VR systems in this context is that they can provide a safe environment to allow individuals to improve their confidence in

an activity which can be dangerous [73], and which can allow individuals to be exposed to situation which are increasingly difficult, such as dark roads, or roads which are congested with traffic [73]. In terms of assessing the suitability of drivers to return to the road, an analysis of performance within a driving-focused VE can lead directly to the calculation of objective measures which can be compared against standards [75, 76]. Results of these measures are likely to be significantly more ecologically-valid than results obtained using more traditional driver-assessment protocols, which tend to involve evaluations performed in a real car, but in relatively safe conditions, and the deployment of various neuropsychological tests [77].

Beyond driving, other examples of systems used to provide training and assessment of skills include work by Todorov, Shadmehr and Bizzi [24], who performed a number of studies with a VR system that provided training in the use of a table tennis bat to hit a ball, and Holden et al [78], who developed a system which provided training in the posting of a letter into a letter-box for severely-disabled patients. In both of these cases, participant movements in the real world were tracked, using a set of electro-magnetic sensors, and were recreated in a VE, alongside a pre-recorded visualisation of a teacher performing these movements. Participants were encouraged to learn to recreate the movement of the expert, through a training process that was spread across several sessions, under the guidance of a therapist, and were provided with facilities to change the speed at which the teacher moved. Both of these studies provided evidence that skills learned in the VE were transferable to equivalent situations in the real world, motivating the use of this kind of training in rehabilitation. Outside of movement therapies, another example of a VR system which has been constructed around a real-world task is presented in work by Christiansen et al [79], who developed a simple VR simulation of a kitchen, intended to assist individuals in the rehabilitation of the kinds of cognitive skills that are required to make use of facilities present in this setting.

In contrast to the approach of training real-world skills, a second category of systems which have been identified from the literature are those which use VEs to motivate the performance of significant quantities of rehabilitational movements, but which are not specifically targeted at training individuals in specific tasks that they are likely to encounter in the real world. A good example here is an ankle rehabilitation system which involves the use of

a VR flight simulator [80]. This involves the use of the "Rutgers Ankle System", a device which can sense ankle movements in 6 degree of freedom, and which can provide therapist-controlled resistance in any of these degrees of freedom. Deutsch et al [80] describe a case study in which a stroke survivor with reduced ankle strength and mobility used this device to fly a VR plane, and therefore performed a significant amount of exercise with his disabled ankle. This participant was unlikely to ever fly a plane in his life; rather, the appealing nature of the plane simulation provided a motivation to use his ankle in a manner which was designed to be rehabilitational.

A similar example of the targeting of an input device to a disability in a specific part of the body, and the use of appealing content to motivate the use of this part of the body, is provided by Jack et al [21] and Merians et al [81]. In this research, two different augmented gloves were used, through an intervention that aimed to increase hand and finger strength and mobility. One glove was used to sense finger movement, and was linked to a series of activities that gave rewards for the performance of exercise that had been designed to provide rehabilitational benefit for such movement. A second glove was capable of providing force feedback to hand movements, and was linked to activities that involved training for strength.

In another example, Grealy, Johnson and Rushton [23] describe a system intended to stimulate the use of an exercise bicycle to improve strength and co-ordination for participants who were experiencing deficits in lower limb abilities post-stroke. Their system featured a recumbent exercise bike, linked to a VR which displayed a number of supposedly pleasing environments through which the user could ride, namely a tropical island, some rolling countryside, and snowy mountains. They provide evidence that such a system is more motivational than the provision of an exercise bike alone, especially in the context of the hospital environment, which can be lacking in interesting stimuli.

Also in the hospital environment, Broeren et al [82] provide an example of a VR exercise station, consisting of a haptic feedback device, and a set of VR games that involved the use of such a device for interaction. They provide evidence that the playing of these games is motivational, and argue that the analysis of user performance in games, by a therapist, can provide for a diagnosis of certain cognitive deficits that are common in stroke survivors, such as visuo-spatial neglect.

Moving beyond movement therapies that relate to specific disabilities, a final example demonstrates the utility of virtual reality in motivating whole-body rehabilitational exercise, an activity that tends to be useful for stroke survivors who are at an advanced stage in rehabilitation. A good example of this approach is provided in work by Kizony, Katz and Weiss [83], who made use of Gesture Xtreme, a commercial VR system which makes use of video capture and projection to allow video feeds of participants to appear in virtual reality. In their research, these authors created a number of motivational VR scenarios with a rehabilitational benefit, and studied the use of these scenarios by survivors of stroke. Scenarios included "birds and balls", "soccer" and "snowboard". In "birds and balls", users "see themselves standing in a pastoral setting", with balls of different colours floating towards them [83]. Hitting the balls too hard causes them to explode, whilst tapping them lightly causes them to morph into other forms. In "soccer", footballs fly towards the use, who has to knock them away with a part of their body.

3.1.2 Large-scale robotic and force-feedback systems

Research into the use of robotic and force-feedback systems in stroke rehabilitation has taken place since at least 1991, although some of this research has roots in earlier medical work on the use of mechanical systems to promote recovery of movement. Because of the expense and bulk of robotic systems, much of this research has focused on the lab or medical environment, although the recent advent of commodity force feedback devices has allowed for research to take place which is focused on the home. Robotics tends to be presented as a distinct strand of rehabilitation to research on virtual rehabilitation systems in the literature, but there are some links between the two areas. There are also links between robotics, gaming and telerehabilitation, areas which will be reviewed later in this section.

Some of the earliest work on stroke rehabilitation took place as a collaboration between occupational therapist and technologists, and involved a robotic system which was intended to guide a patient through a series of reaching exercises [19]. The technology chosen for this investigation consisted of a robotic arm, onto the end of which had been mounted a switch. Under the control of a set of pre-defined programs, from which a therapist could make a selection, the arm moved through a series of positions, and paused at each. At each pause, patients were encouraged to operate the switch, which involved

them performing a reach in a variety of directions. Patient performance on the system was assessed through a metric based upon the number of successful switch activations; this metric was provided to therapists to assess the progress of their patients. This research was designed as part of an effort to reduce the cost of therapy, and to increase its quality; authors imagined a system which could precisely guide patients through therapeutically useful exercises, and which reduced the staff cost of therapeutic interventions [19]. An evaluation exercise was carried out with therapists, to determine their acceptance of the technology, which demonstrated general acceptance, with some worries as to the safety of such a system.

In contrast to this system, which required patients to actively choose to perform movements, a second early system was constructed around the idea that rehabilitative benefit could be obtained by passively moving parts of the body through particularly movements [84]. This approach is rooted in earlier medical work on continuous passive motion systems [85] and the central hypothesis here in relation to stroke is that there are rehabilitational benefits to the movement of body parts over which a stroke survivor has no voluntary control. The system featured in this early research consisted of a prosthetic device, connected to the lower and upper arm; this featured a piston, which could be opened and closed, through a range of movement and at a speed which were under control of the therapist. Opening the piston caused the elbow joint to extend, and closing it caused the elbow joint to flex. The system could also be used in a mode in which the piston was fixed, and used as a force-sensing device. This was seen as a way of assessing progress in patients using the system; patients could be asked to apply as much force as possible to the prosthetic, and the development of increase force application potential over time could be recorded and monitored.

Although there seems to be no evidence that this particular device has ever been used in a therapeutic setting, it does seem to be the first in a series of research projects which have investigated the use of robotics to passively move single disabled limbs. Rather than using a device strapped to the body, many of these systems have used externally-mounted robotic arms, to which limbs have been attached to allow for the guidance and sensing of movement. Such setups are more bulky, but allow for a much greater range of passive and active movements to be generated, thereby potentially increasing their use in rehabilitation. In addition, many of these systems have been tied to

content which has been designed to motivate movement; many also measure forces that have been applied to the arm by the patient, and use this to provide feedback to therapists and users as to their progress.

One example of such a system, MIT-MANUS, is provided by Krebs et al [20]. This consists of a robotic arm which allows for the movement of the hand over a planar surface, which was linked to a computer system that prompted participants to use the arm to draw a variety of shapes. As each shape was presented, participants were first given the opportunity to actively control the arm in drawing it, against a resistance which was specified by the therapist. If they failed to perform this in a certain time, the system then shifted into passive movement mode, and guided the user through the movement required to construct the shape. Safety considerations in this system were covered through the use of a magnetic lock and a wrist-mounted prosthetic to attach the participant's arm to the robot. This could therefore be released rapidly in the event of system difficulties, and would disconnect automatically in the event of excessive forces being applied to the arm of the participant.

A similar approach is used in work by Colombo et al [86], who investigated the use of two different robots for the rehabilitation of a disabled arm, one of which provided for a one dimensional movement of the wrist, and the other of which provided for a planar movement of the hand. Engagement in this system was motivated by a task requiring a patient to move a green dot on a screen from one position to the next, through a series of segments, and the system only provided assistance if a user failed to complete a segment in three seconds. A partial assistance mode was also provided in which the robotic arm only provided a proportion of the force that was required to move the arm; in this, the force applied would be in the direction of the instantaneous force which the user was applying to the arm, and this mode was designed to encourage users who had made some recovery.

A slightly different approach to the use of a single robotic arm is demonstrated by research carried out at Stanford University over a lengthy period of time. This programme involved an investigation into the use of robotic systems which encourage participants to use both of their upper limbs in parallel, and is linked to neuroscience research suggesting the rehabilitation benefits of this approach [87, 32]. An early investigation into this topic involved the use of a virtual reality system, featuring a custom-designed steering wheel, linked to a VR system, with attachments that allowed it to be

grasped by both hands [88]. Later work involved investigations into the use of pairs of robotic arms, with an interesting innovation being the linking of these arms, through a variety of mechanisms, allowing the participant to use their non-disabled arm to guide their disabled arm through a series of movements [89, 90]. Robotic arms employed progressed from a number of early systems allowing only planar movement of the hand, to a much more complex system allowing for the full six degrees of freedom that are possible in the movement of the human arm. All systems provided a mode in which the disabled arm was moved passively, under the control of the non-disabled arm. However, the planar system included a mode in which the user was asked to provide a certain amount of force through their disabled limb, and was provided with feedback about the actual force applied. The more complex system also provided a mode in which only the disabled arm was used, and in which simulated, spring-like forces were used to constrain active movements that the participant made in three dimensional space.

A similar approach to providing support for three-dimensional movement is described by Loureiro et al [91], in a system allowing for three dimensions of reaching movement; this system provided active, spring-like support which was used to guide a disabled arm along a pre-specified trajectory, and was linked to a VR system which demonstrated the movement of the arm. A quite different approach to training for three dimensional movement is provided by Patton and Mussa-Ivalidi [92], through a system that sensed deficits in movement, and applied forces designed to provoke physical development capable of correcting them. As an example, consider a participant lacking the strength or co-ordination to keep their arm sufficiently to the right in a reach exercise; the system would sense this, and would repeatedly apply a force from the right to the left, in the aim of provoking the participant to learn how to apply a greater force to the right, and hopefully therefore to improve their capabilities of applying these forces outside of system use.

3.1.3 Use of commodity technologies to support rehabilitation

Previous sections in this chapter have focused on two approaches, virtual reality and robotics, which tend to require bulky, expensive equipment. As such, where evaluations of technology have taken place, they have tended to

focus on the hospital or lab environment, where space is likely to be available, where the use of expensive equipment for research purposes can be justified, and where, if deployed over a lengthy period of time, the cost per patient use of these systems would be low. However, if rehabilitation is to take place outside of the hospital environment, then an approach to technology design which is more focused on commodity solutions that have a low cost per unit is likely to be necessary, to allow individuals to purchase their own machines, or to allow other providers (such as charities or national health providers) to take on this role. Investigations into solutions which are commodity, or which could conceivably be commodified in the near future, are a theme which has emerged more recently in the research literature, and which seems to be related to the increasing availability of cost-effective, powerful and network-enabled computing systems such as games consoles. The use of such devices has been approached in a number of different ways by researchers and practitioners, and this section now summarises some of the approaches that have been taken.

Firstly, the simplest approach to using such systems seems to have been to use them directly, without modification, but in a context that encourages use which has therapeutic value. An example of such an approach is presented in work by Deutsch et al [28], who describe the use of a Nintendo Wii in the rehabilitation of a child with cerebral palsy. During an intervention which took place across 11 sessions that were supervised by a therapist, the child was allowed to choose which game they wished to play, but the therapist made essential clinical decisions [28] such as whether each game should be played standing or seated, and when each session should stop due to fatigue (and therefore reduced quality of movement). The authors of this paper report some success, in that their participant seemed to engage with their game for substantial periods of time. They also observe that their participant reported learning new physical skills through participation in a multi-player session with a normally-abled child of a similar age. Use of the Wii in a variety of therapeutic settings, including stroke, seems to have grown dramatically since its release, and a number of therapists have set up a web-site to share practice [93].

A second console device that has been used in this manner is the PlayStation EyeToy, which is a single-camera, vision-based tracking system [22], which captures video of a user, and which integrates it into a virtual environment.

In a paper which compares the capabilities of the EyeToy to that of the Gesture Extreme system (previously introduced in section 3.1.1 above), Rand, Kizony and Weiss [22] present data which suggests that this system was usable in the home by a cohort of healthy elderly people, but that many of the twenty-three games supplied with it were too hard for a cohort of stroke survivors. To an extent, this latter finding is replicated by a single case study, featuring a deployment of the EyeToy into the home of a professional physiotherapist who had suffered a stroke, and who used it across twenty rehabilitation sessions [94]. However, this individual presented a series of positive reflections on her use of this device, suggesting that it allowed her to exercise for longer, without noticing, that it provided a mechanism through which she could set targets for herself, and that it allowed her to engage with a young grandchild, who enjoyed playing it with her.

A second approach to the use of commodity gaming systems is to take advantage of facilities that allow them to be reprogrammed thereby converting them into systems that have greater rehabilitational potential for use in the home. In one example of this approach, researchers repurposed a PlayStation 3 by installing a new operating system (OS), custom software, and a set of device drivers that allowed for the use of a glove-based sensing device to be used as an input device [95]. In a second example, an X-Box was repurposed in a similar way, through a procedure that involved a new OS, a replacement BIOS chip, and modifications to in-built functionality for device IO [96]. Of course, such changes resulted in a device which is more expensive, per unit, than a pure commodity system, and which may therefore not be financially viable for use in a deployment involving a large number of units. However, such modifications can be seen as a stage in a prototyping process, carried out in the expectation that future devices will be supplied with more of the functionality that is required for their use as therapeutic systems.

In some ways, such an eventuality has been catered for, by a rapid decrease in the cost of personal computing for the home, and a rapid increase in the performance of Personal Computers (PCs). As such, some research work has focused on the use of PCs as a commodity rehabilitation platform, often through the use of commodity interaction devices along with custom software. In one example, an inexpensive force-feedback steering wheel was paired with a custom driving simulator, which sensed the forces that were being applied by users, and which altered the parameters of the simulation dynamically

to ensure that the user was exercising at the correct level [97]. In a second, an inexpensive force-feedback joystick was used to control a series of on-line challenges, and, in a similar manner to many of the robotic systems reviewed above, the force-feedback features of the joystick were used to guide the hand of the participant if they failed to complete any of these exercises [98]. In both examples, data captured from users could be made available to their therapists, allowing their use to be monitored, and for interventions to be made where necessary. In the latter example, such interventions consisted of a therapist making a selection of content for a patient, and potentially placing limits on the length of particular sessions.

3.2 Relevant research from the HCI and CSCW literatures

The previous section has provided a review of research literature that can be specifically related to rehabilitation technology. This section now reviews three key themes from the HCI and CSCW, namely:

- Exertion interfaces and exergames

- Persuasive technology research

- The unique nature of domestic life and home in relation to technology design

All are relevant to work in this thesis, and contributions made by this thesis are relevant to all of them. Links between the work presented in this thesis and the existing literature around these three topics are therefore explored in this section.

3.2.1 Exertion interfaces and exergames

In many developed nations, and in some developing nations, chronic levels of obesity are becoming a major public health problem [99], often associated with decreasing levels of physical exertion and increasing levels of calorie intake [99]. A variety of authors (e.g [100]) have then linked a lack of physical exertion with increases in time spent playing computer games. This then

raises an intriguing question for research - can computer games as a medium be appropriated to increase levels of exertion, thereby providing benefits to both individuals, in terms of reductions in health problems, and society more generally, in terms of a reduction in the costs associated with these problems? In relation to this and similar questions, a variety of authors, including Muller and Agamanolis [101], have proposed a category of intervention which has become known as an "exertion interface", in which physical exertion is the primary interaction mechanism in relation to a specific technology. A substantial number of researchers are exploring the design of exertion interfaces, and much of this work has been published in core HCI venues. An open question for research is then how to design interfaces that successfully integrate exertion as an interaction mechanism.

Much of this effort has focussed on the development of games that are either directly controlled or strongly influenced by physical exertion, producing a category of intervention known as an "ExerGame", which has then been explored by a significant number of authors. Burke et al [102] have described good games as being highly engaging (or even addictive), and may then have the potential to incite very substantial levels of exercise. Yim and Graham [103] have provided a substantial review of ExerGames, and have highlighted a number of key design considerations including the integration of music into the exertion experience, the provision of exertion goals that are attainable in both the short and long term and the provision of support for social ExerGaming. A proportion of the rehabilitation literature presented above has been constructed around the use of gaming mechanisms to motivate interaction, and there is therefore a potentially interesting crossover between research into ExerGaming and research into the use of gaming to motivate rehabilitational exercise.

In the context of this thesis, it is then interesting to consider the question of what differentiates an exertion game from a rehabilitation game, especially in the context of rehabilitation from physical disability acquired through a brain injury. For those individuals who have only acquired very limited disabilities, or who have made very substantial progress in their recovery, there may in fact be very little to distinguish these two categories; such users require a high level of very integrated exercise to make further progress, and interaction with generic ExerGames has the potential to provide benefits. Work by authors such as Rand, Kizony and Weiss [22], as summarised

earlier in this section, provides an example of a set of games which are intended to provide rehabilitational benefits for brain injury survivors who require highly-integrated exercise, but which might also be categorised as ExerGames, thereby providing for an interesting cross-over between these two areas of research.

For those individuals who have acquired much more serious disabilities, or who are earlier in the process of recovery, there are then much more substantial differences between ExerGames as commonly discussed in the HCI literature and the kind of rehabilitation technologies that have been described above. Many ExerGames are designed to improve fitness, and therefore require the capacity to motivate quite high levels of physical exertion on a regular basis, often embedding technologies such as heart-rate monitoring [104, 105] to automatically adapt the operation of the game in a manner that ensures a sufficiently high level of general exertion. In contrast, players with serious physical disabilities may need to repeat a set of very specific and often very localised exercises as part of the process of rehabilitation - such as the ankle exercises inherent in the Rutgers ankle system [80]. Small localised exercises may involve relatively small amounts of exertion, and hence games that are intended to respond to exertion are likely to be inappropriate. An additional consideration is that a substantial proportion of professional practice in the movement therapies emphasises the importance of movement that is intensive but also high in quality (e.g see discussion of the Bobath [49] approach to rehabilitation provided in Chapter 2). This then highlights the potential danger to the longer term rehabilitation process of any technology that prioritises volume of movement over quality of movement, which is potentially a danger of many of the more general ExerGames discussed in the HCI literature. Games intended to promote physical rehabilitation from brain injury might then be seen as a subset of ExerGames as a whole, with a very specific definition of exertion as it relates to small and potentially very constrained movements.

Inherent in this differentiation is that a very different model of the person is required in the process of design in relation to rehabilitation technologies. Many general-purpose ExerGames adopt a model in which the person is inherently capable of most activities, even through improvements in fitness may take some time to develop. How to support general improvements in fitness is then a topic which is relatively well-understood within the sports-science

literature, thereby allowing the integration of relatively standard algorithms such as those that calculate effective heart-rate zones for a user to exercise within (e.g. see [105] and [106]).

In the case of players who have acquired a set of disabilities through a brain injury, however, this model is inappropriate, in that their difficulties are not caused by a lack of fitness, but instead by a brain injury. Any algorithms that adapt rehabilitational games to the needs of players with physical disabilities will then need to embed a very different, and potentially much more complex model of the person to be effective.

As part of a general exploration of the experience of a stroke, Chapter 5 then makes a contribution that highlights key features of this experience that are important to understand in the context of designing appropriate rehabilitation technologies. The relevance of this contribution to the broader HCI literature is then discussed in more detail towards the end of this chapter.

3.2.2 Persuasive technology research

As noted above, some ExerGames and exertion interfaces are constructed around a specific manifesto of addressing widespread health difficulties such as obesity through a mechanism of encouraging higher levels of exercise. Rehabilitation technologies also have a specific purpose, of supporting a process through which individuals can recover specific abilities that they have lost. In both cases, long-term changes in behaviour are required, and designs for technologies are specifically targeted at supporting or inciting these changes. Research relating to the question of how to design technologies that lead to behavioural change (or also changes in attitudes, beliefs or other cognitive processes) has become known as "persuasive technology" or "persuasive computing" research. Fogg [107], writing in 2002, provided an early exploration of this concept, and it has since become a significant focus for HCI researchers.

Much of this work has focussed on designing technologies that have the potential to influence the conduct of a very large number of individuals, or on phenomena which require change on the part of a large group of individual for their resolution. How to support changes in behaviour that are beneficial to health has been one significant topic of research; two examples (of many) are then provided in work by Graham et al [108], who designed the Quit-

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Coach, an interactive web-site intended to support cessation of smoking, and work by Consolvo et al [109], who have explored and presented a range of strategies for encouraging greater levels of physical activity in everday life. Another topic that has been considered in detail by researchers is that of how to use technology to support a more sustainable society, through methods such as motivating changes in behaviours to reduce energy consumption (see [110] for an early discussion of the key issues). In these contexts, persuasive computing has some crossovers with approaches that have emerged from the social and political sciences, such as those that attempt to "nudge" people in directions that are favoured by political actors [111]. This then raises some interesting dangers for research; Brynjarsdttir et al have argued that the use of persuasive technologies to encourage others to reduce energy consumption could then represent a potentially undemocratic centralisation of power in the hands of those people who design the persuasive technologies [112]. In relation to work around smoking cessation [108], Graham et al note "quitting smoking is a shared goal for both smokers and the stakeholders", which may then make this a less problematic area of inquiry, especially when engagement with services is voluntary.

Given some of the topics presented above, a core question within HCI research into persuasive technologies is that of how to identify methods that can support changes in behaviour. How to do this is still an open area for research. Some interventions take some inspiration from established psychological theories of behaviour change, with an example being QuitCoach, which makes use of a modified version of the Trans-Theoretical Model of behaviour change (TTM) [113] to understand and structure interaction with individuals who are attempting to give up smoking. Another interesting example is Beating the Blues [114], a commercial web-interface which attempts to support recovery from anxiety and depression by explicitly teaching concepts from Cognitive-Behavioural Therapy (CBT), a psychologically-informed approach to the the treatment of mental health issues, with the intention of engendering long-term beneficial changes in cognition and behaviour. Other interventions focus more on social aspects of human life, treating human relationships as a resource to be manipulated in light of specific goals. As an example, Moere et al [115] describe an intervention allowing for the display of daily consumption onto the façades of houses in a neighbourhood. Through this, they provide an exploration of its social implications, which include competitive efforts to reduce energy consumption on the part of householders.

Early work by Fogg [107], introduced above, has provided an influential categorisation of the roles that technology can take in persuasive interventions, which can be summarised as persuasive technology as *tool*, *media* and *social actor*. This is then a model that has clear implications for the design of technologies, and which can support the process of designing a particular intervention. A set of useful models have also been provided by Harri and Marja [116], expressed as eight postulates relevant to the design of persuasive technologies. These include a dichotomy between direct and indirect approaches to persuasion, an identification of the need to support incremental changes in behaviour over time and a "principle of unobtrusiveness" which states that persuasive technologies should

> "avoid disturbing users while they are performing their primary tasks"

Where relevant to a particular setting, designers can then work inside these categorisations, developing interventions that can be studied, and knowledge that can support a better understanding of the relevance of the categorisation itself, as well as how to integrate it into the process of design.

Research work presented in this thesis is focussed on the design of technologies to support recovery from disabilities acquired through stroke. As discussed in Chapter 2, professional practice in the movement therapies is then constructed around interventions that motivate substantial volumes of high-quality exercise; as such, the orientation of work presented later in this thesis is to the design of technological interventions that have the capacity to do the same. In relation to the persuasive technology literature, part of the focus of this work is on identifying the nature of individual *motivations* for recovery, and on using these motivations as a resource in the process of design. As such, work presented in this thesis makes a contribution that supports an understanding of how to develop persuasive technologies that are informed by an understanding of these motivations. In doing so, it does not seek to adopt any particular theory of motivation (although many are present in the psychological literature). Rather, it treats personal motivation as a rich and detailed phenomenon that is comprehensible for the individual involved, through a process of introspection, and which can therefore be understood through an inquiry which is structured around discussions with individuals. This then raises the question of how to proceed from an understanding of

motivation to an understanding of how to embed this understanding into individual designs, which is then a topic which is addressed in Chapter 6.

3.2.3 Domestic life and the home

As noted in Chapter 2, recovery from stroke can continue indefinitely. Since many survivors will be discharged from hospital into their own homes, and are then likely to spend a significant amount of time in this environment, this then makes the home an interesting target for the design of rehabilitation technology; raising the question of how to design technologies that are effective and appropriate for usage in this environment. Technology and the home is a topic that has been subject to a very significant volume of prior research, much of which has been produced by the Computer-Supported Co-operative Work (CSCW) community. As such, a brief review of relevant work within this literature is provided here.

An important strand of work within this literature has focussed upon the unique nature of the home in relation to the challenge of technology design. An early example of this kind of work is a paper by Hindus et al, published in 1999 [117], which carefully considers the difference between the home and the workplace in terms of drivers for technology in both. The specific focus of this paper was on communications technology; at the time of its publication, digital communications technologies were becoming increasingly available in the domestic environment, and this was a trend that was expected to continue. As an attempt to guide research into this phenomenon, this paper highlights a number of key features of life in the home which are relevant to technology design, through a mechanism of comparing the home to the workplace (which had previously been a major focus of CSCW research). Three key observations are then as follows (these have been paraphrased from the paper itself).

Homes are not workplaces. Workplaces are often designed so that their physical structures are adept at accommodating new technology, but many homes are not. Installations of technology into workplaces are generally conducted and supported by professionals, whilst installations into the homes are more likely to be carried out by the residents themselves. Installations into the home may need to be robust in light of usage by visitors, children and pets.

Consumers are not knowledge workers. In workplaces, decisions are driven by the needs of efficiency, but in the home, decisions are more likely to be driven by "aesthetics, fashion and self-image".

Families are not organisations. Corporate organisations are often explicitly structured, whereas family structures are often "complex and non-hierarchical". The way that decisions are made, and values set, is very different between workplaces and the home.

A broad conclusion that can then be drawn from the analysis provided by Hindus et al is is that homes are inherently messy and difficult places in which to make technology work, with limited capacity for technological additions, no clear structures for decision making or control and a frequent lack of professional expertise on the part of those who are installing or operating technology. Given that survivors of stroke are likely to be experiencing cognitive, sensor or motor disabilities, this then raises the possibility of the homes of stroke survivors being even more difficult environments for technology. A recent photo-based study of a number of exemplar homes, by Axelrod et al [118], has provided evidence to support this contention, which is also touched on by Greenwood et al [119], who have provided a useful literature review of ethnographies of the lives of stroke survivors. Understanding the potentially unique challenge of designing appropriate technologies for the homes of stroke survivors might also shed light on the challenges of designing technologies for the homes of individuals who have experienced other major health problems, or significant changes to their daily life.

Stroke is an illness which affects a substantial proportion of the population, and in the UK alone, several hundred thousand people are living with the after-effects of stroke. Designing technologies that can be deployed on a sufficiently large scale to make a significant difference is then a challenge, and requires an understanding of the costs and benefits of different technological approaches. Some key results from the CSCW are then very relevant in supporting this kind of analysis. One very relevant piece of research is then provided in an analysis by Rodden and Benford [120], who have presented a model by the architect Stuart Brand [121] that considers the cost of making changes to a home. They have also considered its implications for the design of domestic technologies.

This model divides the architecture of a building into five layers, and presents an estimate of how frequently these layers change, and the relative costs of

these changes. A table presenting these five layers is provided in Figure 3.1, which has been taken directly from the paper. Changes are most expensive at the top of the table, and most frequent at the bottom. Rodden and Benford then argue that most technological change takes place in the "stuff" layer, with occasional changes required at the higher levels (an example would be the installation of a central heating system, potentially requiring change at the "services" and "space plan" level). To be cost-effective, the design of rehabilitation technologies might focus on changes only at the "stuff" level; this then raises an interesting question about interventions such as those described by Reinkensmeyer et al [98] which require networking connectivity to report exercise information back to therapists. Does the provision of networking support require change at levels higher (and therefore more expensive) than "stuff"? If so, might they be too expensive for large-scale deployments?

SITE (Fixed)	This is the geographical setting, location, and the legally defined lot, whose boundaries and context outlast generations of ephemeral buildings.
STRUCTURE (30-300 yrs)	The foundation and load-bearing elements are perilous and expensive to change, so people don't. These *are* the building. Structural life ranges from 30 to 300 years
SKIN (20-30 yrs)	Exterior surfaces now change every 20 years or so, to keep up with fashion, technology, or for repair.
SERVICES (20-30yrs)	These are the working guts of a building: communications wiring, electrical wiring, and plumbing. Buildings are demolished early if their outdated systems are too embedded to replace easily.
SPACE PLAN (3-30yrs)	The interior layout – where walls, ceilings, floors, and doors go. Turbulent spaces can change every 3 years or so; exceptionally quiet homes might wait 20-30 years.
STUFF (Continual)	Chairs, desks, phones, pictures, kitchen appliances, lamps, hairbrushes; all the things that twitch around daily to monthly. Furniture is called *mobilia* in Italian for good reason.

Figure 3.1: A model describing how buildings change, sourced from [120].

In the UK at least, domestic networking technologies tend to only require change at the "stuff" level, as they are often provided through "broadband" services that appropriate existing copper telephony connections, making use of electronic devices to squeeze more data through these connections than they were originally designed for. This retrofitting of networking into the home, making use of an existing physical medium that was not designed for this particular use then requires the installation and configuration of a variety of technologies, especially where a wireless network is desired. A variety of studies have then highlighted the challenging nature of this work, and the difficulties that it can cause in many domestic situations. Here, Grinter et al

[122] have documented the "work to make a network work", highlighting the administrative and troubleshooting effort that is often required. Tolmie et al [123] have then explored the competencies involved in these tasks, arguing that they are at least equivalent in complexity to the work of a domestic tradesperson such as a plumber. Because of the difficulties inherent in their operation, Sventek et al [124] have argued that existing home networking technologies are actually a road-block to next generation healthcare applications, and have cited a report from the Consumer Electronics Association claiming that

> "home networking equipment is the most returned consumer electronics item with return rates for new products in excess of 25%"

They have also presented an initial exploration of new algorithms and interfaces intended to simplify home-networking for domestic residents.

It may well be that home-networking will become simpler as technology progresses, and familiarity with networking technologies should raise the level of knowledge on the part of residents. However, it could still be the case that, to support cost-effective deployments on a large scale, design work might more effectively focus on technologies that do not require a network connection to operate, or which only require periodic access, if such technologies could be proven to provide therapeutic benefits. This might then exclude a use case in which clinicians utilise networking technologies to explore data collected in the homes of stroke survivors, as imagined by [98] (although clinicians could of course explore data collected on a periodic basis through visits to the home). It is, however, an open question as to whether clinicians or therapists would actually wish to utilise this kind of data, and it would necessarily involve a significant change to the working practices inherent in these professions. Technologies that are not networked might fit better into existing working practices, and could be easier to integrate into professional practice.

3.2.3.1 Methods appropriate to studying and designing for the home

Another important contribution of research into technology and the domestic environment has been a greater understanding of how to study the home

- not easy, given its often private nature [125]. Part of this understanding relates to the question of what aspects of home life to study, given that a choice clearly has to be made between competing priorities. A significant body of work has then been informed by ethnomethodology [126], which argues for an analytical focus on the various mechanisms by which social order is actively maintained. In the home, this has then lead to a strand of research which focusses on understanding domestic routines (e.g. [127, 128]) and considering aspects of those routines which are amenable and productive in relation to technological intervention [29]. O'Brian et al [125] have argued that a focus on domestic routine then provides a rationale for fieldwork constructed around occasional visits at key points in particular routines rather than the obtrusive insertion of a field-worker into the home on a long-term basis, which would then necessarily disrupt the life of the home. An example is then then the presence of a field-worker at a family meal, or during occasional evening visits, with the argument being that these are important points in particular routines, which can then shed light onto the routine as a whole.

Fieldwork, such as the examples cited above, allows for an understanding of the home itself, which can be used to identify potential implications for design. There is, in addition, a long tradition of research constructed around the study of technological interventions made in the home, developing knowledge which supports an understanding of the impact of the intervention, but also of the home itself. Much of this work can be related to the idea of a technology probe [129], described by Hutchinson et al as:

> "simple, flexible, adaptable technologies with three interdisciplinary goals: the social science goal of understanding the needs and desires of users in a real-world setting, the engineering goal of field-testing the technology and the design goal of inspring users and researchers to think about technologies"

Ideal technology probes for the home are often robust but incomplete prototypes, deliberately positioned to allow residents to appropriate and critique them [129], potentially supporting the deployment of more refined interventions in the future.

How to structure design processes that generate interventions suited to the home has also been a major topic of exploration, much of it informed by

the observations made by Hindus and others in relation to its unique nature. An interesting strand of this work has focussed on the home as a place for relaxing and creativity, drawing on Huizinga's notion of "Homo Ludens" [130], i.e. humans as playful creatures, introduced to the HCI community by Gaver [131]. Examples of innovative design processes include work on the "Curious Home" project [132, 6], which explored the design of novel items of furniture which embedded interactive technologies. Gaver et al have also introduced the idea of a "cultural probe" [8], a carefully-selected package of material intended to support creative communication between recipient and designer, and to produce "inspirational responses" to guide the process of design. How to design cultural probes for different settings has become a topic of research in its own right; a number of papers have considered the design of probes relevant to participants who are experiencing significant difficulties with their health, including discharged psychiatric patients and elders who are dependent on the care of others [133].

Methods for studying and intervening in the home are considered in more detail in the following chapter, which presents a clear statement of those methods that have been adopted in the work of constructing this thesis. Before this, a statement of the contribution made by research presented in this is provided, which builds on an overview presented in Chapter 1.

3.3 Thesis contribution statement

Having provided a review of the relevant literature, this chapter now concludes with a statement of the contributions to research that are made in succeeding chapters. A description of the methodological and structural basis of these contributions is then provided in Chapter 4, with further details of the implementation of the work provided in succeeding chapters. Four categories of contribution are central to the work of this thesis. These are summarised and justified below.

Understanding how to design rehabilitation technology that are appropriate for the homes of stroke survivors

As identified through this literature review, there is a very substantial body of research focussing on the design and evaluation of rehabilitation technologies for stroke. Much of this work has focussed on high-value systems intended for high-throughput environments such as hospitals, often incorporating elements of robotic or virtual reality technologies. A more recent strand of research has then focussed on the design of rehabilitation technologies for the home, presumably because the ever-increasing capabilities of home computing are allowing for more ambitious and potentially cost-effective technologies created. Much of the existing research on this topic has been technologically-focussed, and little has taken into account an understanding of the home as a uniquely complex and messy target for technology design, as present in the CSCW and HCI literatures. This thesis therefore contributes an exploration of how to design technologies that are informed by an understanding of the home, and which are respectful of its unique nature. This is then a contribution which is of specific interest to health technology researchers, and of general interest to HCI/CSCW researchers. Informed by the discussion of networking technologies presented above, the presumption of this work is to avoid a dependency upon a network connection, so as to develop knowledge about the design of effective technologies that are not dependent on the network.

Stroke is a condition which can occur very suddenly, and which can cause a dramatic change in physical and mental abilities. As such, it can be seen as an exemplar for a broader range of experiences which involve sudden and potentially traumatic changes in life. Knowledge about the design of technologies that are appropriate for the homes of stroke survivors is then generally more applicable to the design of technology that is appropriate for the homes of people who have experienced sudden changes in their life, which would certainly include individuals who had experienced other forms of brain injury, but could extend to support an understanding of the implications of serous physical accidents. As such, an understanding of the nature of the homes of stroke survivors in relation to technology design is then relevant to a broader range of individuals as well.

Considering the implications for technology of the experience of surviving and living with a stroke

In seeking to design technologies that can support rehabilitation, there is a need to understand the experience of having a stroke, and the experience of living with disabilities acquired through it. Much of this experience is well understood, in that it is documented in the medical and sociological literature (e.g. see [119]). However, in almost all of the health technology publications that have been reviewed in this chapter, the nature of this experience has been considered indirectly, often through a mechanism of including professionals experienced in the treatment of stroke in the process of design. There is very little evidence for any significant contribution from survivors of stroke at all to the process of design; in fact, only one of the papers reviewed in Section 3.1 indicates that survivors of stroke were consulted at all, and even that paper does not present any knowledge gained through this consultation. Within the CSCW and HCI literature, there is a well-recognised danger of an indirect consideration of relevant individual perspectives, which carries a specific risk of introducing distortions (see [134] for a discussion). Approaches to addressing this include participatory design - this avoids such distortions by emphasising the direct inclusion of potential users of technology in the process of designing technologies themselves.

Building on these observations, another contribution of this thesis is an exploration of the experience of surviving and living with the consequences of a stroke, and a consideration of some important and specific implications for technology design which have not been considered sufficiently in the existing health technology literature. This contribution is intended to directly inspire future research into rehabilitation technologies. It will also be of interest to HCI researchers interested in the interactional needs of individuals who have experienced traumatic events or illnesses.

This contribution has emerged through a variety of interactions with survivors of stroke and their partners or family members. These have included focus groups, discussions about technology demonstrations, home-based design sessions and discussions about technology deployments. All have been carefully documented so as to present knowledge relevant to researchers and technology designers. Participants have been carefully chosen to maximise the breadth of experiences that are considered.

Exploring the concept of tailoring as it relates to technologies intended to support stroke rehabilitation

Stroke is an occurrence which can cause a broad range of sensory, motor and cognitive disabilities, depending upon the location in the brain at which the stroke occurred, and also factors such as the length of duration of the stroke, the style of medical treatment and the amount and quality of support post-stroke. As such, there may be a need to tailor rehabilitation technologies to the individual needs of stroke survivors. Alankus et al [25], writing in 2010, have raised the question of how this tailoring process might work. Any form of tailoring needs to take into account the broader social and financial context, in that, to be adopted on a broad scale, it would need to be sufficiently cost-effective.

A key contribution of this thesis is then an exploration of the concept of tailoring as it relates to home-based rehabilitation technologies, leading to an identification of a set of mechanisms through which technologies might be tailored. As well as being of interest to researchers interested in health technologies, this is then a contribution of interest to a broader and ongoing debate with HCI about mechanisms for personalisation. It is specifically relevant to research considering the question of how to tailor technologies to the needs of individuals with a variety of health conditions.

Part of this exploration focuses on the topic of how to incorporate individual differences in motivation for recovery into designs for technology. As discussed earlier in this chapter, rehabilitation technologies that respond to and support individual motivations can be thought of as persuasive computing technologies, and this exploration can therefore be considered as a case-study which will then be of broader interest to the persuasive technology research community.

Supporting the design of toolkits catering for the cost-effective deployment of rehabilitation technologies

Given the substantial number of individuals who are living with a stroke, for any technologically-oriented research to have a real impact, there is then a need for it to support the cost-effective deployment of technologies on a large scale. Drawing on all of the research presented in this thesis, a final contribution is then a novel model highlighting how such a toolkit might work, and how it might integrate into the professional practice of therapy. This contribution is presented in Chapter 8. Given that toolkits have been a topic of research for some time, especially within the ubiquitous computing community (e.g see [30, 31]), this is then also a specific contribution which will have a broader interest.

Chapter 4

Approaches and methods in this thesis

The purpose of this chapter is to provide an overview of the approaches and methods that have been influenced construction of this thesis. Specific detail about the application of these is then provided within individual chapters.

The chapter begins with an overview of *Research through Design*, the overarching approach within which this work is located. Research that is situated within this approach often makes contributions that are structured as *sensitizing concepts*, *guidelines for design* or *conceptual frameworks*. There are a variety of definitions present in the research literature for these three constructs. As such, a discussion of the author's orientation to them is therefore provided, which draws on specific examples of their usage within the HCI literature.

As described in the preamble, theses submitted through the *Staff Candidate* mechanism at the University of Nottingham must be constructed around the analysis of datasets that were already in existence at the point of application, rather than requiring new data to be collected. In the case of this thesis, relevant data was collected by the author during his participation in the Motivating Mobility project [5, 4]. As such, an overview of this project is provided, which considers its general scope, relevant research work that was conducted within it, and the author's contribution to this work. Following on from this, the chapter then presents an overview of additional analytical work that has been conducted solely by the author during the construction of this thesis.

Work presented in chapters 5, 6 and 7 required a direct engagement with survivors of stroke and others in their social context. This chapter includes a short discussion of ethical considerations around this style of research, and a summary of the structure of the ethical approach that has been taken in this work. Specific details of approaches taken to ensure ethical research practice are then provided within the chapters themselves.

4.1 An overview of Research through Design

Research through Design (RtD) is an approach to the generation of knowledge which is structured around the application of design processes to particular problems. It is well-accepted within HCI, and has a strong tradition of use. RtD has been discussed substantially in the literature, and a recent paper by Zimmerman, Stolterman and Forlizzi [33] has contributed a detailed review of this literature, which is augmented with the analysis of a set of interviews with experts in RtD and a critique of a number of research projects which have been constructed around RtD as an approach. The remainder of this section draws on this publication for its structure.

Research through Design as a distinct concept has its roots in *Research through Art*. This was first formulated by Frayling in 1993 [135] as a contribution to a debate around acceptable methods for making academic contributions through practice-based, rather than empirical or theoretical work. Since then, the concept of research which draws on creative practice to make a contribution to knowledge has become well-established within the UK university system [136], where it has been referred to by the UK Council for Graduate Education as research consisting of "original creative work accompanied by a reflective and scholarly appraisal" [137]. It is also well-established within the field of HCI, within which numerous examples are present.

RtD conceptualises the design process itself as being a form of research method, and, as such, is particularly amenable to the generation of knowledge intended to support future design work. Because of its holistic approach to the integration of knowledge across disciplines, and because of its iterative approach, Zimmerman et al [33] have motivated RtD as being particularly relevant for problems which are not amenable to reduction into smaller components, which may relate to "messy situations with unclear or conflicting agendas" and for which there are therefore no perfect solutions. They have

then related this class of problem to the concept of a *wicked problem*, as defined by Rittel and Webber in 1973, in the context of social policy planning [138], and have argued that wicked problems are particularly amenable to investigation through RtD. The table presented in Figure 4.1 summarises the ten characteristics that Rittel and Webber used to classify wicked problems.

In an academic context at least, knowledge generated by RtD tends to be encoded in forms that can be directly shared with others, and which can therefore influence and contribute towards debate across a broader community. Zimmerman et al have identified a number of formats for the presentation of knowledge that are already in use by the RtD community, namely:

- Sensitising concepts

- Guidelines for design

- Conceptual frameworks

All three of these constructs are utilised in subsequent chapters of this thesis.

4.1.1 Application of Research through Design in this thesis

In the context of this thesis, Research through Design has been used to generate knowledge which is intended to support the effective design of rehabilitation systems for stroke. This process has involved a set of direct engagements with survivors of stroke and others in their social context, and the analysis of data collected during these engagements to generate specific sets of sensitizing concepts, guidelines for design and conceptual frameworks. Given that there are a range of usages of these concepts in the research literature, then a summary of the author's orientation to these concepts is therefore provided below. In seeking to apply these concepts, the author has adopted practices that are well-established within the HCI literature, and examples of these practices are provided in the following definitions.

4.1.1.1 Sensitizing concepts

Zimmerman et al [33] have presented a discussion of sensitizing concepts which is relatively broad, and which considers them to be constructs that

1	There is no definitive formulation of a wicked problem.
2	Wicked problems have no stopping rule.
3	Solutions to wicked problems are not true-or-false, but better or worse.
4	There is no immediate and no ultimate test of a solution to a wicked problem.
5	Every solution to a wicked problem is a "one-shot operation"; because there is no opportunity to learn by trial and error, every attempt counts significantly.
6	Wicked problems do not have an enumerable (or an exhaustively describable) set of potential solutions, nor is there a well-described set of permissible operations that may be incorporated into the plan.
7	Every wicked problem is essentially unique.
8	Every wicked problem can be considered to be a symptom of another problem.
9	The existence of a discrepancy representing a wicked problem can be explained in numerous ways. The choice of explanation determines the nature of the problem's resolution.
10	The planner has no right to be wrong (planners are liable for the consequences of the actions they generate).

Figure 4.1: Ten key points that define *Wicked Problems*, as presented by Rittel and Webber in 1973 [138].

"help direct designers and researchers in solving design problems". For the purposes of this thesis, a more specific definition has been adopted, in which a sensitizing concept is essentially a short and memorable textual descriptions of an phenomenon which is both present in a particular context and important for a designer to attend to, along with a textual description that provides a justification for the selection of the concepts.

This particular conceptualisation has a rich tradition of use in the social sciences, where sensitizing concepts are used to guide attention to particular events or behaviours [139] and to "give the user a general sense of reference ..." [140] in relation to a specific context. By explicitly presenting concepts that highlight particularly phenomena, the articulation, sharing and discussion of this understanding with a broader community becomes possible [141]. As such, sensitizing concepts as present in the social sciences are not intended to be static, and are more likely to evolve in an iterative way, as the understanding of this domain changes [140]. This means that some concepts defined early in an analysis process can disappear, supplanted by more useful emerging concepts that "displace them altogether" [142].

Given that any process of design takes places in a specific context, then effective design requires an understanding of this context. As such, sensitizing concepts have a strong tradition of use in research relating to the design of interactive systems, where they have often had an influence on the early stages of design. An important example of the usage of this construct is provided by Crabtree et al [29], who use ethnographic work to identify three categories of location in the home which are used for organisation and communication between inhabitants, and which may therefore be amenable to novel computational interventions. These categories have then provided a starting point for the design of a wide variety of novel systems, including the *Drift Table* [132] and *LINC* [143], an electronic family calendar.

Within this thesis, Chapter 5 presents a set of seven sensitizing concepts derived from focus groups with survivors of strokes and their families. These are intended to orientate the reader to features of the experience of these individuals that have not been discussed in the literature on rehabilitation systems. In keeping with Crabtree et al [29], and many other examples in the HCI literature, these are presented as short memorable pieces of text, with an accompanying justification of their importance. In keeping with practices in HCI publications such as [144], quotes taken directly from engagement

with participants are included in these justifications to illustrate the data in which they are grounded.

4.1.1.2 Guidelines for design

Whereas sensitizing concepts are focused on understanding a context, design guidelines are focused on the work of design, and are structured to support this process. Effective guidelines can speed the process of designing usable systems, and can help avoid costly mistakes. They are a common output of HCI and design research, and there are many hundreds of examples to draw on.

Many sets of guidelines are structured to make specific recommendations about the design of features in systems intended for use in particular context. Brown et al [145], for example, have produced a set of guidelines which are intended to support the design of multimedia learning environments, and which are specifically focused on avoiding usability difficulties in interfaces that might be used by individuals with particular disabilities. Such guidelines may be especially useful to designers who have not experienced those disabilities, and may serve to orientate them to specific problems to design around. Within the HCI literature, guidelines for design are frequently presented as textual descriptions, often accompanied by material that either provides a justification for their selection, or which links to material justifying their selection. Sets of guidelines on particular topics are also published by bodies such as standards committees, in which case they may be reproduced as large tables containing short textual descriptions of guidelines, produced through a formal process involving experts on a topic (e.g. see the Web-Content Accessibility Guidelines document produced by the W3C [146]).

As an academic contribution, Chapter 8 provides a small set of guidelines for design. These draw on the documentation of design and deployment processes provided in chapters 6 and 7. These are intended to highlight particular aspects of the home which should be attended to when deploying tailored rehabilitation systems, and are presented with the intention of informing future research work around such systems. In keeping with much of the HCI literature, these guidelines are presented as textual descriptions, with textual justifications for their selection.

4.1.1.3 Conceptual frameworks

Whereas effective design guidelines provide very specific advice about how to design particular features of systems, conceptual frameworks are more focused on the broader question of how to think about a particular category of technology. They also have a long history of use with design and HCI, and can often be used to open up new spaces to be explored through future design work. As a broader and more general contribution, the presentation of conceptual frameworks is generally idiosyncratic to the nature of the framework, but common modes of presentation in the HCI literature include combinations of diagrams and descriptive text.

An illustrative example of a conceptual framework is provided in work by Reeves et al [147], who discuss the issue of how to design interactions with technologies that are intended to be used in public spaces, by performers. Through a process of reflection on a substantial review of prior work, these authors have produced a conceptual framework which identifies two key dimensions to consider in relation to the design of these interactions, namely *manipulations* and *effects*. They have then extended this framework by defining four categories of interaction, namely *magical*, *secretive*, *suspenseful* and *expressive*, which relate to these two dimensions. Finally, they have considered the implications for design of each of these categories of interaction.

The framework itself has then been used to support design work directly (e.g. [148], which describes the design and evaluation of a suspenseful interface). It has also been used to help understand technology which has already been designed [149]. The framework has also been linked to other conceptual frameworks, producing larger entities that can inform the process of design. An example of this includes work by Schnädelbach et al [144], who consider the different roles that individuals can play in relation to technologies used in performance.

Chapter 8 presents a novel conceptual framework which is intended to identify key processes which are necessary to support the deployment of effective rehabilitation systems. Implications for the design of materials to support these processes are also considered. In common with much of the HCI literature, these frameworks are presented through a combination of diagrams and text.

4.1.2 Issues to consider when engaging in Research through Design

Zimmerman et al [33] have argued that Research through Design is appropriate in the case of Wicked Problems, i.e. problems which are not addressable through reductionist methods. In these situations, RtD essentially draws upon the experience and intuitions of a designer, or multiple designers, in navigating the design space and in assessing and presenting solutions. Through this process, data is generated which can be analysed for insights into how to conduct design in that specific setting, which can then be formalised using some of the constructs presented above. Through this approach to research, the designer effectively becomes a possible point of failure. This is clearly a significant risk.

This risk can then be ameliorated through approaches to design which ensure a sufficient exposure to the realities of the setting. Exactly how this is done depends upon the nature of the setting and the chosen set of problems which are to be addressed. Making this process transparent, so that others can reason about the quality of generality of both the solutions and the knowledge developed through a particular piece of RtD is then essential. Transparency is important in both documentation of the process of design and of the process of data analysis. Practices for presenting processes and knowledge in a transparent manner are still evolving within HCI research, and are often relatively limited - it is not yet common, for example, for authors to publish in full the data in which their research is grounded, or to provide a verifiable audit trail allowing for the reconstructions of the analyses that they have performed. In presenting this thesis, the author's intention is to be as transparent as possible in relation to both the process of design and process of analysis.

To provide an initial structure to support an understanding of this research, the remainder of this chapter presents a summary of the process of research conducted in the Motivating Mobility project and analysis carried out by the author in constructing this thesis. Further details of how design and analysis work were carried out are then provided in subsequent chapters. All collected data has been included in a form appropriate to a thesis, and individual chapters present descriptions of the data that was collected and the mode of inclusion. An important principle in the construction of this thesis has been

a detailed and accurate presentation of the design process, and a number of key academic contributions have been developed through the analysis of the process itself. As such, and in the context of RtD, documentation of the design process can be thought of as an important source of data, which then raises an intriguing question of how to capture, analyse and present it.

4.2 Research in the "Motivating Mobility" project

Motivating Mobility: Interactive Systems to Promote Physical Activity and Leisure for People with Limited Mobility was a research project which was funded through an EPSRC sandpit (grant number EP/F00382X/1), and which involved a close collaboration between health science, HCI and engineering researchers. Before the author joined the Motivating Mobility project, a decision was made to focus on systems intended to support the rehabilitation of stroke. Later decisions involved a further narrowing of focus, firstly towards the design of systems to support self-managed rehabilitation in the home, and secondly, towards systems that promoted rehabilitation from stroke-induced physical disability in the upper limb, a term used by health science practitioners to collectively refer to the shoulder, upper and lower arm, elbow, wrist, hand and fingers. This is a part of the body which tends not to be a focus of rehabilitation in hospital-based rehabilitation. As such, at the point of discharge, many survivors of stroke have significant deficits in upper-limb mobility [78, 150, 151].

As the sole researcher at the University of Nottingham, the author took responsibility for work which was orientated around the process of designing novel rehabilitation systems, in collaboration with other project members. This role focused on a variety of methods for securing the participation of stroke survivors and their partners in the process of design, and also on the implementation, deployment and evaluation of four novel prototypes. During the course of this project, the author conducted a substantial qualitative analysis in relation to data collected during a workshop with stroke survivors and their partners. This analysis led to a publication in an international conference [35]. It was then substantially extended and re-purposed during the process of producing Chapter 5 of this thesis, through a second analysis

that provided a deeper understanding of the contents of this workshop.

To facilitate an initial exploration of ideas, the process of design in Motivating Mobility began with the development of a set of seven personas [152] by project members. Personas are realistic descriptions of imaginary users of future systems, which is expressed in sufficient detail to allow a designer to start to reason about the potential needs and desirable patterns of use for such an individual. Personas constructed by Motivating Mobility drew upon the clinical expertise of those project members who were already experienced in treating stroke survivors, and were structured as a two page description. For each persona, these provided a summary of disabilities post-stroke, and highlighted the impact of stroke on their social situation.

Having identified a set of personas, the project team then sketched out a storyboard illustrating features of a candidate design for a computational rehabilitation system. Storyboards, as described in [153], are an accepted part of the design process for many different types of product, and can be presented in a variety of forms, ranging from brief sketches to sequences of photographs. Storyboards developed within Motivating Mobility were used as a resource for supporting discussion within the project, and were also used to facilitate discussion with participants during a series of workshops described below. These storyboards were developed collaboratively, by the author and two other project members.

Design work orientated around personas and storyboards fed into three participatory workshops which were organised by the project team, and in which the author took a lead role. These were structured to facilitate discussions with experts with a variety of perspectives on stroke, including professionals responsible for stroke treatment, survivors of stroke, and individuals who lived with them. Storyboards generated previously in the project were used as discussion points in this workshopping process. Workshops are an accepted part of the process of designing products and systems - for a set of examples, see [154]. In the context of Motivating Mobility, workshops were an opportunity to expose researchers working on the project to the reality of living with and treating disability acquired through stroke, as understood by both survivors and professionals. In the context of a design-led inquiry rooted in Research through Design, this kind of exposure represents both an opportunity to develop academic knowledge about a setting that can be presented to others, and also an opportunity to develop a stronger personal

understanding to enable an effective negotiation of a potentially tricky design space.

The proceedings of the two workshops identified above were audio-recorded, and a variety of textual material was also collected, including researcher's notes and transcripts of notes made by participants. This collected material then represents a substantial corpus of data. After the workshop, audio data was archived and transcribed solely by the author, who integrated it with the workshop notes through a qualitative analysis process. This process was then used to construct a publication, the initial draft of which was solely written by the author, but which was subsequently edited in a minor way by other project members. This paper was accepted for publication at an international conference [35]. It makes two primary contributions. Firstly, it identifies some key aspects of the experience of living with stroke which are relevant to the design of rehabilitation systems. Secondly, it identifies a set of software components which could be present in a future system. This initial analysis has informed a more detailed analysis conducted by the author for the purposes of writing Chapter 5.

Following the conclusion of the workshopping process, the project then moved onto a recruitment and selection phase, which involved the identification of participants for future design work. Each candidate was interviewed by a professional therapist, who utilised a profiling tool which had been designed by academic physiotherapists working on Motivating Mobility. Data collected using this profiling tool influenced the process of designing for selected participants. Recruitment work influenced the process of design presented in Chapter 6, and further details are provided in this chapter.

Having selected four participants, the project then moved onto a design phase, in which tailored bespoke systems were designed for each participant, with the aim of providing case study data for later analysis. The author acted as a primary designer for two of these participants, and documentation of the two resultant systems is presented in Chapter 6, in which it represents the primary practice-based creative contribution of this thesis. For the other two participants, a second project member acted as the primary designer, and documentation of these systems is included in a case-study mode, as an additional source of data for analysis.

Throughout the design and deployment work for all four participants, the author played an important technical role, developing hardware aspects of

computational interfaces that were deployed to participants, and contributing to the development of software aspects of these interfaces. This phase of the project involved the collection of a variety of data, including design notes and logs of system use. These were archived by project members, to an archive which was maintained by the author. This archive has then been used as a resource from which project members could develop publications, and has been a primary source of data for this thesis.

4.3 Analytical work performed in the construction of this thesis

The author was accepted as a staff candidate roughly one year after the conclusion of the Motivating Mobility project. In addition to work carried out during the Motivating Mobility project, a substantial body of analytical work has then been carried out, solely by the author, to support construction of this thesis. This analysis work has supported an exploration of the perspective of stroke survivor and its relevance to design, as described in the introduction. It has also allowed for the development of a conceptual model to support the design of a future toolkit to support the rapid deployment of tailored rehabilitation systems.

As a collaborative and interdisciplinary project, design practice in Motivating Mobility was guided by the practical and academic knowledge of project members who were experts in movement therapy, and who had substantial expertise in working with survivors of stroke. However, to allow a self-contained thesis to be written, the author has carried out a review of the literature around stroke, treatment and rehabilitation. This is presented in Chapter 2 of this thesis, and provides relevant background knowledge that focuses on treatment and rehabilitation as they commonly occur in the UK. A second review, focused on interactive rehabilitation systems for stroke, has also been conducted, and is included in Chapter 3. This provides a foundational understanding on the strengths and limitations of the current state of play in relation to interactive rehabilitation systems, on which the remainder of this thesis is built. In particular, this chapter provides an argument for why the incorporation of the perspective of stroke survivors into the design of interactive rehabilitation systems is important.

One of the three workshops described in Section 4.2 featured extensive discussions with stroke survivors and their partners, and this workshop therefore provided a rich and detailed illustration of the everyday experience of living with stroke which is relevant to an understanding of this perspective. An earlier publication written by the author had provided an integrated analysis of an integrated corpus of data collected during both this workshop and two workshops with professional movement therapists, [35]. For the purposes of this thesis, the author chose to focus only on the workshop that featured stroke survivors, which then provided an opportunity to develop a more detailed understanding of their needs and constraints in relation to technology. Writing Chapter 5 then required a new and more detailed analysis of data gathered during this workshop, albeit one which was informed by the earlier publication. This analysis has been used to identify a set of seven sensitizing concepts which highlight key features of the experience of living with stroke. These concepts have been selected for their power in supporting future design work. A detailed presentation of the analysis and selection process is provided in Chapter 5.

Through the process of working with survivors of stroke in their own homes, design and deployment work conducted by the author and others during Motivating Mobility then provides a rich corpus of data in relation to the process of tailoring of systems to individuals, represented in an archive of field and design notes. Through a process described in detail in chapters 6 and 7, the author abridged this documentation to produce four case studies, each of roughly 2,500 words in length, for the purposes of inclusion in this thesis. In both of these two chapters, case study material is accompanied by a qualitative analysis which highlights key considerations for the design of tailored rehabilitation systems which can be identified through this material. This material was further abridged by the author for the purposes of constructing a project publication [27]

To produce Chapter 8, a final analysis of material presented in chapters 5, 6 and 7 was performed, generating the following contributions:

- A set of guidelines for design

- A discussion of key questions for further research

- A novel conceptual framework intended to support the design of a toolkit for tailored rehabilitation systems.

Collectively, these abstractions are intended to support the design and deployment of more effective rehabilitation systems in the future.

4.4   Ethical considerations around research work

Ethical issues are an interesting source of debate in HCI research, and there is a developing understanding of the damage that can be done through technologies that compromise the rights of individuals, and through research processes that do not sufficiently attend to the needs of their participants. The Motivating Mobility project sought to engage with survivors of stroke, who are then likely to be experiencing both physical and cognitive impairments. They are also more likely to be elderly, and therefore to be experiencing potentially serious co-morbidities. A significant amount of discussion took place within the project team about how to ensure ethical practice in our engagement with participants, and the author played an active role in these discussions. This section therefore provides an overview of the structure of Motivating Mobility work around ethics. It also addresses the question of whether it is acceptable to repurpose research in the context of a PhD that has been constructed after the conclusion of the Motivating Mobility project. Legal aspects of this particular question need to be understood within the context of the data protection act, which regulates the usage of *personal data*, a legally-defined term.

In the case of the Motivating Mobility project, ethical considerations were handled through a process involving the construction of an ethics proposal, which was then considered by an ethics board at one of the participating universities. The agreement of an ethics board does not guarantee that any particular proposal is ethical, as any agreement is subject to human judgement, which can always be subject to faults - here, Lowman and Palys [155] provide a case-study of an ethics board that made some substantial errors of judgement. However, the process of constructing and submitting an ethics application does at least lead to active discussion around the topic, and the design, exploration and documentation of a planned process can lead to the identification and resolution of potential problems. Ethics boards themselves, when properly constituted, can provide an experienced perspective on ethical problems, and should at least be outside of the everyday pressures of a research project, and therefore potentially in a better situation to provide an

informed judgement on proposals.

In the case of Motivating Mobility, an ethics proposal for the workshopping, design and deployment processes described above was written by the project team, and submitted to an ethics board at the University of Sussex, where it was approved. The University of Sussex was a partner in the Motivating Mobility project, and, through prior ethics applications by researchers involved in Motivating Mobility, had substantial experience in the consideration of ethics proposals relating to these kinds of processes. As such, it was considered to be a competent body by researchers involved in the project. The workshop, design and deployment processes described above were carried out as a collaboration between researchers working at the Universities of Nottingham, Sheffield Hallam, Southampton and Dundee, and we therefore verified that each of these universities were willing to accept the agreement of the University of Sussex ethics boards. Derogating judgement to the ethics boards of another UK university is generally accepted with the UK university system (as an example, see ethical regulations published by the University of Bangor [156]), although it is not uncontroversial, in that it could lead to a process in which researchers sought out an ethics board which was known to be more willing to accept proposals which presented ethical difficulties. In the case of the application made to the University of Sussex ethics board, a range of ethical issues were considered, including:

- How to recruit participants, and how to minimize the chance that participants were excluded due to economic, cognitive or physical constraints

- How to ensure that informed consent was provided for engagement in the process of research, especially given the possibility of cognitive deficits caused by stroke

- How to protect against unethical practices during the process of research

Chapters 5, 6 and 7 provide specific detail about some of the processes of research that were adopted with the Motivating Mobility project, and hence specific detail of provisions to support ethical conduct are therefore provided within the body of these chapters.

In the case of this PhD thesis, data collected during the Motivating Mobility project has then been re-analysed and re-purposed for the purposes of its construction, and it is therefore important to consider the implications of this process, and whether it can be ethically and legally justified. With respect to the usage of data beyond the end of a project, such usage was not excluded by the submitted ethics proposal, and no commitment was made to participants, through provided information sheets and consent forms, to limit the usage of data beyond the end of the project. No requests for the withdrawal of data have been made by participants. Participants were also made fully aware through the research process that collected data would be used for the purposes of publicly-accessible publications which might be written beyond the life of the project. As such, it is the author's belief that there are no particular ethical difficulties present.

All data collected during the Motivating Mobility project was anonymised for the purposes of research, thereby providing an additional layer of protection for participants. Anonymised data is not considered to be personal data within the definitions established by the 1998 UK Data Protection Act (DPA) [157], as it cannot be used to identify an individual. As such, there are no particular legal restrictions on the processing of data for the purposes of constructing this thesis. As an aside, even where personal data has been collected for the purposes of research, section 33 of DPA indicates that it is legal to hold such data indefinitely, as long as this is only for the purposes of research [157].

4.5 Summary of the author's contribution to the process of research

This thesis has been produced through a sustained effort across two years as a leading member of the Motivating Mobility project and three years spent registered as a staff doctoral candidate. The approaches and methods adopted through this process have been described in detail above, but to clarify the contribution that the author has made during the process of research described in this chapter, this final section provides a summary of various activities that have taken place. In the case of activities that took place in the context of the Motivating Mobility project, these have been fil-

tered for their relevance to the thesis, and only those activities in which the author played a part have been included. Further specific detail of how some of these activities were carried out in practice is then provided in subsequent chapters, where relevant to the contents of this thesis.

The following relevant activities took place during the Motivating Mobility project:

- A set of relevant personas were designed by two physiotherapists who were working for the project. These seeded ideas for a set of scenarios, which were designed by the author and one other project member.

- A comprehensive ethics proposal was written and submitted, to cover all user engagement work planned in the project. The author was one of a small group of researchers who worked on this proposal, and had a sign2ificant influence on its contents.

- Three discursive workshops were organised, allowing for engagement with stroke survivors, their partners and professionals familiar with the treatment of stroke. The author designed data capture elements of this workshop, and collected and archived all workshop data for the usage of the project. The author also transcribed audio recordings collected during this process.

- Working from this archive, the author conducted an initial qualitative analysis, and wrote a publication which presented lessons learned across all three workshops [35]. This was subsequently edited in a minor way by other project members for the purpose of producing a camera-ready copy.

- Four participants were recruited by physiotherapists working for Motivating Mobility, two in Sheffield and two in Southampton. A design and deployment process was conducted, involving engagements in their own homes. The author was the sole designer for two of these participants, and an active contributor in relation to the other two participants.

- Working from the archive of material produced through the four individualised design case studies, the author and one other project member produced a paper published at CHI [10].

The following activities then took place in the construction of this thesis, where they were carried out solely by the author:

- Two detailed literature reviews were conducted, the results of which can be seen in chapters 2 and 3.

- A focused analysis of data collected during one of the discursive workshops was conducted, leading to a set of sensitizing concepts presented in Chapter 5.

- Working from the archive of documents collected during the design and deployment process, a detailed description and analysis of the process of tailoring technologies to the needs of individuals stroke survivors was produced, which is presented in Chapter 6.

- Working from the same archive, a description and analysis of the process of deploying prototype technologies in the homes of the same set of participants was produced, and is included in Chapter 7.

- A broader set of reflections were developed, including a set of guidelines and a novel conceptual framework. These are included in Chapter 8.

- A larger reflection on the entire process of research was written, and presented in Chapter 9.

Chapter 5

Documenting the experience of living with a stroke: findings from a participatory workshop

Chapter 3 has argued for the importance of research work that explicitly documents the experience of living with a stroke, and which considers the implications of elements of this experience for the design of rehabilitation technologies. This chapter engages directly with this issue. It presents a set of seven concepts which are intended to sensitize designers to particular aspects of the experience of living with a stroke, alongside a discussion of the implications of these concepts for design. Concepts have been chosen for their relevance to design work, and for their novelty in relation to the existing body of work around technology to support rehabilitation.

These concepts are grounded in data gathered during a workshop organised by members of the Motivating Mobility project team, and which was attended by a number of survivors of stroke who were accompanied by their partners, and who were still living in their own home. The structure of this workshop was carefully designed to support discussion around aspects of personal experiences, with a focus on those aspects of personal experience that are directly relevant to the question of how to design rehabilitation technology. The chapter begins by describing and motivating this structure. It then presents material that was prepared for the workshop by the project team and describes the analytical process that was applied to data recorded during the workshop by the author. It concludes by presenting the seven key concepts that have emerged from this process, and also discusses a set of key

implications for design which relate to them.

Chapter 3 has raised the issue of how to design rehabilitation technologies that are sensitive to the unique nature of the home as a place to be lived in. Much of the analysis presented in this chapter is specifically relevant to this question. The concluding discussion therefore considers this issue in more detail.

5.1   Ethics and recruitment

The workshop featured in this chapter took place at Sheffield Hallam University, early in the autumn of 2008. Preparation for the workshop began with the submission of an ethics proposal to the University of Sussex, as described in Chapter 4, which has considered some of the sensitivities around doing research with survivors of stroke. In the case of this workshop, material provided in the accepted proposal considered the following:

- The process of recruitment, including a process for recruiting partners

- The question of how to ensure that informed consent had been gained, especially given the potential for the presence of cognitive deficits

- Logistical issues such as transport

Recruitment was managed by Anna Wilkinson, a physiotherapist employed by Sheffield Hallam University, but a large group of researchers, including the author, contributed to the design of the process. Initially, we considered approaching the UK National Health Service (NHS), with a view to recruiting participants by contacting movement therapists employed by the NHS, and asking them to pass written material onto their clients. However, through initial discussions with the Yorkshire and Humber Research Ethics Committee [158], we learnt that, at this time, the required NHS ethics process was likely to take six months to complete, which was considered to be too long for a research project of only two years duration. At this stage in the project, our plan was to conduct design and deployment activities after the initial workshop process had been completed, and this plan would have been put at risk by such a lengthy ethics process.

As an alternative, the chosen approach to recruitment then involved extensive engagement with charitable groups, with a particular focus on "stroke clubs". These are social clubs that provide active support for survivors of stroke, and are organised by the Stroke Association [38]. Before joining the Motivating Mobility project, Anna had been working as a professional movement therapist, and had already developed a relationship with individuals who organised a number of stroke clubs. Working as a researcher on the project, she then made contact with these clubs, and attended several meetings, where she gave presentations about the project and described the workshops that would take place. She also distributed written material about these workshops, and collected contact details for attendees who were interested in engaging.

A key element of working ethically with people who have had a stroke is then ensuring that these individuals have sufficient cognitive capacity to provide informed consent for the process that we were asking them to engage with. How to do this is not a simple question to address, and we began by considering methods such as standardised assessments of cognitive abilities which have been developed by the medical community. A list of these, many of which are relevant to individuals who have experienced a brain injury such as a stroke, have been published by the British Association of Occupational Therapists [159], who have considered those methods that are used in practice by their members. However, after much discussion, we decided that this approach was simply too heavyweight, as standardised tests were often lengthy and intrusive. As such, we felt that their usage risked damaging developing relationships with those people who had volunteered, with these relationships being key to the success of any form of participatory research.

In the context of providing treatment for stroke, the assessment of cognitive capacity is a key role of movement therapists, as cognitive capacity clearly is an important mediator in the process of rehabilitation. Discussions with the professional therapists working as researchers on the Motivating Mobility project revealed that, in their own professional practice, they rarely used standardised assessments, and instead assessed capacity by conducting detailed interviews with their clients. As such, our chosen approach to assessing capacity, which was agreed by the ethics board at the University of Sussex, therefore involved a telephone interview with interested participants, conducted by one of the therapists working for the project, through which the

capacity of possible participants was assessed. This interview also provided the opportunity to learn about any factors that might limit the ability of participants to engage in the process, including physical disabilities that we needed to cater for. Essentially, in working in this way, we chose to depend upon the judgement of these researchers, based upon their competence as professional therapists.

This approach does then create the possibility of a conflict of interest, in that research could not be carried out if participation was not secured. This situation was discussed in detail in the project, and our approach to resolving it was to develop an alternative research plan that was more focussed on engagement with professionals, and which would be enacted if no participants could be recruited who had sufficient cognitive capacity to give informed consent. This then removed any conflict around the assessment of cognitive capacity in potential participants, thereby reducing the possibility of unethical conduct on the part of researchers.

Through the process of visiting stroke clubs and interviewing interested participants, three individuals were identified who wished to attend, and who had sufficient cognitive capacity to provide informed consent. Following our agreed ethics procedure, we then asked permission to contact their partners, all three of whom agreed to attend as well. All participants were of pensionable age, and there was therefore the possibility that they were living on a relatively low income. We therefore offered to arrange transport to the workshop venue, in the form of taxis. No compensation was offered in advance of the workshop, to ensure that participants were attending through their own interest, rather than for financial reasons. However, at the conclusion of the workshop, shopping vouchers were offered to a value of £50, as a form of compensation for their time. Written information about the process of research was provided, in advance, by post, and this process was also described in detail during the initial telephone interview. In keeping with common practice in relation to research ethics, we committed to anonymising all data, to withdrawing data on request, and informed participants that publications could be generated from these workshops, and that data may be used beyond the end of the project. Each workshop then began with a session, lead by a project member, which introduced the Motivating Mobility project, and which described the purpose of the workshop, and the data that would be collected during it. After this session, a final check was made

with participants as to their desire to take part, and all confirmed that they wished to.

5.2 Structure of the workshop

High levels of fatigue are a known and expected result of experiencing a stroke, even many years post recovery. As such, we discussed in detail an appropriate length for the workshops, and how to handle difficulties with fatigue if they developed in any of our participants. We agreed a total duration of no more than three hours, with frequent breaks, which was considered appropriate by the movement therapists working for the project. We also ordered workshop activities so that activities were carried out in order of importance, to maximise our chances of obtaining useful data even if participants had to withdraw from the process partway through for reasons of fatigue.

As described above, the workshop itself began with a single session, led by a project member, which described the project and the purposes of running it. Attendees were then split into two groups one containing stroke survivors, and the other containing their partners. A group interview was then carried out with each, led by a member of the Motivating Mobility team, and the proceedings of this interview were captured using an audio-recording device. The focus of these interviews was on eliciting descriptions of the impact of stroke on the lives of our participants. Interviews were conducted by project members who were familiar with the process of designing new technologies, so that they could use their experience to direct the interviews towards topics that could be informative in a technology design context. Participants were split into these groups so that we could explore their perspectives separately - in the hope that this might then elicit a more detailed description of their experience than if interviewed together.

At the conclusion of this interviewing process, participants were then brought back into one group. They were presented with a set of prototypes which illustrated possible designs for novel rehabilitation technologies. Participants were asked to explore these prototypes at their own rate, to imagine themselves using them, and to describe their own responses to them. All responses were recorded on post-it notes for later analysis, either by the participants themselves, or by team members who were observing the process. At the conclusion of the workshop, post-it notes recorded in relation to each proto-

Personas	Design of seven personas to represent archetypical survivors of stroke
Storyboards	Design of storyboards illustrating hypothetical rehabilitation systems for these personas
Selection	Selection of four storyboards for further development
Illustrative material	Production of material used to illustrate these storyboards at the workshop

Figure 5.1: An overview of processes involved in preparation for the workshop.

type were collected by the author, who organised them by the prototype to which they referred. The author also collected all recording devices that had been used during interview sessions, and assembled an archive of the audio files that they contained.

5.3 Prototype design process

The process of preparing prototypes for this series of workshops is summarised in the table presented in Figure 5.1. This process began with the development of a set of seven personas by the author and three other project members. Taking these personas as an inspiration, the author and two other project members then developed a set of seven storyboards which described technologies that we believed could hypothetically provide some ongoing therapeutic potential for the imaginary individuals that they represented. For the workshops, we then selected four of these storyboards, and designed a set of prototypes to be used at the workshop to illustrate these, described later in this section. The presentation of these prototypes at the workshop facilitated an active discussion around stroke and rehabilitation from the perspective of survivors and their partners, and in the context of this thesis, an analysis of these discussions has then contributed knowledge and material which has influenced the sensitising concepts presented in Section 5.6. Direct feedback provided by participants on this material has also influenced the process of design presented in Chapter 6.

The following prototypes were then selected for inclusion in the workshop.

5.3.1 Prototype A - Torches

Prototype A consisted of a piece of working technology - a system which had previously been constructed by researchers at the University of Nottingham, and which allowed for the use of an electric torch as an interaction device [160, 161]. This system has been deployed in a number of museums [162], and allows for the triggering of the replay of a variety of different types of media when a torch beam is shone onto a pre-defined area of a wall. This technology was chosen for use as a prototype during the workshop series as its use requires the co-ordination of a number of physical movements. These included the grasp (and later release) of a torch, and the use of wrist, arm and shoulder to control the direction in which it pointed. The demonstration deployed in the workshops involved a number of photographs of planets in the Solar System which had been attached to a vertical wall. The torches system was configured so that, when the torch was shone onto the planet, a recording of an orchestra playing a movement from The Planets suite was played [1]. A variety of different torches were provided for participants to use, each of which had a different form factor, with variations in weight, size and shape. A representative image of the torches system in use is provided in Figure 5.2. This image was not taken at the workshop, and is instead a stock image which has been provided by the developers of the torches technology. Further information about the content of this figure is provided by Cobb et al [163].

5.3.2 Prototype B - Chess

Prototype B consisted of a short video segment that appeared to show a piece of working technology, but which had actually been constructed through careful editing of mocked-up video footage. This video was produced by the author and one other project member, working from material recorded by the author. It was displayed on a large screen in each of the workshops, where it was played repeatedly at the request of workshop participants. Figure 5.3 presents a series of screenshot taken from the video. These illustrate a large tangible interaction device, with touch sensitive areas that could be

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[1]The Planets is a suite of classical music written by Gustav Holst. It contains seven movements one each for the planets Mars, Venus, Mercury, Jupiter, Saturn, Uranus and Neptune

Figure 5.2: The interactive torches system in use. Sourced from [163].

used to control an electronic chess game. The intention of this prototype was to illustrate a system that required movement of the arm and shoulder for interaction, and which might therefore provide therapeutic value if used over a long period of time. The full version of this video is available from the Motivating Mobility project website [5].

5.3.3 Prototype C - Google Earth

Prototype C also consisted of a mocked-up video of an interaction device and application. Whereas prototype B required movements involving just the arm and shoulder, prototype C required a relatively precise grasp and release of objects, which had to be placed onto particular locations to generate an event used to control an interface. The interface consisted of a cut-down version of Google Earth, which allowed a user to navigate around a three-dimensional space by movement and placement of blocks. A series of screenshots of this video are shown in Figure 5.4. The full version of the video is available from the Motivating Mobility project website [5]. Screenshots in this figure show a single interaction used to zoom into the map of the UK. When a block is first placed onto the pressure pad, the map begins to zoom, and zooming is concluded by removing the block from the pad[2].

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[2]Please note the production error in the video. Text displayed in the video says "The screen zooms in when he lets go of the block". It should have said "The screen zooms in
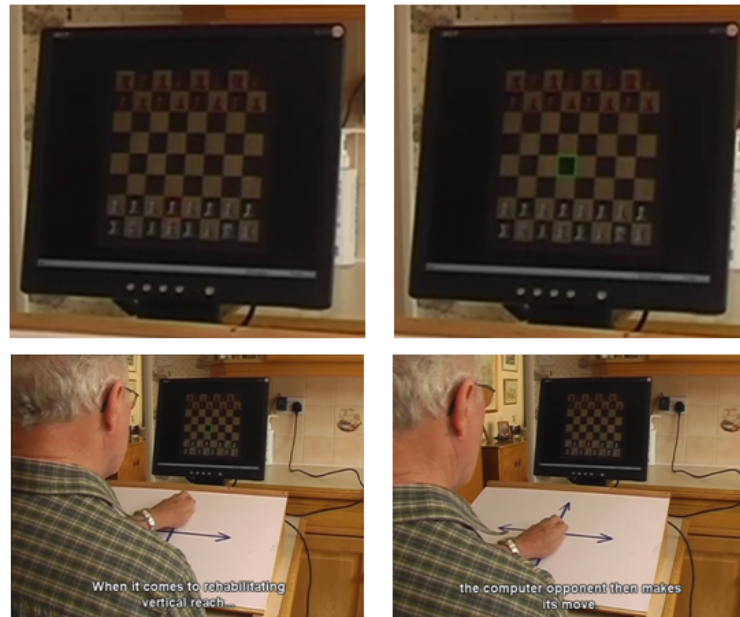
Figure 5.3: Screenshots from "CHESS" video. Left (top and bottom): Initiating interaction. Right (top and bottom): Concluding interaction.

Figure 5.4: Screenshots from "Google Earth" video. Left: Initiating interaction. Right: Concluding interaction.

Figure 5.5: Interactive tapestry design poster.

5.3.4 Prototype D - Tapestry

Unlike the other three prototypes, prototype D was presented directly as a storyboard, which illustrated a piece of interactive tapestry design software which was intended to provide rehabilitative value. This storyboard was integrated into a poster which provided explanatory material, which is included in figure 5.5. Presenting a prototype as a poster provides an interesting opportunity for reflection on the part of participants, in that they can take their time to study and respond to it, unlike a more linear form of media such as video.

5.4 The process of analysis with respesct to workshop data

After the workshop, the author transcribed all audio recordings, and integrated the hand-written contents of the post-it notes into a document. This corpus of material has been included in appendix B. During the course of the Motivating Mobility project, the author conducted an initial analysis which

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until he lets go of the block"

considered this data alongside project data collected through two workshops with stroke professionals, which was used to generate a publication for an international conference on health technology [35]. This publication presented an analysis which was used to highlight the individual software components that might make up an effective tailored rehabilitation system for stroke.

During the course of constructing this thesis, and in light of this earlier publication, the author then returned to the data collected only during the workshop described in this chapter, and conducted a fresh analysis which revealed a level of detail not fully present in the previous broader analysis that considered all three workshops. This process involved five phases, each of which is described below. In the first three of these phases, material collected during each of the three sessions of the workshop identified above was treated separately, so that each could be considered in detail without referencing the others; this then maximised the opportunity for extracting useful information from each. Through the final two phases, a set of seven sensitizing concepts were produced. These integrated across all three sessions of the workshop, and were intended to highlight the most interesting, novel and useful elements of knowledge that had emerged from the analysis process.

Phase 1: Identifying and discarding relevant and irrelevant material

In this first phase, all of the material presented in appendix B was printed out. Key quotes that highlighted potentially interesting elements of experience, or interesting ideas to pursue, were then identified, and were collated by cutting them out of the transcript. This then allowed a certain amount of irrelevant, uninteresting or repetitive material to be discarded.

Phase 2: Identification of key themes for each section of the workshop

Each set of quotes was then grouped into representative themes, which were selected to be as disjoint as possible. The process itself involved physically sticking quotes to pieces of paper, with themes being defined by groups of quotes. During this process, quotes were moved around until a complete coverage of the material had been obtained. Ocassionally, a quote was relevant

to several themes, in which case printed replicas of it were made and stuck to the relevant sheets of paper. Once this process was completed, this physical material was then kept as a reference for later analyses.

Phase 3: Developing written descriptions of themes

To support the exploration of this thematic data, text was then written to describe the material present in each theme, which is then included below. This text then provides an easily comprehensible summary of the interesting content present in each component of the workshop, and is therefore a useful contribution in its own right. Some of the knowledge present in these descriptions is also present in the health technology literature, as presented in Chapter 3, and hence not all of the material presented in these descriptions can be considered novel. However, this initial process did start to reveal some interesting findings that had not been considered in the health technology literature, and therefore confirmed the potential of the analytical work to present a novel research contribution in its own right.

Phase 4: Identifying themes that integrated across the three sections of the workshop

These textual descriptions were then treated as a secondary source of data, and were themselves printed. Cross-overs between the three components of the workshop were identified, and a composite set of interesting themes emerged through this process. The focus in this phase was on the identification of elements which had not been fully considered in the literature. As such, themes were chosen for their potential to influence the design of future systems and for their novelty within HCI research around interactive rehabilitation systems. This then meant that a substantial amount of material was discarded in this phase. This process drew on the broader experience of the author in designing interactive experiences in a research context, and on specific literature material presented earlier in this thesis.

Phase 5: Expressing sensitizing concepts

Through this process, a set of seven particularly interesting themes were identified, which were then chosen as candidates to turn into sensitizing concepts. For this transformation, a sentence was chosen for each, which was intended to be short, representative, memorable and explanatory. A written description of the meaning of this sentence was also produced. Since the analysis presented in Phase 4 had been on secondary material, this then introduced a danger of distorting the meaning of data. To resolve this, illustrative quotes were selected from the material generated in Phase 4, and were incorporated into the descriptive text. This allowed for a verification that concepts were at least grounded in quotes selected from the raw material produced by the workshop.

5.5 Initial thematic analysis

The following three sets of themes were produced through Phases 1, 2 and 3 of the analysis. Each theme in each set is represented through a textual description, which has been developed from a set of quotes grouped using the process identified above. This descriptive material is then an interesting output of the workshop, and an intermediate stage in the process of producing identifying and presenting sensitizing concepts. It has been reproduced verbatim from documents generated by the analytical process.

5.5.1 Descriptive material produced through interviews with stroke survivors

Theme 1: Stroke treatment takes place in a variety of settings

Participants described treatment that took place in a variety of settings. Treatment primarily consisted of physiotherapy, and this was experienced in hospitals, community treatment centres, private physiotherapy clinics and during home visits by therapists. Treatment also included hydrotherapy i.e. physical therapy that was experienced during immersion in water, which was provided through a local stroke club. Experiences of treatment were very different in different settings. One hospital provided a particularly poor

experience - a participant described how she was told just to "sit in that chair, don't move, sit in that chair". Another hospital, with a specialist stroke unit, seemed to be thought of much more highly.

Theme 2: Adjusting to life post-stroke can be difficult

Participants described a variety of difficulties that they were trying to overcome as they recovered from stroke. One participant described being overly optimistic about the rate at which she would recover, which was linked in to more general difficulties caused by not knowing how much recovery to expect. Another participant described repeatedly asking therapists about her prospects, but then becoming very worried when a therapist told her that most recovery took place in the first 12 months (at this point, she was 11 months post-stroke). Several participants talked about it being harder for them to realise how much recovery they had made, in comparison to others who could observe their progress from the outside. One participant, who was involved in multiple programmes of treatment, some of which were experimental, described the confusion that was caused by not knowing what components of this treatment were most effective, and therefore not being able to work out how to improve further once particular phases of treatment had been concluded.

Particular difficulties seemed to be caused by ongoing psychological effects of stroke. One participant described a period lasting four years where she felt locked inside herself, and where she felt like someone else for much of the time. A second participant described a strange feeling of someone constantly being by her side, even when no one was there. More generally, all participants described a sense of frustration about not being able to do activities that were previously accessible to them, including cooking, knitting, opening jars, and even ironing. One participant described feeling completely useless in her own home, as her husband had to perform many tasks. Another described having a stroke as being completely shattering, and also described a strong sense of anger about having to live the rest of her life in that state, especially given the impact that this was having on her husband's quality of life. Another participant described the pressure that she felt to act positively, to keep friends and relatives happy, whilst not feeling positive at all inside.

Theme 3: Loss of control over certain aspects of life

All participants described aspects of their life that had previously been under their control, but which they had lost control of post-stroke. A particularly strong theme was that of the control that they had over the functioning of their body. Several participants described how their levels of energy varied dramatically, in an unpredictable way. Participants also described body parts that would work one day, and then pack up the next, only to start working again unexpectedly, or with therapeutic intervention. Because of this, one participant described always carrying a walking-stick with her not because she needed it most of the time, but because the times when she needed it were not predictable. The same participant feared leaving the house without her husband for the same reasons, but missed the independence that she used to have.

Beyond bodily aspects of control, other aspects of life were also described as being out of control by participants. One participant described how she was unable to dress or wash herself without help, which was provided by her husband. A second participant described not being allowed out of hospital until a care package had been organised, even though she may have wanted to return home earlier. Aspects of the physiotherapy process were also outside of the control of participants. One described a therapy programme being discontinued by a therapist who felt that she had made sufficient recovery, whilst another talked about the limited duration of therapeutic programmes that she had experienced. Finally, participants described aspects of physiotherapy which had been out of their control, and which they had felt uncomfortable with. One described a therapist who had told her not to move her arm at all, which then led to ongoing problems with neglect of that arm that had so far taken two years to correct. Similarly, another described how all the effort of a particular treatment programme had focused on mobility in her legs, which meant that, once discharged, she had not regained sufficient ability in her upper limb to engage in hobbies that she wanted to do.

Theme 4: Support and motivation for life

For all participants, elements of their social situation provided support post-stroke. One participant described how she had been allocated a carer who came three times a day, four days a week. Another described a carer who

took her to hydrotherapy sessions at a local stroke club. Another participant had a very supportive GP. Stroke clubs seemed to be a good source of support one participant described a discussion group that allowed her to talk about her experiences, and to pick up tips from other survivors of stroke. All participants emphasised the support that their partners provided - ranging from household tasks, such as cooking and cleaning, to the provision of motivation to engage in exercise. Some participants were keen on making contributions that supported others. One participant described raising money for a local stroke charity by trying to knit items that could be sold. Another participant described taking part in experimental stroke treatments, although it is not clear whether her motivation was to seek improvement, or to assist the development of knowledge in respect to treatment programmes for stroke.

5.5.2 Descriptive material produced through interviews with partners of stroke survivors

Theme 1: Changes to domestic life of the participant caused by the stroke

All participants described major changes to the role that they took in the relationship that were caused by the after-effects of stroke. Two participants had previously only done cleaning work at home - they described the difficulties of learning new skills, such as cooking, or planning new domestic routines. All participants described having almost no personal time, as they were looking after their partner continuously. One participant described difficulties that he was experiencing with long-term injuries that made the provision of such care difficult. Another participant talked about how changes to domestic life had caused him to become "withdrawn" - because the world that his wife and he had had together had been disrupted. A number of participants described a motivational role that they performed in relation to rehabilitative exercise, and some participants had developed a certain level of therapeutic skill, including learning massage skills to help relieve some physical difficulties caused by stroke. A number of participants also described missing the nice food that their partners used to make for them and, when asked, believed that their partners would want to regain the ability to carry out domestic functions.

Theme 2: Changes to the home caused by the stroke

All participants described how their partner's stroke had changed the way that their home was used. One participant indicated that his partner could no longer use the stairs. She was, however, unwilling to have a bed installed in a downstairs room (due to bad memories of her mother doing the same), and they had therefore had to move home, to a flat. Another participant described an alarm system that he had installed in the home, that allowed his partner to call him if she was in trouble, along with hand-rails that he had also installed. The third participant described how, before discharge from hospital, they had had to install a bed in their dining room, which was then moved once a stairlift had been fitted.

Theme 3: The immediate impact of stroke

For the partners, stroke seems to have been a very scary occurrence, which was followed by a long period of serious disruption to their life. One participant described having to live in a caravan for 6 weeks, as his wife had had a stroke whilst they were on holiday. Another found his wife collapsed on the bedroom floor, which was followed by a 3-month period in hospital. For the third participant, his wife was in hospital for several months, and wasn't allowed out until major changes had been made to their home.

Theme 4: The impact of social care

All participants described paying for additional social care support for their partner. One participant described a good carer, whose attendance allowed him time off to go to the gym. Other participants described difficult experiences with social carers that they had paid for. Some carers seem to have turned up at inappropriate times (for example, turning up at 7 to put someone to bed). Others failed to fulfill all of the tasks that they had been paid for, turned up for much less time than they had been paid for, or failed to respect the house that they were visiting (for example, by treading mud into clean carpets).

5.5.3 Descriptive material produced through an analysis of participant responses to prototyping materials

Theme 1: Feedback on content

Demonstration of the prototype systems generated a number of suggestions for content that had the potential to be motivating. Participants suggested the use of electronic versions of traditional games - these included patience, snakes and ladders, solitaire, scrabble, drafts, monopoly, ludo and a variety of card games. In the context of the torches prototype, one participant suggested that the torch could be used to reveal photographs which were randomly selected from a previously-constructed album. One participant suggested that an interface to online-shopping facilities could provide motivation for use, but there was some debate about this - other participants pointed out that the need to shop provided a motivation to leave the house, which was seen as valuable. Competition seemed to be an important theme, and one participant suggested turning the torches prototype into a game, which might require the spot of light generated by the torch to be lifted higher each day. One participant liked the use of music in the torches demonstration. Another participant suggested that a motivational system might need to provide a variety of types of content, to help avoid the potential for boredom created by just one.

Theme 2: Impact of stroke on use of systems

A number of participants raised issues around the patterns of disability that had been caused by their stroke, and their future use of systems such as these. One participant talked about the variability in physical ability that they experienced from day to day, whilst another participant suggested that just a few repetitions of use would cause muscles in her arm to tighten up. A number of participants talked about fatigue setting in as the day progressed; this implies that use of some systems might become impossible after a certain time. In relation to the Chess prototype, one prototype suggested that even flattening her hand sufficiently to apply pressure to a surface would be a challenge. Another participant suggested that the torches system might work well when used in combination with constraint therapy, an approach to

rehabilitation which involves the use of constraints to temporary immobilise non-hemiplegic limbs.

Theme 3: Issues around performing exercise correctly

A number of participants talked about the issue of needing to perform exercises correctly to generate rehabilitational benefits. One participant suggested that future systems could incorporate an animated mannequin which demonstrated correct movements, and a second participant then suggested that this mannequin might only respond if movements were performed correctly. In relation to the interface provided to the Chess game, a participant suggested that a variation in the angle of the interface device could change the difficulty of using it. In relation to the torch prototype, participants noted that it would be particularly easy to gain a positive result without performing rehabilitative exercise. This was because there were so many different ways to change the position of the spot of light generated by the torch (such as twisting a wrist rather than lifting an arm).

Theme 4: Suggestions for physical interface design

A number of participants raised issues around poor eye-sight and distaste for computers - suggestions for the chess prototype involved replacing the computer monitor with a physical chess-board, with embedded actuators to move pieces. One participant suggested that a torch could be replaced with a television remote control, to make its manipulation more realistic. Another participant suggested that the Google Earth system just required too many individual interactions to be usable during rehabilitative exercise.

Theme 5: Relationship to the social context

Participants also discussed their social context, and its relevance to system use. One participant indicated that she would be more likely to use a system if her therapist suggested the amount that she should use it. Another participant suggested that, if the content was really motivational, then she might be tempted to use her non-hemiplegic upper limb to interact with it, to speed up the results that she got. One partner suggested that, in this situation, he could enforce the use of the hemiplegic limb. However, a motivation for

Concept 5.1	Stroke can lead to significant changes in established patterns of domestic life
Concept 5.2	Survivors of stroke may experience psychological difficulties that have the potential to affect their rehabilitation
Concept 5.3	The physical abilities of stroke survivors can change very dynamically
Concept 5.4	Aspects of hospital life can be detrimental to rehabilitation
Concept 5.5	Partners can be involved in rehabilitation efforts
Concept 5.6	Community organisations can play a significant role in rehabilitation
Concept 5.7	Stroke can cause a significant level of existential stress, even years after it occurs

Figure 5.6: A summary of the seven sensitizing concepts identified through analytical work.

some participants to use such systems seemed to be a desire to give their partners a break from caring for them - one participant suggested the design of a system that she could use on her own, so that her partner did not have to be there.

5.6 A set of seven sensitizing concepts

The following seven sensitizing concepts have then been developed through Phases 4 and 5 of the analysis described above. These concepts are summarised in the table presented in Figure 5.6. They are also accompanied by a short discussion orientated around traditional games.

Concept 5.1: Stroke can lead to significant changes in established patterns of domestic life

One topic that was discussed during the workshop was that of domestic roles and relationship. All three couples that attended this workshop were

in their seventies or eighties, and it seems that, for all three, stroke had caused a dramatic shift in the roles that each member played in the home, which had been uncomfortable for some. One participant described feeling "absolutely useless", and how she just wanted "to be able to iron" to help out her husband, who had taken on most of the responsibilities of running a household after her stroke. Another participant, whose partner had suffered a stroke, described how hard it had been to learn how to take on these roles:

> "I did nothing at home ... swept up did that type of thing ... my wife was a full time housewife. I used to come home from work and my tea were ready and that kind of thing ... when the wife got out of hospital got home, I didn't know how to turn the oven on that is a fact ... I didn't know there was an electric switch in the bottom of the cupboard to turn it on. I had to ring her sister up ... and then you had to get into the routine of when you do the washing "

In addition to changes in domestic roles, however, participants also described key changes in their relationship with their partner. One participant described how, during the course of their marriage, and especially since their children had left home, he and his partner had developed "their own little world", which had then been lost because of her stroke. Another described how:

> "you get close together. That's the only person you got, even if you got friends etc. ... It's the home life it affects ..."

Finally, all participants talked about changes to physical aspects of the home that were related to stroke. In some cases, this involved relatively minor changes, such as fitting hand-rails. Slightly more major changes included fitting stair-lifts, or having a hospital bed installed in the living room. One participant, when talking about the views of his partner, described the emotional discomfort of this change:

> "[anon] was dead against that ... because her mother had a bed downstairs, and once she got in it, she didn't get out"

For one couple, living in a house with two floors became impossible after one of them had a stroke, and hence they had been forced to sell the house and move; the unaffected partner then described how this change had

"affected me a lot actually, I became very withdrawn ..."

Concept 5.2: Survivors of stroke may experience psychological difficulties that have the potential to affect their rehabilitation

Stroke clearly has the potential to be a traumatic event; one participant described some very profound psychological effects that had made it particularly hard to adjust to what had happened to her:

"Yes I think so yes, but the thing is when I first had my stroke, I had this feeling that I was locked inside myself, I was some else and not me I kept on saying to my husband, 'I can't believe this has happened to me'. I was saying that up to four years"

"I thought I was different from others because I used to think that I couldn't see out, I felt like, have you seen that advert for glasses at spec-savers, there's a sausage and he has glasses on, that's how I felt for ages, its gone now but that's how I felt. I was inside something and something was tied up here."

"I always feel as if somebody is at my side, yes you know, I'll be sat in a chair at home and I'll be oh there was someone who sat there"

"I think that holds you back, I just feel that there's always somebody hanging onto my hand"

These observations might be related to a recent research study [164] which suggests that survivors of stroke have a high risk of Post-Traumatic Stress Disorder.

In a second example of psychological disturbance, another participant described how:

"you're grieving for what you've lost and everything. So it takes
a little while to get over that ..."

Finally, one participant described potentially irrational fears around making
a recovery that were related to a misunderstanding of the recovery process:

"Yeah it worried me in a way that um she didn't do it, uh I was
asking the question but I was saying to Maggie, you remember
Maggie the senior one she kept on saying to her you know, they
are always asking people how are you going to do because you
want to do your best and she says well the best recovery and the
most recovery is in the 12 months. And because your brains all
mixed up your thinking, 'I'm no better and 12 months is in 2
weeks' That's another sort of fear that because you cant get on
at first your not going to."

Concept 5.3: The physical abilities of stroke survivors can change very dynamically

All participants who had experienced a stroke described how unpredictable
the physical aspects of their condition can be. One participant described this
in detail:

"I feel that this is a vicious circle. I found my legs getting better
and then my arm packs up, and so I do some exercises on the
arm, and it feels better ..."

Other participants talked about having unpredictable levels of movement in
their hands and legs, and how even small amounts of exercise can lead to
difficulties:

"well I roll a ball round with it you know and try and squeeze a
small ball and let go because my fingers sometimes tighten up so
much that I can't let go of things"

Participants did report some predictability in their physical abilities, such as
being particularly stiff in the mornings, or being on a 'downwards slide' after
6pm.

Participants also reported significant benefits from physiotherapy:

> "... they [i.e a part of her body] are lovely when she's been working on them, they feel very easy when you've had your physio."

Concept 5.4: Aspects of hospital life can be detrimental to rehabilitation

Some participants reported receiving insufficient or inappropriate rehabilitation support in hospital. One participant only received physiotherapy from Monday to Thursday, and suggested that "three sessions a week is a waste of time!". Another described how access to physiotherapy depended upon "sickness and holidays", and that sometimes she would be overwhelmed by three physiotherapists arriving at the same time. One partner described how hospital phsyiotherapists had "concentrated on getting her up" and a survivor of stroke talked about a focus on "getting your leg to onto your feet" (i.e. getting you to the stage where you can walk again). One couple described ongoing problems that they attributed to errors made by physiotherapists in hospital:

> "they've realised since that they should have been working on the arm as well as the leg at the same time"

> "they didn't work on the leg and the arm at the same time"

Concept 5.5: Partners can be involved in rehabilitation efforts

There was evidence from the interviews that the partners had got directly involved in the rehabilitation process, and had provided effective support:

> "we do exercises, about 100 exercises in the morning, but ... also massage, her neck, her arms, her shoulders, her face ... "

> "[my partner] takes me to Bakewell swimming pool and every Thursday afternoon"

"well really I don't know its just [my partner] pushing me on, we have to have a walk every day. And I think that's it you know [in response to a question about what motivates her to exercise]"

Concept 5.6: Community organisations can play a significant role in rehabilitation

All participants talked about community organisations and the support that they provided. One participant discussed a community group where

"we used to sit around a table, the six of us, and we used to talk about ... you know, what we were experiencing"

Another participant talked about a group called "Different Strokes" who provided access to a hydrotherapy pool, whilst a thrid talked about a disabled session run by a local swimming pool, and which provided hoists and life jackets.

Concept 5.7: Stroke can cause a significant level of existential stress, even years after it occurs

One concept that emerges very clearly through reading all the concepts presented above is that, because of a stroke, all three couples were continuing to live at a level of stress that they would not have encountered otherwise. In addition to points presented above, participants also reported significant problems in relation to paid carers provided through the social care system:

"the carers would come in twice a day, it was like that for a year, then we had to get rid of the social workers because they weren't playing ball, they were turning up when they felt like it ..."

"they'd come at 10am in the morning to get her out of bed, too late ... different people, you didn't know who was coming the next day"

The pressure of having to care for their partners also had the potential to create stress for those doing the caring, especially if they had health problems in their own right:

"you've no free time, the only free time I have now is three mornings a week where the carer comes to get her out of bed"

"but my biceps are causing me problems now, with dragging carpets for many years, they're gone, and they're ... a year last January, I did collapse with this problem, and really jarred it, and I had to have treatment for that, and I'm getting old, parts are wearing out"

Other ideas emerging from workshop material

A particularly prevalent response to the technology prototypes presented at the workshop was a discussion of interest in traditional games. Participants discussed a variety of examples, including patience, solitaire, chess, scrabble, checkers, monopoly and dominoes. Several participants indicated that they were no longer able to play these games post-stroke, and that they missed the entertainment provided by these activities.

5.7 Technological implications of sensitizing concepts

Chapter 3 has provided a detailed review of research into rehabilitation systems for stroke, and a critique provided at the end of this chapter has highlighted a lack of research which explicitly considers the perspective of survivors of stroke and others in their immediate social context. Concepts presented in the current chapter are grounded in an analysis of material collected during a workshop with three survivors of stroke and their partners, and the presentation of these concepts therefore represent a contribution which begins to address this deficit. This chapter now continues with a brief discussion of the relevance of these concepts to research into the design of rehabilitation systems for stroke, which highlights three key themes that together span all of the concepts.

5.7.1 Locations to consider when designing rehabilitation systems - implications of concepts 5.4 and 5.6

A review of the literature presented in Chapter 2 has considered the different types of location in which rehabilitation takes place, which includes hospitals, homes and care-homes. Many of the existing technologies presented in Chapter 3 have been intended for use in hospitals, and others have been intended for use in the home. Very different considerations for design are often relevant in different types of location, and systems intended for one type of location are unlikely to be suitable for use in another type of location. In a hospital, for example, a bespoke system with a high unit cost may be appropriate, as such a system may be used by a significant number of patients, and because such an installation can be supported by professional with relevant knowledge. In a home, in contrast, it may be necessary to focus on systems with a low unit cost as each instance of a system will only be used by one person.

In relation to this, an implication of Concept 5.6, which highlights the support for rehabilitation provided by community organisations, is that such organisations may be an appropriate target for rehabilitation technologies. Because community organisations are very different to hospitals or homes, then the design of such technologies may be very different to the design of technologies intended for hospitals or the home. Whilst reviewing existing technologies to support rehabilitation for Chapter 3, the author found no evidence that researchers had targeted community groups when designing technologies. As such, future work that targets such organisations has the potential to make a novel contribution to research in this space.

An implication of Concept 4, which describes how particular aspects of hospital life can be detrimental to rehabilitation, is that hospitals are not an undifferentiated environment in relation to rehabilitation. One participant described only having three therapy sessions per week whilst in hospital, which she considered a waste of time in terms of recovery. When not taking part in rehabilitation, this participant must have spent a considerable amount of time elsewhere in hospital, and visits by the author to UK hospitals have suggested that many survivors of stroke spend a significant proportion of their time in hospital wards, which tend to consist of large groups of

beds positioned in a communal space. Systems whose design targets hospital wards may have the potential to support rehabilitation. However, the author has found no evidence for systems that are intended for such locations.

5.7.2 Recommendations for the design of systems targetted at the home - implications of Concepts 5.3 and 5.5

Of the systems presented in Chapter 3 which are intended for use in the home, none provide for a significant role for partners, friends or family members, all of whom may already have a significant role in the home environment. However, Concept 5.5 highlights the significant role that a number of partners are already playing in providing support for rehabilitation, either by supporting motivation to exercise, by getting involved in exercise directly, or by providing support that allows exercise to take place (such as driving stroke survivors to places that offer support for rehabilitation). In relation to systems that support rehabilitation, a novel implication of this concept is therefore that design could potentially consider a role for a partners, or others in the social context, and this is an observation which requires further exploration to unpack. In relation to this observation, participatory design work presented in Chapter 6 included contributions from both stroke survivors and their partners, and analysis of this design work, presented in Chapters 6 and 8, partly discusses potential roles for partners and others in more detail.

In addition, Concept 5.3 highlights the extreme variations in physical ability that can result from stroke, and which relate to the fact that the primary cause of physical disability acquired through stroke is a brain injury, not a muscle or joint injury. To stay motivated, it seems likely that the user of a rehabilitation system should regularly experience success when using the system, and the design of systems must somehow take into account the extreme variability in ability that survivors of stroke experience. Some systems presented in Chapter 3 do describe an ability to adapt to the current abilities of the user. However, as described, the scope of these adaptations does not seem sufficiently broad to cope with the extremes of variation described by our participants. How to build a system that does not demotivate users by setting challenges that are difficult is therefore an open research question, and

one which is particularly relevant for systems intended for the home. This is because systems deployed in hospitals are often designed around the availability of professional support, and with the assumption that a professional will set a level for a particular exercise session (for example, the robotic arm described by Dijkers et al [19]). In contrast, in the home, such professional support is less likely to be available, although this may be a situation where partners, or survivors themselves, may be able to develop sufficient expertise to regulate the level of exercise provided.

5.7.3 Barriers to the use of rehabilitation systems - implications of concepts 5.1, 5.2 and 5.7

Concepts 5.1,5.2 and 5.7 all highlight potential barriers to the effectiveness of rehabilitation systems, especially those intended for use in the home, that have not been considered in sufficient detail in the literature. Concept 5.1 highlights significant changes to the domestic environment that can be caused by stroke-acquired disability, and implies that the environment in which a stroke survivor is living may be used very differently to a similar environment pre-stroke. This then suggests that careful attention is paid to current use of the domestic environment during the process of design, especially in relation to prior patterns of use, and this is a topic which is returned to in Chapters 6 and 8. Concept 5.2 highlights the potential for psychological disturbance that may be cause by stroke; use of a rehabilitation system may then be a significant challenge for survivors who are experiencing symptoms of conditions such as post-traumatic stress disorder, or any of the anxiety disorders. Related observations are provided through Concept 5.7, which highlights the extreme levels of stress which may be inherent in the lives of survivors of stroke and others that live with them, even many years after the stroke. Together, these concepts highlight significant practical barriers which may need careful design to overcome. In particular, they suggest that systems which introduce additional stress into the lives of survivors are unlikely to be effective. In contrast, systems which somehow reduce levels of stress may be much more effective. Chapter 6 describes a participatory design process which has led to a number of systems that have proven effective for survivors of stroke, and Chapter 8 provides a discussion of these systems in the context of the barriers highlighted in Concepts 5.1, 5.2 and 5.7. In contrast, many of the home-based systems considered in the technology review presented in

Chapter 3 seem to have the potential to cause additional stress; examples include systems that require sensors to be accurately attached to limbs on a regular basis, or systems which require the effective functioning of a home network (and which may therefore create additional work around keeping such a network functional).

5.8   Summary and next steps

This chapter has presented a set of sensitizing concepts grounded in discussions with stroke survivors and their partners and has related these concepts to challenges in the design of interactive systems to support rehabilitation. Chapter 6 now presents a set of four case studies of participatory design processes with survivors of stroke and their partners, which together provide additional material that can be related to some of these concepts. Chapter 8 then draws on knowledge presented in all proceeding chapters, including Chapter 6, to present a set of frameworks and guidelines intended to support future design and evaluation work.

Chapter 6

Tailoring rehabilitational technologies to the needs of stroke survivors: outcomes of four design case studies

This chapter presents four descriptive case studies of engagement with individuals who have survived a stroke. Each of these case studies describes the process of tailoring technologies so that they were suited to the rehabilitational needs of the individual, with technologies being intended for usage in their own home. Each involved the direct participation of the individuals and members of their family in the process of design, and each lead to the production of a working prototype. The chapter concludes with a broader discussion of the process of tailoring technologies. The subsequent deployment and evaluation of these prototypes is then described in the following chapter.

Engagement with participants took place in their own home, through either three or four design sessions lead by a project member. Conducting design sessions in the home, so that designers can make observations and inferences about its usage, and involving potential users of technologies in the process itself, so that designers can discuss their needs and motivations with them, then creates the right conditions to develop technologies that are sensitive to the needs of the homes and those who live in them.

Research through Design, introduced in Chapter 4, emphasises a contribution

to knowledge that originates from the design process itself, and which is intended to support the process of design in the future. In this context, the four case studies presented in this chapter should be seen as a record of a process, and therefore as a useful source of data for analysis. The key challenge present in writing this chapter has then been to present these processes in a manner that is accurate and amenable to further analysis. Further details on how this challenge has been addressed are provided below.

As described in Chapter 4, these case studies were carried out during the Motivating Mobility project. In seeking to produce four tailored pieces of technology in a limited time-scale, our orientation as a project was to making use of existing technology wherever possible, thereby minimizing the technical development that was required. This approach is in keeping with an exploration of the concept of tailoring. Even given this approach, the design and production of these systems was a time-intensive process, and, as such, is unlikely to be suitable for the production of tailored systems for the broader population of stroke survivors. However, a justification for approach presented in this chapter is that Research through Design emphasises temporarily setting aside constraints such as financial or temporal pressures in order to develop knowledge that can support more constrained and realistic design work in the future [33]. Drawing on material presented in this and other chapters, Chapter 8 then presents a discussion of how to simplify the process of tailoring so that it is more accessible on a larger scale.

This chapter begins by summarising details of how participants were recruited and how ethical issues were accounted for, with the latter being particularly important in an inquiry that depended upon access to the homes of stroke survivors. Sections 6.3.1, 6.3.2, 6.3.3 and 6.3.4 then present the four case studies in detail. In working with each participant, either three or four design meetings were conducted, and the case-studies below are structured around this schedule of meetings. Each case-study concludes with a description of the final design that was adopted for each participant. Chapter 7 then discusses the deployment of prototype implementations of these designs.

It should be noted at this stage that, although work presented in this chapter took place after the workshopping process described in Chapter 5, it did not take place after the analysis process presented in that chapter. It was therefore not informed by the sensitizing concepts that were identified during this process.

6.1 Ethics and recruitment

The process of design that is described in this chapter, and the process of deployment that is described in Chapter 7, took place across two centres of effort - one of which involved two participants who lived close to the city of Sheffield, and the other of which involved two participants who lived close to the city of Southampton. Of these, the author carried lead design work for participants in Sheffield, and contributed to design work for Southampton participants. The two Sheffield participants were selected from the group of three stroke survivors who attended the workshop described in chapter 5. The two Southampton participants were recruited through private physiotherapy clinics in the Southampton area.

A set of selection criteria for participants were determined in advance of the recruitment process, and were agreed as part of an accepted ethics application considered in previous chapters. These criteria are summarised in the table presented in Figure 6.1. The selection of these criteria was influenced by the need to ensure that the planned style of intervention was appropriate for each participant, and by the need to ensure the ethical conduct of research. The process of selecting effective criteria was lead by professional physiotherapists who were working for the project, but other researchers, including the author, were involved in the discussion.

The recruitment process itself was managed by two of the physiotherapists who were working for the project, who used a profiling tool which had been designed for the project to identify suitable participants and to collect information about their physical and mental state. In the previous chapter, the argument was made that this kind of systematic method was too heavyweight for use with participants, and risked damage to a developing relationship between researchers and participants. However, by this point in the project, how to design an appropriate profiling tool that was more lightweight, but which was still effective, had become a question for research for the physiotherapists involved in the project, and the recruitment process then became an opportunity to pilot a new tool. At the time of submission, the design of this tool had not been published, and hence a reference cannot be provided.

As in the workshop presented in Chapter 5, recruited participants were informed that they could withdraw at any time, that they could request the withdrawal of any collected data, that all data would be anonymised and

Condition 1	Participants must have been diagnosed as experiencing at least one stroke which was more than one year in the past.
Condition 2	Participants must have at least one hemiplegic upper limb, where this hemiplegia was believed to have been caused by stroke.
Condition 3	Participants must have sufficient residual physical ability in that limb that partial rehabilitation through physical exercise was a possibility.
Condition 4	Participants must be sufficiently cognitively able to give informed consent for the design and deployment process.
Condition 5	Participants must live in their own home, rather than in any form of sheltered housing.
Condition 6	Participants must have access to a phone, in case of emergency.
Condition 7	Participants must not have a life-threatening co-morbidity.
Condition 8	Participants must be sufficiently interested in the project and its outcomes that they were likely to want to engage throughout the lengthy process that it is expected to involve.

Figure 6.1: Inclusion criteria for study participants.

that data would be used for the purposes of publication.

Given that the process of design required access to their homes, this then introduced an additional sensitivity to the process. As a project, we wanted to ensure that our participants had a channel through which they could report any difficulties or emotional discomfort caused by the process, as a means of protecting them from any risk of unethical conduct on the part of the researchers. To allow for this, all participants were provided with contact details of an independent researcher, who had been allocated by the ethics board at the University of Sussex. The need for an additional channel of communication in case of difficulties then provides a rationale for only recruiting participants who had a telephone (see inclusion criteria 6 in Figure 6.1).

In case participants developed any questions about the disabilities that they had acquired through stroke, each participant was allocated to one of the physiotherapist who were working for the project, were provided with contact details for this individual, and were told that they could ring them at any point in the process. In practice, the allocated physiotherapists attended almost all design sessions, and acted to provide designers with professional advice on necessary choices around the design of technologies that could provide a rehabilitational benefit.

6.2 Preparation of case studies for inclusion in the thesis

Through the process of design, project members were careful to document their choices, and all design documents were collected and archived by the author, thereby allowing for an effective and accurate descriptions of the process to be written. In preparing for the construction of this chapter, individual documents were collected into one very large document for each case study. These were then abridged for inclusion in this thesis, with the process of abridgement focusing on discarding repeated information and documentation of internal project discussions, and retaining documentation of:

- interactions between project members and participants

- observations made by project members in the homes of participants

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As such, abridged documents deliberately retain information about the homes and needs of survivors of stroke, and therefore retain the potential to be useful in analytical work that considers the process of tailoring. The process of abridging these longer documents for the purposes of this chapter has reduced the volume of recorded material from approximately 10,000 words per case study to approximately 2,500 words per case study. Due to the PhD regulations of the University of Nottingham, which limits total thesis length to 100,000 words, including appendices, then it has not been possible to include the unabridged documents as appendices in this document, but the abridged versions represent an accurate and transparent record of the process itself. In presenting abridged documents in this chapter, additional commentary has been added to support an understanding of the chosen approaches, tactics and orientations adopted in the process of design.

In presenting design work, it would be a common practice in the context of HCI publications to include photographic evidence, which can support a reader in understanding the context of design. It is then a generally accepted principle of ethical research that photographs should only be taken of participants who consent to this. In the case of work described in this chapter, only one of our participants consented to photographs being taken that included himself and his home, and all other participants expressed a strong desire not to be photographed at any stage of this process, with these decisions appearing to be a consequence of the psychological effects of experiencing a stroke. For the participant who consented, photographs taken in his home are included to illustrate particularly elements of the process. For the other three participants, textual descriptions are the only available mechanism for describing the context, and included photographic material has been taken in the studio.

6.3 Four case studies of tailored technology design

The following four sections now present the case study material itself, as described above. For the purposes of this section, participants have been given fictional names. "Irene" and "Joan" were the two participants at Sheffield, whilst "Sophie" and "Solomon" were the participants in Southampton. Engagement began with Irene and and Joan. Engagement with Sophie and Solomon started several months later. This was because participants based in Southampton needed to be specifically recruited for this phase of the project. In contrast, participants in Sheffield were selected from the larger group of participants who attended the workshop described in Chapter 5, therefore allowing design work to begin more quickly.

6.3.1 Irene - the Rehab Reader

Three design sessions were carried out with Irene and her husband, referred to in this text as Eddie, who were both living in a small, ground-floor flat near Sheffield. Both were in their seventies. Before the process of design began, an assessment was carried out by one of the project physiotherapists, to collect a range of relevant information, which was provided to the author as a written report. This revealed that Irene was right-hand dominant, and had experienced a stroke which caused physical difficulties with the whole of the left-hand side of her body, affecting her ability to walk, to manipulate her upper limb, and to see through her left eye. She was receiving regular physiotherapy through a private clinic, and was making good progress. Early therapy was aimed at improving her posture, with the aim of helping her to walk. More recently, therapy began to focus on regaining movement in her left hand, arm and shoulder, and this was showing some success. Irene had previously experimented with using a Nintendo Wii, owned by Eddie, but had found it difficult. She also reported experiencing some difficulties with anxiety, and tended to get upset easily. During the workshop presented in Chapter 5, Irene had reported bad experiences with previous researchers, in that, after several meetings, they had never been contacted again. Design sessions with Irene were attended by the author and by the physiotherapist who had conducted her assessment.

Design session one

Given Irene's reported difficulties with anxiety, and given her prior bad experiences with researchers, a deliberate choice was made to take a very cautious approach during the first design session. A specific choice was made not to take prototypes, or to ask Irene to engage in design exercises, in case this was too overwhelming at a first meeting. Instead, the focus of the first session was to make observations about the usage of Irene's home, and to try and understand her own needs and motivations in relation to recovery. A chosen tactic was then to ask her directly about the nature of her personal motivations; this then allowed her the opportunity to express these in her own words, potentially providing a sufficiently rich understanding to guide the process of design. In designing the set of prototypes presented during the earlier workshop described in Chapter 5, we had imagined some technologies that enabled users to engage with hobbies that might interest them, using these as a motivation for engaging in physical exercise. Building on this idea, a choice was made to ask Irene about hobbies that had been affected by her stroke, and which she would like to return to.

Motivational issues were then discussed early in the first design session, and when asked about her personal motivations, Irene immediately stated that her motivation was to "get back to normal". She also stated that she would like to regain an ability to crochet, which would then require an increase in her ability to grasp and release objects with her left hand. She also seemed interested in jigsaw puzzles and crosswords, which has been a hobby before her stroke, but was experiencing some cognitive difficulties with word recollection which appeared to disrupt her abilities to engage in these. As part of this discussion, Irene clearly told us that she disliked computers intensely, and that she had experienced headaches whilst using a Nintendo Wii, which appeared to be related to the stress of using this device. Interestingly, she showed us a hand-held electronic crossword puzzle, which she seemed happy to use. Further discussion revealed that she did not think of this as a computer, and hence had no difficulties in using it. From this point on, we were then very careful about our usage of the term "computer", both to avoid creating any negative associations with technology that we might design and deploy, and also to avoid disrupting her own understanding of the many computational devices that could already be found in her own home.

As well as considering her personal motivations for recovery, this design ses-

sion also provided the opportunity to make observations about the physical environment in which the couple lived, and to discuss these observations with them. During this discussion, Irene stated that she only used two rooms in the house - the lounge and the bedroom. For her, the kitchen felt out of bounds. This seemed to be a psychological consequence of her stroke, rather than being caused by her physical disability. It provides a very real illustration of the significant impact that a stroke can have on existing patterns of domestic life, as identified in concept 5.1, as described in Chapter 5.

Within the lounge, Irene seemed to use only one chair. The environment around this seemed to have been constructed to provide stimuli; it was situated near a window with a pleasant view over a shared garden, and several metres in front of it was a media unit, containing a large, modern, flat-screen television, a digital video recorder and an electronic picture frame. This frame seemed to be an important feature for Irene; it looped through pictures of her children and grandchildren and often provided a distraction whilst we were talking to her, although when asked about it she complained that pictures sometimes moved on too quickly for her. Other than the media unit, there were few other flat surfaces in the lounger, other than a small table, containing an assortment of objects.

Design session one then concluded with a brief discussion of how the remainder of the process might be structured, during which we introduced the idea of bringing a prototype for her to consider. After the design meeting, observations were discussed with other project members, and given her stated motivations in terms of regaining an ability to crochet, a decision was made to target grasp-and-release exercises, potentially using a squeeze switch to

Figure 6.2: Irene - UMPC and pressure switch.

sense these. A promising idea seemed to be to work with the digital photo
frame, and to develop a version that allowed her to control the change of
photos by squeezing a switch. We decided to develop a prototype that had
a similar form factor, but which allowed for control over the display of pho-
tographs. For this prototype, the author suggested the use of a Ubiquio 701,
which is a 7-inch tablet PC, and a commodity squeeze switch, sourced from
an assistive technology company.

The author and another project member then developed a simple software
application for this platform, which allowed Irene to progress linearly through
a series of pre-loaded images. This was assembled from readily-available tech-
nology, requiring only a very small amount of work on software to provide a
bridge between these. Work presented in this chapter took place before the
wide availability of eReader devices, which would have made such a proto-
type even simpler to construct. In re-purposing a squeeze switch intended to
provide access to technology with physical disabilities, this prototype then
provides an initial example of transforming assistive technology into rehabil-
itation technology.

The prototype itself is shown in figure 6.2, and was taken to the next design
meeting for further discussion. It should be noted that, at this point, an or-
dered squeeze switch had not arrived, and instead, a temporary substitution
was made for a pressure pad, which had a similar mode of operation.

Design session two

At the start of the second design session, the prototype photo-frame was demonstrated to Irene, working initially with pre-loaded photographs, and then with images provided, in advance, by Eddie. One potential difficulty was whether Irene could generate sufficient pressure to operate the pressure pad. However, as a piece of commodity assistive technology, this had a wide range of calibration, which was then sufficient to adapt its activation pressure to her needs. We found that Irene liked the prototype, and continued to use it throughout the rest of the meeting even while talking to us, using the tablet PC by placing it on her lap, with the pressure pad on the arm of her chair.

Recovery from physical disability requires regular and repeated exercise, and a significant question around this prototype was whether it could provide sufficient motivational value in this context. To keep the photographic content fresh, Eddie offered to load new photographs onto it. However, both were worried that it would not hold her interest over a longer period. As an explanation, Eddie observed that none of the designers would want to sit for hours each day looking at photographs.

Inspired by the prototype itself, Eddie then suggested the use of the same setup to read through novels. At this point in time, Irene was struggling to read, due to issues with finding books with sufficiently large text, and due to her inability to grasp a book with her left hand. Both felt that a setup in which a squeeze switch was linked to progress through a novel would be more heavily used, and less prone to tedium than the photo frame idea. We also talked through the possibility of providing both applications, so that Irene could switch between them when she wanted. This idea was liked, and we talked about the idea of using the buttons on the right hand side of the UMPC to move between different types of content.

Design session three

For the purposes of design session three, a modified prototype was produced that displayed text from a copyright-free novel. By this point, a squeeze switch had arrived, and therefore replaced the pressure pad. In designing this prototype, care needed to be taken around providing content that was readable for Irene, given known difficulties with the sight in her left eye,
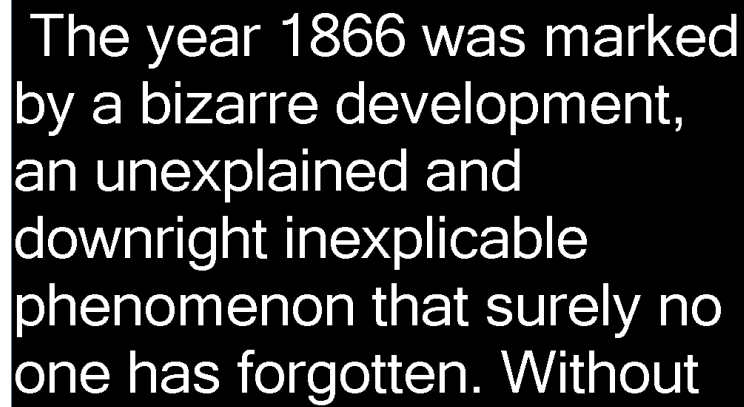
Figure 6.3: Irene - Single clause version of interface.

and given the potential cognitive difficulties that had been discussed in re-
lation to crossword puzzles. To allow for an exploration of visual aspects
of design, the modified prototype was programmed to be customisable in a
number of different ways. Two versions were provided. The first version,
shown in Figure 6.3, displayed one clause at a time from the text, which
was horizontally and vertically centred on the screen. Squeezing the switch
caused the next clause to be displayed. The second version, shown in Figure
6.4 placed as many lines of text as possible onto the screen, with a squeeze
causing these lines of text to scroll vertically, revealing a new line of text at
the bottom. Both of these interfaces featured configurable foreground and
background colours, and configurable font sizes. Experimentation during the
third design session suggested that white text on a black background was
most readable for Irene, with a font size of 60 points being optimal. All
attendees of the design session preferred version one of the interface. Version
2 was criticised as being too cluttered for easy comprehension.

During the remainder of the design session, Irene used the device for roughly
20 minutes, after which there seemed to be very noticeable improvements in
her ability to move her fingers, in comparison to when she first started using
the interface. During this time period, she reported only minor fatigue, and
indicated that she would like to use the interface for roughly an hour per day.
The physiotherapist involved in this process thought that some time might
be required before she could exercise for this period of time, and suggested
that it would be useful from a rehabilitational perspective to have alternative
physical interfaces to the device, to avoid doing one movement repetitively,
and to encourage better functional recovery. She also indicated that Irene

The year 1866 was marked by a bizarre development, an unexplained and downright inexplicable phenomenon that surely no one has forgotten. Without

Figure 6.4: Irene - Scrolling version of interface.

was initially using the squeeze switch with too much wrist flexion. Irene was then encouraged to use her hand rather than her wrist to initiate the movement, and at this point, the quality of the movement did improve.

The original concept for using a book as a motivator had come from Eddie, and discussion with him focused on mechanisms for developing the prototype further. During this session, he made suggestions for an interface that allowed him to download books from the Internet and onto the device. He also suggested the addition of functionality that allowed the display of text from newspapers, which Irene was struggling to read at the time. He suggested that the device might additionally provide a gateway to the Internet for her, but she seemed very unhappy with this suggestion, as she didn't appear interested in the Internet at all. Finally, he suggested the use of his laptop to run the book reading software, rather than the Ubiquio, as this had a larger screen. Irene also seemed very unhappy with this suggestion, so we decided to stick with the system built around the Ubiquio.

Such strong differences in opinion between two people were an interesting phenomenon in this session, and whilst Eddie's original idea of a book reader seemed strong, his other suggestions seemed more tailored to his own interests and beliefs rather than those of Irene.

6.3.1.1 Final version of system

Following on from design session three, the author and another project member engineered a robust prototype which had been tested sufficiently to support a deployment of several months. For simplicity, this prototype was

Figure 6.5: Irene - System intended for deployment.

loaded with only one book (a classic novel, which had been chosen by Irene). The prototype persistently stored the most recent line that had been read, allowing Irene to read a book across multiple sessions, even when the Ubiquio had been shut down. It was also configured to automatically load the book-reading software on startup, and to avoid showing any trace of its Windows XP OS. The result was an artefact which had been constructed from a general-purpose PC, but which had been specialised to act as a book-reader (this artefact is shown in figure 6.5). An important aim here was to avoid Irene thinking of this device as a computer, to avoid any anxiety issues caused by this.

6.3.2 Joan - the Exercise Machine

The second case study presented in this thesis features engagements with Joan and her husband (referred to as David). Both were living in a terraced house near to Sheffield, both were in their seventies, and both were previously very active before her stroke. Joan was right-side dominant, and initially had a stroke which affected the left side of her body, for which she was hospitalised. Whilst in hospital, she believed that she had a second stroke, which affected the right side of her body, but failed to report this, in case she then had to wait longer for discharge. After discharge from hospital, Joan received no further physical therapy, and reported feeling abandoned by the healthcare system.

These experiences then make this in an interesting case study, as Joan's recovery post-discharge had essentially been self-motivated and un-supported. The 2007 National Stroke Strategy [15] strongly recommends the provision of ongoing support post-discharge, but acknowledges that insufficient support is provided in many case. As such, even in a relatively wealthy nation such as the UK, the lack of support received by Joan may be representative of the experience of a significant number of survivors of stroke, which then makes it a very relevant challenge for design.

Like Irene, an initial assessment was conducted with Joan before the design process began. This revealed her main physical difficulties as being weakness in both lower limbs, and a weakness and lack of dexterity throughout her right upper limb, which meant that she could not lift her right arm into the air. Like Irene, the assessment suggested that Joan was experiencing some difficulties with anxiety. During the assessment, Joan described struggling to look after her appearance (specifically: her hair).

Design session one

Like Irene, engagement with Joan began with a consideration of her own personal motivation. During the first design session, Joan gave the impression that she was highly motivated to improve her physical health. Despite a lack of physiotherapy support, she had already developed the abilities of the fingers of her right hand through self-administered stretching exercises, but expressed a lack of knowledge in how to progress further, presumably related to the lack of support that she had received post-discharge. When asked what she was motivated for, she talked about wanting to be more active around the house, and wanting to regain strength in her arms and legs. Joan was asked about specific activities that she wanted to return to, but could not name any. She did talk about losing her driving license after her stroke, and the difficulties caused by being reliant on public transport, or on transportation provided for elderly or disabled people. This made it harder for her and her husband to visit places that they had previously had access to. When asked, she seemed open to any kind of exercise that would improve her physical response, and both her and David stated that they were prepared to adjust their home to suit any intervention that was made.

In addition to discussions around motivation, the first design session also provided an opportunity to make observations about the physical environment in which Joan and her husband lived. This consisted of a number of rooms, spread across two floors, all of which were accessible to Joan, and all of which she used regularly. One of these was a reasonably large lounge, containing a number of chairs, all of which could be easily moved (due to having castors). One exit from this lounge led to a small kitchen. Despite her disabilities, Joan was regularly involved in cooking meals, but was unable to lift pans. All lifting and carrying of these was done by her husband, under her supervision (to ensure correct timing of food preparation).

Because Joan was less motivated by specific activities, and more driven by general improvement to her physical condition, then this session concluded with discussion of the concept of deploying an "exercise machine", with which she would engage periodically, and which had features which would allow her to develop her physical abilities through exercises that required relatively integrated movements of her entire body. Given her lack of knowledge of how to recover, this kind of intervention then carried the potential to provide some guidance in relation to this process. A key question here was how such an intervention might be integrated into available physical space. We did identify that there was a spare space in the lounge, behind two chairs, which could be used for it, and returned to the question of physical space in later design sessions.

Initial concepts

Following on from this session, the author discussed design ideas with other members of the project team, and through this discussion, identified three candidate concepts for discussion at the following meeting. These were not intended to be completed designs in any way; instead they were intended to promote discussion as part of the process of selecting a final design. All were incomplete, in that they did not even attempt to provide a workable solution to the problem. Given that Joan's desire was for a general improvement, rather than addressing specific disabilities, then the key challenge in identifying these concepts was to find a way of motivating exercises that was not targeted at a specific goal. Each concept addresses this challenge in a different way.

Figure 6.6: Joan - Mock-up of virtual battery interface.

Concept 1: music as a motivator for exercise

Observations during design session one suggested that there were no visible facility to play music in the couple's home. In response to this, concept 1 uses music as a reward for exercise. It involves a system which would monitor Joan as she performed exercises, and which would generate a display showing the level of charge in a battery. Once this had reached a certain level, she would then be given an allocation of time during which music could be played. A mock-up of this interface, constructed by another project member, is shown in Figure 6.6.

Concept 2: the personalised and interactive exercise video

Exercise videos are readily available to the population at large, and are commonly used to guide people through the process of improving fitness. However, as noted in Chapter 5 (concept 5.3), improving physical fitness is not an appropriate model for recovery from disability acquired through stroke, as disabilities are caused by damage to the brain. This then means that abilities can vary dramatically on the scale of minutes or days, and that exercises may need to be tailored to the unique needs of individuals. This then suggests that a commodity exercise video targeted at improving fitness might not be responsive enough or personalised enough to support the process of rehabilitation.

As discussed in Chapter 2, movement therapists commonly respond to the challenge of personalisation by using exercise sheets, which illustrate particular exercises to be performed, and which can then be personalised to individuals. However, there are known difficulties in interpreting these sheets, and individuals often report that engagement with exercise sheets is dull.

Drawing on these observations, concept 2 then involved a personalised and interactive exercise video, which would guide Joan through a series of exercises on a regular basis, and which would monitor her progress through these exercises, potentially adjusting them to her needs. It would require a mechanism for monitoring exercise, an algorithm to select exercises and a mechanism for producing instructions. This concept represents a complex design space in its own right. Questions to address might include the mode of presentation of exercises, the physical appearance of the interface, and the mode of presentation of feedback of her progress.

Concept 3: the virtual garden

Inspired by previously published work which suggested the motivational potential of looking after virtual organisms [165], this concept involved a display of a virtual garden, which would become healthier if Joan performed a required amount of exercise. For design session two, this concept was not developed in much detail; it did, however, represent an opportunity to draw on prior and potentially relevant HCI research.

Design session two

The intention of design session two was to ask Joan and her husband for feedback on these three concepts, as part of the process of working towards a concrete prototype design for future deployment. Discussion around these concepts provided some interesting insights into the design of rehabilitation systems for homes that are shared, and which have been tailored by those living in them.

When presented with the three concepts during the second session, Joan was interested in concept 1, but indicated that the couple had regular conflicts over music, since they had very different musical tastes. She also liked concept 3, but was drawn to concept 2, which she thought would be regularly used. Further discussion around this concept then took place. During these Joan suggested that any exercise frame would have to stand freely, to avoid any damage to their wall-paper. Here, an important consideration seemed to be that the home itself was immaculately decorated, to a style which was clearly determined by Joan and David. Although the couple had stated in design session one that they would be prepared to make any changes to their home that were required, discussion around this concept suggested that there

were clearly limits to changes that could be imposed through a rehabilitation technology.

Having settled on concept 2, a key question was then the mode of delivery of instructions. Joan was asked whether exercise instructions should be given verbally, through text displayed on a screen, or through an ambient mechanism (such as lights that indicated which exercise she should engage with). Of these, she preferred the verbal option, which she considered to be less intrusive to her home.

Given that survivors of stroke can experiences difficulties with memory, then how to prompt engagement with rehabilitation systems is an open area of research, which is also being explored by HCI researchers more broadly - for a detailed discussion of the latter see [166]. One possibility in this context was the design of a system that generated some form of prompt to encourage engagement. Joan was asked about this issue directly, and stated that she would prefer to be prompted to exercise at a certain time by the machine, with 3pm being a time that she was regularly available.

Following on from this session, the author started to develop an outline physical specification for an exercise machine. The physiotherapist involved in this design process suggested that exercises supported by this machine should require Joan to integrate movements involving the grasp and release of objects and the movement of her elbow and shoulder; such exercises should be performed by both upper limbs, and should involve movement through the full range available to her, in all directions available to her. Based upon measurements of her height and reaching ability that had been taken previously, Figure 6.7 illustrates the required dimensions of such a machine. Rather than introducing new objects into there home, it was decided to design exercises around objects that were already available, with possibilities including the grasp, lifting and release of bottles and pans, potentially using different amounts of water to vary their weight.

More generally, these initial considerations then highlight the importance of considering ergonomics and physical design in the context of rehabilitation technologies - design session 3 then provided an opportunity to consider this issue further.
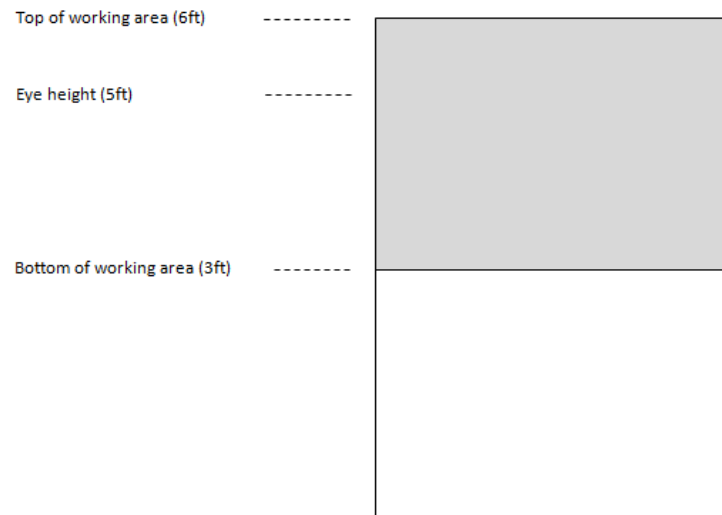
Figure 6.7: Joan - Estimate of frame dimensions.

Design session three

To facilitate discussions aimed at refining the exercise machine concept, the author constructed a rough interactive prototype which was presented during design session three. This consisted of a set of IKEA shelves (figure 6.8), two large buttons provided by an assistive technology company (one red, one green) and a laptop (to which the buttons where connected), which ran custom software written by the author. The shelving unit was placed into an empty space in the couple's lounge, and the laptop was placed on its bottom shelf. When custom software on this laptop was first run, an audio message was played, asking Joan if she wished to participate in exercise today. To participate, she was instructed to push the green button. The software then played a message explaining the task to be performed, and asking her to hit the green button when ready. It then gives an instruction for randomly-selected exercise. If she was successful in performing this exercise, she was instructed to hit the green button, and the red button if not. After a certain number of exercises, the software stopped giving instructions, and told her how many she had successfully performed.

A key question around this system was then how to promote exercise that was high in quality, and that was carried out effectively. This issue was discussed in session three, and David suggested that he could take on a role of "policing" Joan's usage, although he would then need some training to do this effectively.

Figure 6.8: Joan - IKEA shelving unit. Sourced from http://www.ikea.com.

Figure 6.9: Joan - Red button. Sourced from http://www.barrierbreak.com.

The session then concluded with some experiments with available objects, in which we identified appropriate weights for exercise. At this point in the process, it was identified that Joan could handle objects that weighed up to 2kg, and that a minimum weight of 0.5kg would be necessary to provide a challenge.

6.3.2.1 Final version of system

Following on from this design session, project time was short, and it became increasingly important to develop a robust system for deployment. At this stage, therefore, the author decided to identify the simplest possible system that could be justified within the discussions that had taken place during the design sessions, and which could actually be developed and deployed rapidly.

This design consisted of a Ubiquio 701 tablet PC, to which a pair of speakers and a single green button had been attached, and which ran a custom application developed by the author. This application started when the Ubiquio was started, and generated a display featuring a count of the number of exercises that had been requested that day, and which therefore reset to 0 overnight. Hitting the green button caused an audio-recording of an instruction for an exercise to be played, and caused the on-screen count to increment by one, with this number turning green when a pre-specified threshold had been released.

To provide some variation, exercises were constructed from randomly-selected samples that indicated the nature of the exercise, the limb that should be used to perform it (left or right), the number of repetitions that should be performed (5,6,7 or 8) and the object that should be used during its performance. Available exercises included taking the selected limb out to the side or lifting it up, bending the elbow, or rolling the wrist. Selected objects included bottles (containing water), cups and pans. In the period between design session three and the deployment of a prototype of this system (described in chapter 7) Joan's physical abilities had substantially declined, despite a gap of just a few weeks. As such, objects with a significantly smaller weight were required to allow the potential for successful exercise. This kind of variability in ability is then a key challenge in the design of technologies that can be deployed into the home and remain functional.

Like the system intended for Irene, the system intended for Joan was con-

structed from a generic PC and a piece of technology purchased from an assistive technology company. However, the software which acted as a bridge between these was more complex, and in of itself this assembly might be thought of more as a piece of bespoke design rather than the tailoring of an existing piece of technology. The design itself, however, might be appropriate to a broader group of users, but could then be tailored to individuals through mechanisms such as selecting personalised exercises, or choosing objects that were appropriate to individuals.

6.3.3   Sophie - the Ball FunNel

Sophie was the first participant living close to Southampton with which we engaged. At the time of intervention, Sophie was in her early thirties. Six years previously, she had been operated on to remove a brain tumour, and this had caused a massive stroke, which seriously affected all of the right side of her body, leading to major disabilities in her upper and lower limb, to partial blindness in her right eye, and to a variety of cognitive deficits, some of which were manifest in deficits in speech production. Strokes in younger individuals are relatively uncommon - one substantial survey has indicated that individuals under fourty five years of age only made up 8.5% of patients admitted to a hospital over a five years period [167]. Strokes experienced by younger people are then more likely to be related to specific causes such as tumours or accidents. In general, it might be reasonable to assume that there could be some significant differences in the needs and motivations of survivors of stroke who are much younger than those who typically experience this illness, and understanding these differences is then useful in the broader context of an exploration into how to tailor rehabilitational technology.

Before her stroke, Sophie was a PE teacher, and was involved in skiing, swimming and sailing. She still continued these hobbies post-stroke, despite her disability. Eighteen months before the intervention began she gave birth to a son, Felix (not his real name). Sophie lives with Felix and her husband in a house near Southampton. The presence of a young child then differentiates this case study from the the other three case studies, all of which focussed on married couples whose children had left home.

Design session one

The first design session provided the opportunity to learn about various aspects of the context in which Sophie lived, and to discuss initial ideas with her. This first meeting was attended by Sophie, her mother and two members of the Motivating Mobility project (neither of which was the author). Her son was also in the house, and Sophie spent some time playing with him during the meeting. The description of the first design session has been assembled from notes written by two members of the Motivating Mobility team.

Through this first meeting, the importance of Sophie's son in the context of her own life and rehabilitation became very clear. Throughout the meeting, she seemed to take great pleasure in making funny sounds for him, often breaking off conversations to do so. She also described how his birth was a stimulus for her to start trying to recover her abilities, and she has started talking much more frequently and fluently since his birth.

Sophie's parents also seemed to have an important role to play in her life and rehabilitation, which then raises some interesting questions around the design of technology for this setting. By this point in time, Sophie's parents had already paid for a large amount of rehabilitation treatment since her stroke, and this had included physiotherapy three times a week for the last five years, and a three-month stay in a rehabilitation hospital. They were also involved in her day-to-day support. Her mother was playing an especially important role in this, by visiting most days, thereby allowing Sophie the flexibility to take part in various hobbies. Her mother played an active role during the first design session, sometimes talking on Sophie's behalf, and sometimes supporting communication with her. This level of parental involvement then differentiates this case study from the other three, and raises the potential of a larger group of participants having an interest in the design of a technology.

Part of this parental role then involved providing motivational support for the process of rehabilitation. Sophie's mother seemed to hold strong views about the goals that she should aim for, with a principal focus on regaining voluntary movement in her damaged arm. Sophie seemed more ambiguous about this aim, describing how it is currently much quicker to just use her left arm for activities, and stating that she was beginning to come to terms with not having a working right arm. She did, however, acknowledge during this session that there were some activities that would benefit from the use of

both arms, including assembling toys owned by her son. Previously, through interaction with a private physiotherapist, Sophie had acquired a Saeboflex device, which supported the voluntary movement of the fingers of her right arm. Sophie demonstrated her use of this device during the meeting (the Saeboflex is described in Chapter 2 of this thesis).

This session also provided an opportunity to make some observations about the physical environment. Sophie lived in a large house, with an open plan kitchen and living-room area, which joins onto a conservatory. Sophie could access all of this space, with some difficulty, and the conservatory area seemed to be her favourite. During the meeting, she described feeling safe within the house, and confident of her own abilities to look after herself in that environment. She felt much less confident outside of this environment, especially due to the responsibility of looking after her son there.

Following on from the first design session, the attending researchers developed three outline concepts to present to Sophie. These focused on activities that would seek to integrate use of her right arm into day-to-day activities, and which could be carried out from a seated position, due to continuing difficulties with balance when standing. Several of these concepts were structured to encourage interaction with her son, in recognition of his important role in her life. In summary, these concepts were:

- The Ball FUNnel: this would involve Sophie using her right arm to bat a ball along a surface and into a hole. The ball would then travel through a tunnel, and roll out of the bottom of the device, ready for her son to catch and play with.

- The Sound Manipulator: this is an artefact that would allow Sophie and her son to record and play sounds during the day. It would have a physical interface that would require use of her right arm in some way.

- The Diary: this is an artefact that would allow Sophie to take pictures or videos to share with friends at a distance. It would present a physical interface that would encourage the use of her right arm in interaction.

- A pair of communicating tangible devices that supported communication with her husband.

Design session two

These four ideas were presented to Sophie during the second design session. The diary was discarded due to Sophie stating that she had no friends to communicate with, and the pair of tangible devices was discarded as her mother thought that her husband would not want to be involved with a trial. Sophie clearly liked the Ball FUNnel, and during the meeting, attendees discussed the integration of the sound manipulator concept to produce a device that allowed sounds to be recorded onto coloured balls by Sophie or her mother, and played back when they were knocked into a tunnel. Sophie's mother talked about the educational potential that this might provide for Felix. Sophie talked about the need for the top surface of the Ball FUNnel to have a raised border, to avoid the frustration of the balls dropping off it if she missed a hole. The idea of having a single-player mode in which Sophie competed against herself was also raised as a possibility.

Design session three

In advance of the design session, the author constructed a rough prototype device to aid discussion. This consisted of a wooden box, with a hole in the top surface, and a hole in the side. A tennis ball could be knocked into the top hole and would emerge from the side hole, and a raised rim stopped a ball from rolling off the top surface. Two micro-switches had been fitted to the box - one on the side, and one just inside the hole in the top surface. These were attached to a Phidget InterfaceKit [1], which was connected by a long cable to a laptop, as was a microphone, which was attached to the side of the box.

The author and another project member had constructed a piece of custom software which was installed onto the laptop. This allowed a sound to be recorded through the microphone when a tennis ball was held onto the micro-switch on the side of the box. This sound was replayed when the ball was knocked into the hole in the top of the box, triggering the internal micro-switch. An external view of this prototype device is shown in Figure 6.10.

During the design session, Sophie experimented with using her left hand to

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[1]This is a USB device to which a variety of inputs can be connected, including micro-switches. A device driver supplied with the device makes these inputs available to software written in a variety of languages

Figure 6.10: Sophie - first prototype of Ball FUNnel

hold the ball on the switch, and recorded a variety of sounds. She struggled to bat the ball into the ball, however. This led us to propose a design with more restrictions on movement, and with the hole placed closer to a raised edge. We also realised that the box needed to be raised by roughly 15cm to be usable when she was seated, and that padding would need to be placed on the top surface, and around the raised edge. An extremely important consideration for design here was that Sophie had limited sensation in her right arm, and tended to hit the edge quite hard when using it. Incorrect design decisions in the context of limited sensation could potentially lead to physical damage, and a limited sensorium is a consequence of stroke for many survivors.

Having demonstrated the device to Sophie, her son was then invited into the room, and quickly started playing with the device by putting balls into the top hole. To avoid this disrupting Sophie's use of the box, we then placed it on a coffee table, so that its top surface would be out his reach. Sophie and her son then played a game where she knocked the ball into the hole, and he returned this. We then started talking about a deployment of a future device, and Sophie's mother talked about this being acceptable for 4-6 weeks, as part of their contribution to our research. At this point, we strenuously tried to explain that we wanted to produce something that was appealing and fun to use, but both Sophie and her mother seemed to struggle to understand this concept. For them, they already seemed to have generated an association between physiotherapy and dull exercise that had to be endured rather than enjoyed, and saw our efforts as an extension of this

paradigm. This example illustrates the powerful impact that beliefs about the process of rehabilitation can have on attitudes; any technology deployed for the process of rehabilitation will then be deployed into an environment in which a set of beliefs and attitudes have already been developed, some of which could act against the success of such a technology.

Preparing for a passive deployment

At this point, at the suggestion of the author, we decided to leave a version of the artefact with no computing technology embedded into it with Sophie, to see if she actually enjoyed interacting with it. This was constructed, by the author, from wood, in light of the modifications that were suggested by the third design session. Sophie and her mother were provided with an audio device to record their thoughts onto. After a period of roughly two weeks, the artefact and the recorder were collected, and transcriptions of any recordings were made by another member of the project team.

Analysis of data collected during passive deployment

Short recordings made by Sophie's mother suggest that she, Felix and Sophie commonly played with the device together, with Sophie's mother retrieving balls if Felix was uninterested. Early in the deployment, Sophie's mother rang the project team, and indicated that Sophie had experienced neck pain after using it for 20 minutes. A modification was then made to the device by Sophie's father, under the supervision of Sophie's private physiotherapist; this solved this problem by raising it by roughly 8cm further from the ground. Sophie's father also added an additional block of wood onto the front of the device, to stop Sophie from leaning to close to it, and to therefore encourage her to stand up straight when using it. This is an interesting example of the physical tailoring of a device to the needs of an individual, in this case to improve ergonomics so as not to cause damage during the process of use.

Design session four

This session provided further feedback on the deployment of the passive prototype. Sophie indicated that she had enjoyed playing with the box with her son, with Sophie batting the ball into the hole, and Felix returning it.

Figure 6.11: Sophie - deployed prototype of Ball FUNnel.

Other objects had been found in the box, suggesting that Felix was playing with it when others were not around. Sophie's mother liked the box, and suggested selling the idea to Mothercare. Suggested future changes included raising the rim around the top surface, and providing different surfaces that could be slotted in, with holes in different places. During this meeting, Sophie's mother expressed enthusiasm for being able to record a sound onto individual balls. We also talked through options for avoiding trip hazards when an active prototype was deployed.

6.3.3.1 Final version of system

At this point, an active system was prepared for deployment. This involved a set of coloured foam balls, into each of which an RFID tag had been inserted. The previous passive prototype was then modified through the addition of three RFID readers one on the side, and two internally. Placing each ball against an RFID reader allowed a sound to be recorded, with this sound being replayed if either internal RFID reader was triggered by the ball dropping through the hole in the top surface. The prototype was also painted in bright colours with the aim of making it more appealing to Felix. An image of this prototype is shown in Figure 6.11.

To avoid dangers associated with cabling, the Ball FUNnel was attached to a laptop, through a USB cable which detached easily, and which only ever carried 5v. To use the device, the laptop had to be switched on, at which

point the custom software would automatically load. This software logged all interactions with the device. Logging information included:

- All recorded sound files (stamped with the date and time of recording)

- Each trigger of either of the internal RFID readers (stamped with date and time)

The prototype was then deployed for roughly a month, after which an exit interview was carried out in Sophie's home. In addition, a paper diary was provided to record any written messages for later analysis.

6.3.4 Solomon - the Chess Game

At the time of intervention, Solomon was a self-employed accountant who was in his 50s when he had a stroke. This affected the whole of the left side of his body, and has caused some difficulties in walking, and severe difficulties in using his left hand and arm. He also believed that it had reduced his ability to concentrate, and to make complex decisions, thereby impacting his working life, and has caused him to lose clients. Of all the participants, Solomon had the most severe physical disabilities, and identifying technology that could respond to his ability to move was a significant challenge.

Design session one

Discussions in the first design meeting focused on eliciting information about Solomon's motivations, and on making observations about his housing. Solomon lived in a two story house with his partner, and could access all of it. In his living room, he had a chair that he preferred to sit in. This had been fitted with a movable table, attached to an arm, which he could swing in front of him, or push to the side. He often used this table to work on this laptop. The chair was set up to face a large television, and had a view out of a well-lit window.

Solomon clearly stated during this meeting that his motivation was to return to normal, so that he could continue with his working life. This motivation then encompassed a desire to regain his ability to concentrate and process information, and also to regain fine control in the fingers of his left hand, as

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this would enable him to type more effectively. At the time of intervention, Solomon had an extremely limited ability to manipulate his fingers, which barely allowed him to lightly grasp an object. Solomon is an experienced technology user. He owns and regularly uses a laptop, an iPhone, a DVD player and a Sky+ box. He has also bought a Nintendo Wii, on advice from his physiotherapist, and he and his partner play games together on it.

Following on from this design meeting, the attending project members developed a set of initial concepts that were orientated around motivating finger exercise, and which also involved a cognitive element, as the development of his cognitive abilities seemed so important to Solomon. This is then the only case study in which rehabilitation of cognitive capacity was a specific target of design. The initial set of broad concepts were:

- Horse racing: a game where more exercise causes more information about a horse to be revealed, supporting a process of virtual betting

- A touch-typing game

- A game involving betting in relation to exercise - which would allow Solomon to bet how much exercise he can do in a day, possibly in competition with friends

- A chess game which was controlled by exercise

- A puzzle game, involving Morse code, which was controlled by exercise

Design session two

All of these ideas were discussed at the design session, but the chess game was clearly Solomon's favourite. At the time of intervention, he was playing chess against a computer at least once a day, focusing on quick games (lasting less than 10 minutes), and was also hoping to enter local chess tournaments. He stated that he would play for up to an hour a day if this supported his rehabilitation. He also stated that he would prefer a chess game to be set up at home, rather than in his office. He also seemed happier to play against a computer than his partner, as this would then make him less dependent upon her for exercise. This seemed a key consideration for design in this particular case, as dependency on his partner would have reduced his opportunities for

rehabilitation, given that she had a busy job and he was often at home on his own.

Further details of interactions with a chess system were also discussed in the meeting, which focused on the use of Phalanger [168], a vision tracking system, developed at Sussex University, to recognise hand gestures. Early in the meeting, the idea of assigning a gesture to each type of piece was discussed in detail, and we spent some time working with Solomon to learn about the range of gestures that he could generate. Following on from this exploration, the idea of using a gesture-based system was then abandoned, as it became apparent that the extremely limited set of gestures that Solomons left hand was capable of would preclude gesture-based interaction.

At this point, an alternative design, using a tangible interface, was developed. This involved a horizontal board, into which six vertical objects had been fastened. Each of these objects represented a type of piece. To allow the movement of a piece on a virtual board, Solomon was required to grasp the relevant object with his left-hand, and to then use his right-hand to enter co-ordinates for that piece to move to, with the movement occurring when he released the vertical object.

An interesting topic for exploration here was then the possibility of recording information that tracked Solomon's abilities, and which could potentially be used to provide him with some feedback about his progress. We wondered whether the system could record the pressure that Solomon was able to apply to the piece, and might use a variable threshold to modify the difficulty level of the task.

An initial prototype of this system was constructed by the author and another project member, building on an open-source chess program and a set of Phidget pressure sensors[2]. This prototype is shown in Figure 6.12.

Design session three

The first prototype was taken along to this design session for Solomon to use, and it quickly became apparent that even grasping a slim object was difficult for him, thereby highlighting the extreme difficulty of providing for a physical interaction that was both rehabilitationally meaningful and physically

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[2]Available from http://www.phidgets.com
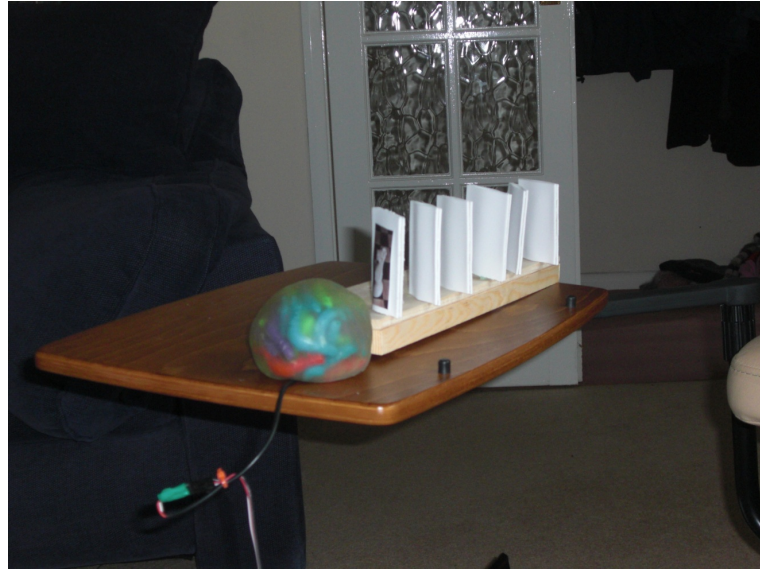
Figure 6.12: Solomon - Prototype device. Pressure sensors are embedded into white cardboard objects. Artefact has been placed on the swinging table that is attached to Solomons chair.

possible. Grasping this object for every move of a piece would then have lead to a game of chess could potentially become very slow, which might therefore have been demotivating for him. Additionally, to allow Solomon to grasp the vertical objects representing types of pieces, these would need to be more widely spaced. This would be difficult to implement effectively, given both the limited space on the swinging table attached to Solomons chair, and the limited range of his ability to reach forwards.

During this design session, an alternative design was discussed. In this, at the start of each game, Solomon would be able to choose two pieces to control through grasping by placing just two of a choice of six vertical objects into a much smaller board. This choice of objects would determine the pieces that Solomon had to select by grasping during the remainder of the game, with the remainder of the pieces being controlled by his right hand. We discussed making the vertical objects as slim as possible, to make it easier for Solomon to grasp them. However, he was keen to have one that was thicker than another, so that one provided a greater challenge for him when grasping.

Following on from this design session, the author constructed a working prototype interface device. This is shown in figure 6.13. The object representing a type of piece is composed of two sheets of acrylic, with a piece of foam in between, which has holes in it. Squeezing the acrylic sheets together allowed
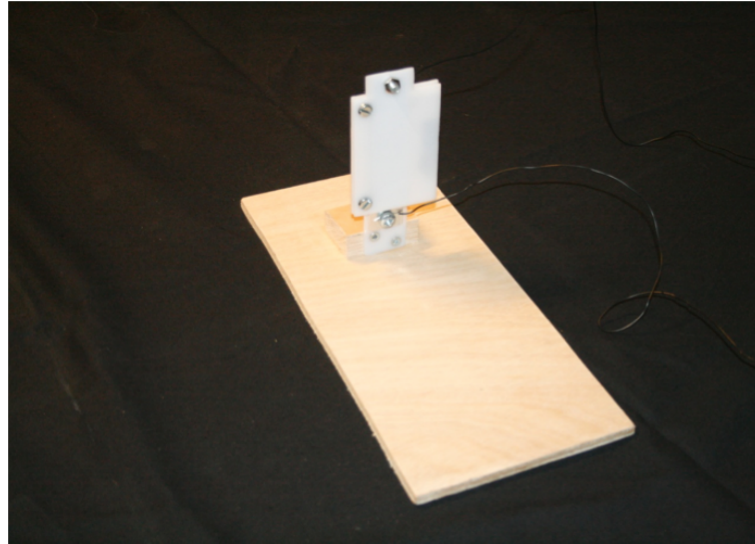
Figure 6.13: Solomon - Prototype squeeze sensor.

a contact to be made between two strips of conductive aluminium foil. The pressure needed to activate this switch could be easily modified, through the use of pieces of foam with different widths or sizes of hole, or through the use of different positions for the foam within the acrylic sheets.

Design session four

This session was attended by the author, and focused on collecting sufficient information to allow a fully-working prototype of the game to be developed. The prototype squeeze sensor was tested, and was found to require too much pressure, even given very thin foam with many holes. An alternate design was then identified. We also discussed the idea of using Solomon's television to display the graphical component of the chess interface, and identified requirements for an arm rest, to be attached to this chair. This would support his arm whilst squeezing the pressure sensor, allowing him to focus purely on grasp and release movements, rather than on trying to support his arm at the same time.

6.3.4.1 Final version of system

A prototype system for deployment was then constructed. This consisted of two squeeze sensors, a board to which they could be attached and a modified chess game. Sensors were permanently attached to the board during the final

Figure 6.14: Solomon - System as deployed.

deployment meeting, to ensure that they were positioned in the optimum ergonomic position for Solomon to use. A non-slip mat was placed under the sensor board, to avoid it slipping off Solomon's table when in use.

Modifications to the open-source chess program that we had found had also been made. This primarily involved the addition of an extra screen, which was displayed before the start of each game. This allowed Solomon to use his mouse to create a mapping between each squeeze sensor and the type of chess piece which it would control. Solomon could also choose to use 0,1 or 2 squeeze sensors for each game. During the deployment meeting, an arm rest was attached to the windowsill, near Solomon's chair, and an improvised restraining device was added to it, consisting of a rubber band and a piece of foam. The setup, as deployed, is shown in Figure 6.14.

6.4 Discussion

Having presented four case studies of the process of designing technologies which are intended to support rehabilitation, this chapter now closes with a discussion of two key issues which have a broader relevance to research around health technology, and HCI research more generally, specifically:

- Designing technologies that are informed by an understanding of human motivation

- Designing technologies that are tailored to the unique needs of individuals

Chapter 7 then presents knowledge developed through the process of deploying prototype implementations of these designs as technology probes.

6.4.1 Designing technologies that are informed by an understanding of human motivation

As noted in Chapter 3, there is a substantial body of research that considers the question of how to support changes in individual lifestyle, attitudes or behaviours, generally with the intention of supporting change that is beneficial in some way, either to the individual themselves, or to society more generally. Much of this work takes particular psychological theories as a starting point, and explores the design of technologies in light of the insights provided by these theories. When associated with the process of designing and evaluating technology, this area of research is generally known as persuasive computing.

As described in Chapter 2, a key role of professional movement therapists is to support beneficial change in their clients. As such, the professional practice of movement therapists is interesting in the context of persuasive computing; we might label them as *persuasive actors*. In considering this practice, authors such as Maclean [55, 56] have highlighted the important role played by motivation, and have described how professional movement therapists go about understanding the motivational needs of their clients.

Inspired by this work, one focus of the process of design described in this chapter has been on understanding the motivations for recovery of the four participants. Analysis of this material then allows for a discussion of issues

around motivation in relation to the design of technology. The approach in all four case studies was to ask participants directly about their own motivation, with this being the most lightweight mechanism available. Alternatives might have included questionnaires, or other more standardised methods.

Even with just these four participants, significant differences in the nature of their motivation emerge, which might then suggest different approaches to tailoring technology to their needs. Understanding these differences can then provide an insight into differences that might be found in the population at large. This might then support future research that attempts to integrate individual motivations into the design of rehabilitational technology specifically, or persuasive computing technologies more broadly.

In this context, Irene found it easy to name a number of hobbies that she wanted to be able to return to, and that carried the potential to provide a motivation for recovery (i.e. reading and crochet). It was then relatively easy to select exercises that were likely to have a positive impact on physical abilities that related to these hobbies, and this then lead to some candidate technology designs that seemed appropriate in the context of encouraging these exercises. Fear of technology meant that interventions such as a Nintendo Wii were actually demotivating for her, even though they could have been beneficial. As such, careful design was necessary to ensure that she did not perceive future interventions as being technological in nature. Due to difficulties with her eyesight, Irene had stopped reading books, and the configurable nature of interactive technologies allowed the provision of text in a manner that easier to understand, which then removed a significant barrier to reading. The intention of this design was then that her natural motivation to read and to recover sufficient physical ability to crochet would lead her to engage substantially with the technology that was provided, potentially supporting rehabilitational benefits that lived on beyond the use of the technology.

Joan, in contrast, struggled to name any specific hobbies or activities that she wanted to return to, but was clearly very well motivated for recovery more generally. Having hidden a second stroke from hospital staff to avoid a longer stay, she had personally devised a series of exercises that had supported the recovery of a significant amount of movement, but lacked the confidence and knowledge to push herself further. The choice in her case was a candidate design that attempted to break down this particular barrier by providing a

set of instructions for exercises to carry out, thereby potentially enabling her own motivation to support the continuing process of recovery.

In the context of a discussion structured around motivation, Sophie is perhaps the most complex case, in that much of her motivation to recovery was being provided by her parents, especially in the case of her damaged arm, which she had partially given up on. She was, however, highly motivated to engage with her son, which then inspired a design which attempted to promote movement through a mechanism of involving him in play. Even engaging with this required the support of her mother (e.g. to pick up and return balls), and she was clearly very dependent upon the social context around her.

Of the four participants, Solomon probably had the highest level of intrinsic motivation, due to a desire to return to work. He did, however, have the most serious physical disability of all of our participants. Design work then focussed on providing an activity with which he could engage, but that was not so difficult that it damaged his motivation to do so.

Collectively, these case studies suggest a pragmatic orientation to the concept of motivation during the process of designing persuasive computing technologies, and which places a specific emphasis on a consideration of individual differences. Some individuals may be motivated by specific activities, other individuals may be more generally motivated to recover, and there are a broad range of factors that can be de-motivational, and which require careful consideration. In many cases, motivation will have a social element, in that other can provide strong support for motivation. The corollary of this, not necessarily seen in these four case studies, is that the attitudes of others can be detrimental to motivation, which is then an important factor to consider in any technology that allows for social interaction between its users.

The table presented in Figure 6.15 summarises the key elements of motivation that were encountered in these case studies, with possible implications for technology. A broader discussion encompassing motivation is then provided in Chapter 9.

Goal-orientated motivation	Individuals might be motivated towards specific goals, and technology might seek to support work towards those goals.
Motivation to improve	Individuals might be generally motivated to improve, and technology might offer a set of specific routes to improvement.
Social support for motivation	Motivation might be supported by the engagement of others. Technology could offer a mechanism for others to become supportively involved.
De-motivational factors	Incorrectly designed technology can be de-motivational. Technology could be used to address de-motivational factors.

Figure 6.15: A summary of the orientations to motivation uncovered through design work and their implications for technology.

6.4.2 Designing technologies that are tailored to the unique needs of individuals

A key question for research into rehabilitation technologies, as identified but not fully addressed by Alankus et al in 2010 [25], is that of how to tailor technologies to the needs of individual stroke survivors, especially given the wide range of physical, sensory and cognitive difficulties that can be caused by a stroke. Individual differences in motivation are one example of a factor to take into account in a tailoring process, and this chapter has provided a number of example of how to understand and respond to this. There is then a much broader range of other factors that have played a part in the design work presented in this chapter, some of which may be relevant in other contexts. A summary of some key factors is provided below, along with examples drawn from the case studies presented above to highligh their importance. Some of these overlap with the discussion of motivation presented above.

Appearance and form factor: Irene was instinctively nervous about computers in general, and yet we found that, when supplied with a tablet PC with a custom interface, she had no nerves at all. Joan had a home whose appearance was carefully designed, and preferred a technology that fitted into it.

History of therapeutic engagement: Sophie had developed a belief that physiotherapy would always focus on dull, repetitive exercise, which coloured her engagement with the process that we had designed. Joan felt abandoned by the medical system, and had failed to inform any medical professionals about her expected second stroke. Although not directly a medical issue, Irene and her husband had been poorly treated by previous researchers, and a significant amount of effort was invested in gaining her trust.

Role of family members: Irene's husband offered to take charge of downloading photographs or books onto her tablet PC, and Joan's husband offered to ensure that she would perform exercise correctly. In contrast, because Sophie's husband worked long hours, then her parents were her primary carers, and both were already actively supporting her rehabilitation. Joan liked the idea of a system that provided music as a reward, but prior conflicts with her partner over music choice made this unacceptable. Irene's partner was very keen for her to use the tablet PC to access the Internet, and yet Irene was entirely uncomfortable with this.

Ergonomics: Solomon required a supportive arm rest to allow is use of the constructed system. When selecting a set of shelves for a prototype for Joan, careful consideration had to be made of her height to ensure that the right one was selected. The passive prototype deployed for Sophie required modification to provide correct ergonomics. Irene was incapable of holding anything for very long, and hence was provided with a tablet PC that could rest on her lap, and a careful selection of squeeze switch was made to ensure that it was usable for her. The house that Sophie lived in had substantially more capacity to support ergonomically satisfactory design than the house that Irene lived in.

Usage of the home: Irene avoided her kitchen post-stroke, and spend much of her time sitting in a chair whose environs provided her with stimulation. Solomon also had a chair which he preferred, and which had been setup for his comfort. Sophie spend much of her time in the conservatory, which then provided sufficient space for a relatively large artefact.

Given the potential cost of tailoring technologies to the nees of individuals, and given the very large number of individuals who are living with disability acquired through stroke, there is an open question about how to make the process of tailoring amenable for application on a large scale. In the case studies presented above, the process was lead by a designer, and was constructed around a series of observations made by them, and questions asked by them of participants, which then lead onto a series of rough prototypes constructed to elicit feedback from their future users. This is then a time-intensive process, which is unlikely to be applicable on a larger scale. It also contrasts with more traditional forms of participatory design (such as future workshops [134]) in which participants are lead through exercises that allow them to engage with the creative process more directly.

To allow for its wide-scale application, it may be that the process of tailoring technologies to the needs of stroke survivors needs to become more streamlined, potentially involving a toolkit of physical interface devices and software content. This is an issue that is considered in more detail in chapter 8, which considers how such a toolkit might be designed.

Chapter 7

Deployment of prototype systems as technology probes

Having described the process of designing tailored technologies with the participation of survivors of stroke, this chapter now documents the deployment of prototype implementations of these designs, contributing data and analysis which also considered in Chapter 8. In relation to the production of knowledge by this thesis, systems deployed during this process have been conceptualised as *technology probes*, an approach to research which has a substantial history of application within HCI. According to Hutchinson et al [129]. technology probes are artefacts which are intended for deployment into the real world, which are flexible and adaptable, and which play to three related motivations for engagement by researchers:

- understanding the needs and desires of users in a real-world setting

- field-testing technology

- inspiring users and researchers to think about new technologies

Robust prototype systems are often considered to be ideal candidates for deployment as technology probes, as their potentially unfinished nature can make it easier for users to critique them, thereby supporting a debate about their needs. The deployment of technology probes is a common practice within a broader area of research often known as "Research in the Wild" (e.g. see [169]). Deployments "in the wild" often lead to unexpected and interesting findings, which can then be reported, analysed and can then influence further iterations of research.

Prototype implementations of the four designs described in the previous chapter were developed during the Motivating Mobility project. In assembling these prototypes, the author contributed a substantial amount of development work, in collaboration with a project colleague based in Dundee. Of the four prototypes developed, deployment lasted seven months for Irene and one month for all other participants. Each deployment was supervised by a professional physiotherapist, for the purposes of safety. Throughout the deployment process, data has been collected to support an understanding of the usage and impact of these prototypes. For each prototype, this chapter presents an integrated description of this material, which has been written specifically for this thesis. It also presents an analysis that integrates across these descriptions, highlighting a number of key themes that cut across the descriptions, and which are related to the core research questions presented earlier in this thesis.

7.1 Ethical considerations

Ethical issues have been considered in a number of preceding chapters, and key features of the approach to ethics that has been described in those chapters have also been adopted during the process of deployments. As in previous chapters, collected data was anonymised, and participants consented to its publication beyond the project. A channel of communication to an independent researcher was maintained, and participants were reminded that they could contact an allocated physiotherapist at any point. There were also a number of ethical considerations that were distinctive the process of deployment, requiring additional safeguards to be put in place.

One such safeguard related to the nature of our participants, in that all were either of pensionable age, in the case of the two participants at Sheffield, or not earning a living, in the case of the two participants at Southampton. As such, there was the possibility that all were living on a small income. Usage of a computational rehabilitation technology necessarily carried a cost, in terms of electricity usage. For ethical reasons, and also for the purposes of research, we wanted to avoid participants having to make a choice between using our technologies and saving money. As such, we calculated a reasonable compensation for the cost of electricity used, and provided that to participants in advance of their usage.

A second safeguard related to the possibility of acquiring additional disabilities through performing exercises without sufficient attention to quality of movement - see discussion around the Bobath approach to rehabilitation in Chapter 2 for further details on this issue. The chosen approach to resolving this then drew upon the expertise of the movement therapists working for the Motivating Mobility project:

- Each deployment began with a deployment session, conducted in the home of a stroke survivor, in which a physiotherapist described the safe usage of the technology and demonstrated how to perform exercises in a high-quality manner

- The physiotherapist then rang the participant on a weekly basis during the first month of the deployment period, to ask questions about usage and to provide advice about any difficulties

- After one month, a debriefing meeting was held in the home of the stroke survivor, where any issues around exercise could be discussed directly

- For those deployments that continued beyond this debriefing meeting, telephone calls were conducted less regularly, but participants were reminded that they could contact the physiotherapist at any point if they needed further information

The rationale for this approach was then that this level of support generally exceeded the level of support that would be provided through a more traditional movement therapy intervention, and that it would be of sufficient intensity to identify any difficulties caused by usage of the equipment, especially in relation to any physical problems that could develop.

If tailored rehabilitation systems were ever to be deployed on a larger scale, then it may be infeasible to deliver this level of support. This then a topic addressed in more detail later in this thesis.

Irene - the Rehab Reader	A time-stamp for each individual squeeze of the pressure switch, and the section of text which was displayed on the screen both before and after each individual squeeze.
Joan - the Exercise Machine	A time-stamp for each button press, along with a specification of the exercise that was triggered by that button press. Parameters for the exercise specification were *exercise type*, *object type*, *repetitions requested* and *hand requested*.
Sophie - the BallFUNnel	A set of recorded audio files, each of which was time-stamped, and each of which was linked to identifier for the RFID tag to which this sound had been attached. Each activation of either RFID reader was recorded, along with the ID for the RFID tag which caused the activation.
Solomon - the Chess Game	A time-stamp for each squeeze and release of the switch. A record of the types of piece chosen for pressure switch control in each game, a record of all the moves made in each game, and a record of the end result of the game.

Figure 7.1: Logging data collected during each deployment.

7.2 The collection of data through four technology deployments

Four prototypes were deployed, and for each prototype, logging data was collected to provide information about its usage. Logging data was stored directly onto the device, was backed up to an internal SD card inserted into the device, and was collected at the end of the deployment. Generic data logged by each prototype included the start and finish time of each session of use. For each prototype, additional information was then logged which was specific to the design of the system. The table presented in Figure 7.1 describes the specific logging data that was collected for each prototype.

For each participant, a number of interviews were recorded. Interviewing was limited by the availability of participants, and by a desire to avoid disruption

Irene - the Rehab Reader	Two interviews were carried out by phone during the first month, with an interview carried out in person at the end of this period. Additional interviews were carried out during the course of the deployment, whose first phase concluded after roughly 9 months.
Joan - the Exercise Machine	A single interview was recorded after one week, and an exit interview was recorded after one month. A brief telephone call was carried out several days after the exit interview.
Sophie - the BallFUNnel	An exit interview was carried out in Sophie's home, and a paper diary was provided to record written messages.
Solomon - the Chess Game	An exit interview was recorded after one month. A variety of emails were also exchanged during the deployment, and a paper diary was provided to record written messages.

Figure 7.2: Qualitative data collected during each deployment.

of their experience of use. The table presented in Figure 7.2 summarises interview data that was collected for each participant.

7.3 A descriptive analysis of data collected during deployments

Working from an archive of data collected during the Motivating Mobility project, the author has produced the following summaries of data collected in relation to each deployment. For each participant, these present key findings in relation to the use and impact of the prototype. A further analysis of this material is then provided at the end of this chapter.

7.3.1 Irene - the Rehab Reader

The Rehab Reader was collected from Irene after seven months of usage. At this point, system logs suggested that Irene used the device across 14

sessions, with a mean count of 472 squeezes per session, yielding a total of 6621 individual grasp and release exercises. Sessions are highly concentrated during the first two months of the deployment, and tail off for the remainder of the time.

Use of the system began slowly for Irene, as she experienced a burst blood vessel in her left eye the day after the deployment meeting, which was not connected to her use of the system. However, by the end of the first week, she reported reaching chapter 5 in the book, using the device for roughly 30 minutes session. She also reported a personal desire to use the system more the next week. However, she complained that her husband reminded her every day where she had not used it, and said that it "feels like he's bullying me a bit". During the second weekly phone call, she described reaching Chapter 19, that her hand was feeling more mobile but also stiffer, and that her husband was not pushing her so much. At this point, the supervising physiotherapist reminded Irene to stretch her hand with every 15 minutes of use, to avoid causing any further physical difficulties.

During the in-situ interview after one month, Irene told us that she had started to use the system for an hour at a time, but that she felt constrained by aching in her left eye. The physiotherapist then suggested that she needed to build up her use of the system slowly. The possibility of building in a function which enforced a break after a period of time was suggested, but Irene did not like this at all.

When asked about interactions with her husband, Irene described arguments that the system caused. Irene's husband takes regular exercise sessions, earlier in the morning, involving the Nintendo Wii and martial arts videos. She described how he views the system as another exercise device, and tries to push her into using it at the same time every day, before she is ready to use it, even if her eye was tired. For her, it seemed clear that she viewed the device primarily as a means for reading a book, with exercise being a secondary benefit. It seemed clear that, to her, the right time to read it was when she feels comfortable and ready to read, rather than doing it as something she ought to do.

On the theme of arguments, it seemed clear to the author that Irene's personality had changed over the last month. She came to meet us at the door of the house (which she had never done before), was quite frank about her arguments with her husband, and at various times told him not to inter-

rupt her. To the author, she felt more present and individualised in her responses, whereas before she had been much more distant, and reliant upon her husband in interactions.

Irene was next interviewed, by telephone, three months into the deployment. At this point, she indicated that she had reached some chapters that she found dull, and was therefore using the system less. A second interview, two months later, revealed that she had stopped using the system regularly, because of being bored of just one book. Following on from this, a second version of the system was deployed at the seven month mark, which provided the ability to choose between multiple books. However, a third interview, after another month, revealed that she had gained sufficient ability in her left hand to allow her to hold a physical book, and, having obtained some large print novels, was preferring to read these. At this point, it was decided to conclude this phase of deployment with Irene.

7.3.2 Joan - the Exercise Machine

During the first weekly phone call, Joan reported that she was using the system every day, but that she was feeling stiff. At this point, she was provided with a suggestion of a temporary limit to the number of exercises that she should do, to provide her with some time to make a physical adjustment.

At the exit interview, it seemed clear that Joan had made a very significant physical progress. She seemed more energetic, was moving around more, and talked about doing activities that she hadn't done for a long time (such as using her sewing machine). She reported that she and her husband had been doing exercises together every day, inspired by the system, and by exercises that he had done in the armed forces.

On examination of the logs recorded by the system, however, we learned that Joan had only used it across three sessions, during the first week of deployment, as summarised in Figure 7.3. This certainly contradicted statements that she had made about using it every day. Confirmatory evidence for this pattern of usage was provided by an analysis of Windows XP system logs, which indicated that the device had only been turned on three times during the deployment period, at times matching the logs reproduced in Figure 7.3.

Through a brief telephone call with Joan and her husband, several days later,

19/3/2010	62 exercises requested between 11:02 and 14:23
20/3/2010	4 exercises requested between 11:19 and 11:21
21/3/2010	21 exercises requested between 11:09 and 11:30

Figure 7.3: Log entries illustrating the number of exercises requested by Joan during a deployment.

we confirmed that she had only used the system a few times, but that it had provided inspiration for her and her husband to develop their own exercise routine. This then explained the discrepancy between Joan's recorded and reported usage.

More recently, we have learned that Joan has suffered a third stroke, roughly three months after this period of deployment ended. However, we have also learned that, throughout this three month period, she continued to exercise daily with her husband, and has carried on doing so after discharge from hospital.

7.3.3 Sophie - the Ball FunNel

Initially, deployment of this technology suffered from a number of teething problems that related to the cables that attached the sensors to the laptop. A long USB cable which was integral to the design tended to become detached when the box was moved around the home (to make space for other toys), and connections to the RFID sensor also became detached, potentially due to Felix stuffing toys into the Ball FUNnel. Minor modifications to the system were made by a member of the Motivating Mobility team, which fixed these problems for the remainder of the deployment. Sophie and her mother repeatedly raised a further issue during the deployment. Custom software developed by the author and another project member had not been designed to persist recorded sounds to long-term storage, which meant that, when the laptop was powered-down, any recorded sounds were lost. Sophie's mother explained that they would have preferred sounds to be persisted, and expressed annoyance about having to re-record sounds across multiple sessions.

In terms of their usage of the device, Sophie's mother reported that Felix was keen on using it, and tended to initiate play by slapping it, and by

shouting "box". Sophie would then try to put 40 balls through the box, but Felix would tend to get bored after roughly 8 balls, and would start throwing them around the room instead. At this point, Sophie's mother would often have to tidy these balls up. In addition, if the box stopped working due to issues with cabling, Sophie's mother would often try and replicate the sounds that should have been played for each ball, which maintained Felix's interest in playing.

An analysis of logging data suggests that Sophie used the Ball FUNnel across at least 33 sessions, and confirms that, on average, she knocked 40 balls down the hole each session.

However, Sophie failed to respond to requests for an exit interview, and all contact with her was lost at this point in the project. Correspondence with her parents confirmed that she had simply lost interest in engaging with us, thereby limiting the amount of evaluation data that could be collected in relation to this deployment.

7.3.4   Solomon - the Chess Game

Early in the deployment, Solomon experienced a number of technical problems. These had been caused by a late rush to deploy the system before the end of December 2009, as Solomon wished to start another study in February 2010. As such, testing time for the final implementation was extremely limited. These technical problems were, however, resolved, and logging data suggested that Solomon conducted 11 sessions of use with the device, squeezing the sensor 16 times on average per session, and carrying out 175 squeezes in total.

The exit interview carried out with Solomon after one month provided some interesting insights on his experience of using the system. In particular:

- Solomon described how using the device had got him into the habit of doing repetitive exercise, and that this did not feel like a chore whilst he was using the game.

- Using the television as a display device has not worked very well. Solomon preferred it, but his partner often wanted to use the television for her own purposes.

- Solomon did not find the game aesthetically pleasing, and cleared it away when others visited the house. His partner did not like the appearance of the device used to provide input, and disliked the clutter that it caused in the living room.

- Solomon's enjoyment of playing chess did, at times, support him in overlooking some of the difficulties in using the technology, such as the need to place his arm into a support to do so.

7.4 Discussion of key issues

Having provided a descriptive analysis of the outcomes of deploying these four prototypes, this chapter now concludes by highlighting three key points that have emerged from these descriptions. These are then considered in more detail in analysis and discussions presented in succeeding chapters.

The implications of linking rehabilitational exercise to individual motivations

Design work presented in Chapter 6 has considered the tailoring of technologies to individual differences in motivation for recovery. Deployment of prototype implementations of these designers has then produced knowledge about the implications of this approach which can then inform future work.

Specifically, in focusing on motivating factors, then exercise becomes more dependent on motivation, which then creates certain dangers. In the case of Irene, for example, a book was used as motivation for engagement. As such, when she approached a section of the book that she found less interesting, she then did less exercise. In addition, later in the deployment, she also became de-motivated by only being able to read one book, and her exercise was reduced as a result. In both cases, this reduction in exercise would then limit the rehabilitational benefits of her usage of the system.

In the case of Sophie, both her and her parents had expressed a clear desire for a system that was constructed around interaction with her son. However, through the deployment of a prototype of this system, it became clear that the amount of exercise that was engendered by the system was very

dependent upon his level of engagement, which then varied depending on his interests.

This issue was less important for Solomon, who used a chess program with an automated opponent. The level of play of this opponent could be increased as his chess abilities improved, and he could also select a harder exercise task by choosing to control more pieces with his hemiplegic hand. Joan seems to have used her system as a stimulus to change her pattern of everyday life, and started doing exercises with her husband; as such, she rapidly detached herself from any dependency on the system, which seems like a very beneficial outcome.

Collectively, these examples highlight the dynamic and social nature of motivation. Given that efforts to engender rehabilitation may have to continue for multiple years, then the nature of technology that is tailored to individuals in light of an understanding of their personal motivations may need to be repeatedly changed, suggesting either the need for interventions from an external professional, or interfaces that allow individuals to become involved in the tailoring of the interventions themselves. In general, when seeking to engender long-term engagement with a process of rehabilitation, a one-off assessment of individual motivations is unlikely to sufficient - assessments may need to be repeated on a regular basis.

In the case of Solomon, exertion was linked to interaction with an activity (i.e. playing Chess against a computer), that he could engage with more easily through use of his working hand. This then raised a question of whether this technology might actually damage his motivation, in that it could have reduced his enjoyment of Chess by making it more difficult. Through the process of design, efforts were made to avoid this, in that Solomon was some control over the required level of difficulty of his physical movements. Interviews with Solomon provided no evidence for any damage to his enjoyment of playing Chess; instead, his enjoyment of the game seemed to help him in establishing a pattern of regular activity, and in overcoming some initial distaste for the aesthetic appearance of the technology. Whether this would be true for all users of such technology is an open question, with wider implications for the design of exertion interfaces more generally.

The necessity of therapeutic intervention to ensure participant safety

All of the prototypes described above were intended for usage in the home. As part of the process of ensuring the ethical conduct of the Motivating Mobility project, telephone interviews with professional therapists were provided at regular interviews, and an emergency phone number with direct access to a therapist was provided. In the case of both Irene and Joan, the therapist felt the need to recommend temporary limitations on the volume of exercise, to avoid engendering physical problems. This then suggests that none of these designs were appropriate for fully unsupervised usage in the home, which then raises the question of how to support unsupervised usage, given that the necessity of involving a therapist raises the cost of interventions.

In both cases, the problem identified by the therapist was over-exercise. It might then be possible to develop automated functions that identified over exercise, and restricted usage where necessary. It should be noted, however, that when asked, Irene argued very strongly against this kind of functionality. How to ensure that exercise continues to be therapeutic, rather than excessive, is then an interesting issue for future design work to engage with. The parameters of any solution might depend upon the social, clinical and organisational context into which the system is deployed, in that some settings may have more resources for direct social support for interventions than others.

How best to identify and respond to over-exercise is then an open question for research, and one that is applicable more broadly to exertion interfaces that are constructed around a manifesto of encouraging appropriate levels of exertion. Existing responses to this challenge, in the context of research into exertion interfaces, include the use of heart-rate monitors to sense when users are working within an acceptable range of target heart-rates, coupled with the design of game mechanics that rewarded exercise within that range (e.g. see [106]). This kind of approach works well because heart-rate is simple and cheap to sense, and over-exertion is relatively easy to identify and respond to. However, in the case of stroke rehabilitation, exertion may often be specifically focussed on just a part of the body, and heart rate is then unlikely to be a good proxy measure to adopt.

In relation to this question, a number of authors have conducted lab-based

studies to explore the use of body-mounted sensors to detect and characterise quality of movement (e.g. see [170]). However, whether it is realistic to expect stroke survivors living in their own homes to attach sensors to themselves is an open question, and a whole range of alternative mechanisms to ensure safety might be possible.

Implications of the social nature of the home

All of these prototypes were deployed into the homes which were shared with others. As such, these are inherently social environments, and interactions with others in these environments had an influence on how systems were used:

- Irene and her husband had a very different conceptualisation of the intention of the prototype, and this let to arguments between them, and pressure on Irene to use it in a manner that was potentially damaging to her motivation and rehabilitation

- Joan and her husband were inspired by the system to develop their own exercise routine, which has even persisted beyond a third stroke

- Sophie's usage of the system was strongly tied to the interest of her son, and the amount of exercise that she did depended on her usage

- Solomon's prototype interfered with the aesthetics of his lounge space, which he shared with his wife

Collectively, these observations highlight the various ways in which the social nature of the home can impact usage of a technology, which is then an important issue to consider in the design of future technologies. This topic is then discussed in much more detail in Chapter 8.

7.5 The limitations of participant reflection

This chapter is shorter than many in this thesis, as reflective feedback provided by participants during interviews conducted in-situ and by telephone was relatively limited, and much more limited than the author has encountered in other processes involving technology probes. On reflection, this then

suggests that interviews were not the optimal method for collecting evaluation data, and that other methods may have been more appropriate.

This issue is considered further in Chapter 9, which provides a reflective discussion of the methods described in this thesis. How best to conduct ethical research with individuals who are experiencing cognitive difficulties is still an open question, and one which is potentially of interest to HCI research which engages with individuals with a variety of different health conditions in which cognitive difficulties are associated, such as dementia or Alzheimer's disease.

Chapter 8

Abstractions to support future work

The introduction to this thesis has raised the question of how to

1. tailor rehabilitation technologies to the needs of individual stroke survivors

2. design rehabilitation technologies that are sensitive to the unique needs of the home as an environment

3. structure a toolkit to support the wider-scale deployment of rehabilitation technologies

Working from these questions, the three previous chapters have then presented a set of sensitizing concepts intended to support an understanding of elements of the experience of life post-stroke that are relevant to technology design and described the design and deployment of technologies tailored to the needs of four stroke survivors, and intended for usage in their home.

The purpose of this chapter is to contribute a set of abstractions which are intended to support the work of designing better rehabilitation technologies in the future. These are grounded in material presented in these chapters and in literature review work presented in Chapters 2 and 3.

To identify these abstractions, the author has reflected on material presented throughout the thesis, identified themes that link this material together, and made a series of judgements about the novelty of these themes and their

relevance to the design of interactive systems. This judgement has drawn on the the review of literature relating to rehabilitation systems presented in Chapter 3, and on the author's knowledge of literature relating to domains such as HCI and CSCW, which it references throughout.

A broader reflection on the process of research is then presented in chapter 9, which summarises the contributions that have been made, presents some open questions for future research, and reflects on the successes and limitations of the chosen research methodology.

8.1 A set of guidelines to support the design of home-centric rehabilitation technologies

As described in Chapter 3, the home is currently a focus of research around rehabilitation systems. In many countries, survivors of stroke are being discharged more quickly from hospital, which then raises the importance of supporting rehabilitation at home. In addition, because rehabilitation can continue for many years, then much of it must take place outside of the hospital environment. This then implies a substantial proportion might then be supported through interventions targeted at the home, in which survivors of stroke may spend a large proportion of their time.

Much of the existing research around home-based rehabilitation systems has been conducted from a perspective which is system-centric, in that it focuses on describing the design and evaluation of individual systems. Where deployments have been made, they have often involved the deployment of systems that have been pre-designed, and which are not tailored to the needs of the home or its participants. Users are therefore expected to adjust their domestic routines to the needs of the system, rather than the other way round. System-centric viewpoints are therefore potentially disruptive to domestic life, and this may then limit the ways in which systems are appropriated and used.

In contrast to this system-centric approach, a significant strand of prior research within HCI and CSCW has focused on describing the unique nature of the home as a place in which people live (e.g. see work by Gaver et al [6],

Crabtree et al [29] and Hindus [117]). This prior research then suggests an orientation to analysis which is home-centric, and which considers the challenge of designing systems which are less disruptive, and which are rooted in an understanding of the unique nature of the home. Such an orientation may be particularly important in relation to stroke, given the significant changes to domestic organisation which can be caused by it (concept 5.1, Chapter 5), and that survivors and their families can experience severe levels of existential stress even many years post-stroke (concept 5.7, Chapter 5). Given the participatory nature of the processes described in Chapters 6 and 7, how to design systems that fit into the home as a place of living is then one topic that an analysis rooted in these chapters can speak to, and is the focus of this section.

Homes are complex places, and designers cannot expect to attend to every aspect of home life in when making decisions around designs. In seeking to establish the designs presented in Chapter 6, designers made a choice of which phenomena to attend to, and this then had implications for the designs that were presented. An analysis of this process can then provide guidance about such phenomena, which can then simplify the process of design in the future.

In seeking to support a process of design which is home-centric, this section therefore begins by presenting four guidelines which highlight phenomena to attend to. These guidelines are rooted in evidence collected in Chapters 6 and 7.

These guidelines then raise the immediate question of how to design materials that support an assessment of the home in relation to systems that might be designed for them, and how to support a more systematised process of design and deployment. This is then a key question in relation to the development of a toolkit which allows for cost-effective deployments. A conceptual framework to support the design of such a toolkit is then considered in more detail in Section 8.4 which concludes this chapter.

Guideline 8.1: Understand patterns of domestic usage which have been caused by stroke, and consider these when producing designs

For all four participants, stroke had disrupted their patterns of usage of their home. Sensitivity to those patterns was then important in establishing effective designs, and these patterns impacted on the four different designs in different ways.

This issue was particularly clear for Irene, who stated early in the process of design that her kitchen was completely out of bounds for her. This seemed to be a psychological consequence of stroke, and related to her changed role in the organisation of the processes of the household. In response to this, it was observed that a *comfortable place* had been constructed around a chair, positioned by a window, with direct access to entertainment equipment. Understanding this usage of space then suggested the value of designing a system which could be used in this location. Small changes then facilitated the integration of this system into everyday life; these included the long-term placement of a table next to the chair; the system was placed onto this when not in use, and this allowed it to be picked up when required, without Irene having to move from the chair. A system which was not as suited to the current usage of space may not have been as successful, which then points to the value of considering this issue in design and deployment.

Similar considerations were at play for the other participants as well:

- Solomon clearly had a chair which he spent a lot of time in; a system was then constructed which could be used from this chair, although it did require the addition of a movement support for his arm and a tray to place the system on.

- Sophie spent a lot of time in her conservatory, and hence a system appropriate for this environment was designed. This system was bulky, and might have been inappropriate for the spaces inhabited by other participants, but was appropriate for Sophie's home, which had plenty of storage space

Whereas for these participants, one aspect of design involved the identification of usable space, a slightly different situation was at play for Joan. This

participant had a substantially more minor disability, and felt comfortable using all of the spaces in her home. She had also maintained control of domestic tasks such as cooking, but had insufficient strength to manipulate some of the heavier items found in the kitchen, such as pans. A system that featured exercises constructed around domestic items was then designed, to provide motivation to engage. This system then led onto the establishment of a regular exercise routine involving some of these items, so appears to have been successful.

Guideline 8.2: Consider the social possibilities of the home

Almost all homes have social elements. Even homes with one inhabitant are likely to have at least occasional visitors. In the case of the homes featured in Chapters 6 and 7, all were occupied by both a survivor of stroke and a partner. In addition, three of these (Irene, Joan and Solomon) had regular visits from adult children, whilst Sophie's home had regular visits from her parents, and was lived in by her child. For Irene, Joan and Sophie, the social context in their homes had an important influence on both the design and deployment phases. In particular:

- *Irene*: she had a partner who played an important role in the process of design, often by providing a critique of ideas that we suggested, partly based on an understanding of the needs of his partner. This couple had experienced difficulties in relationships with other researchers with whom they had engaged, and he therefore acted as a gatekeeper to the home, and he was forthright in arguing for a process that reflected their best interests. However, during the process of deployment, his contribution might be perceived as disruptive; he appeared to pressurize Irene to use the system too frequently, which carried the danger of reducing her enjoyment of it, and also risked physical difficulties caused by overuse.

- *Joan*: her partner did not suggest ideas during the process of design, but his contribution to the process of deployment was vital; after having used the system three times, he and his partner then chose to design their own exercise routine together, aspects of which drew on his time in the army.

- *Sophie*: her parents suggested ideas during the design phase. They also monitored her use of the system, and suggested and made improvements to its ergonomics. The system itself was constructed around her relationship with her child, Felix, and was intended to support play between herself and Felix. Her mother also actively engaged with the system, encouraging her usage, and helping to make play as fun as possible.

In the case of Solomon, we constructed a prototype system that required him to use his partially disabled hand during the process of playing chess against a computer. However, Solomon described an ideal system that used this mechanism, but that would have involved him playing chess against others, over the Internet. There was insufficient time to construct such a system, but if it existed, then it would have utilised elements of the social context that were outside of the home, but which were experienced inside the home, as a motivation. Similarly, for Irene, the presence of a digital photo frame that cycled through photos of her children hinted at the importance of the comfortable place in the lounger where she tended to sit. This then led, through a prototype that gave her direct control of the progression of photos on a frame, to a prototype that gave her direct control over progress through an electronic book.

Given the opportunities provided by the social context, the design of systems which involve an explicit contribution from members of the social context then seem an important topic for future research. One opportunity might be to develop interfaces to such systems that are usable by others in the social context. As an example, an interface that provides training in how to effectively carry out relevant exercises to support might be beneficial.

Guideline 8.3: Respect the home as a place of living

For all participants involved in this study, their home was the place in which they normally lived, and spent a substantial amount of time in. As such, for some participants, there were elements which were important to respect, but also elements with which some flexibility could be associated. For Joan, for example, a clearly-stated desire was for a system which did not introduce clutter, which could be tidied away easily, and which did not cause any damage to the decoration of the home, which had clearly been a long and valued

project. As such, a system was designed which had a small technological footprint, and which could easily be moved. In contrast, Irene and her partner were less worried about any changes caused by a system, and were happy to make any changes required. As such, during our discussions, they motivated the design of a system that was as effective as possible, regardless of its size and impact. For Solomon, a system was designed which was intended to make use of a television as a video output device. However, usage of this television was shared with his partner, as part of their domestic routine, and hence this aspect of the system did not work effectively. Instead, Solomon began to use his laptop whilst using the system, but this caused difficulties with ergonomics and with clutter. Both Solomon and his partner disliked the part-finished nature of the prototype that was deployed, and especially the appearance of the squeeze sensor shown in Figure 6.14. They described how this was particularly important when visitors came. As such, this aspect of the design of this system played insufficient respect to their home as a place of living.

The issue of respecting the home seems particularly important to consider given the substantial changes to a home that can be required post-stroke, and the levels of stress that survivors and their family members can experience. Systems that do not respect the home as a place of living, and which any cause further change which is not desired might add to stress levels which can already be very high. As such, we might then expect them not to be used as effectively as they might, and potentially just hidden away and not used at all.

Given the importance of respecting the home as a place of living, prior work constructed around issues such as aesthetic design and the home is very relevant. Many existing systems intended to support rehabilitation appear relatively utilitarian, with an aesthetic grounded in the medical perspective. However, Hindus et al [171] have described the home as a "sanctuary". For those homes where this is true, then home-based rehabilitation systems need to respect this value, rather than creating additional stress by disturbing it. Systems that invovle ugly, bulky hardware, or the strapping of sensors to affected limbs, are unlikely to do so.

Interesting questions include how to apply design tactics which have proven successful in producing artefacts that are appealing enough to gain a place in the home, and to be used regularly, but at the same time to retain sufficient

rehabilitational value. The author find work such as the Drift Table [132] particularly inspiring. Are there equivalent artefacts that work as rehabilitation systems?

Guideline 8.4: Consider the architectural and organisational affordances of the home

Homes are physical spaces, and the four homes with which we engaged were very different. For example, Irene and her partner lived in a small flat, whereas Sophie and her husband lived in a very large detached home. Different systems have different footprints, and, to be effective, it seems important that they match to the affordances of the home for which they are defined. The system for Irene might not have been as effective at all if it were not for the availability of a small table which could be used as a semi-permanent storage space for it. Similarly, Joan had a gap along a long wall that could be used when she wished to work with the system; it also had a sufficiently-small footprint that it could be easily stored when not in use. How to assess such affordances is one question that relates strongly to the future design of a toolkit to support the deployment of effective rehabilitation systems.

8.2 From "technology as a motivator for exercise" to "technology that provides a pathway back to normal activities"

Chapter 3 has provided a detailed review of existing rehabilitation technologies for stroke and other forms of brain injury, which has focused on robotic technologies, on uses for virtual reality and virtual environments, and on technologies specifically designed for the home. Cutting across these three approaches are a number of orientations to methods for supporting rehabilitation. Of the systems reviewed by the author, the most common approach seems to be to provide content that motivates engagement, and to provide a physical interface that requires usage by a part of the body in which a disability has been acquired. The assumption here, which is rooted in therapeutic approaches such as Bobath [49], is that rehabilitation requires movement, and that systems need to motivate movement to be effective. A danger of

such systems is that abilities acquired through this form of interaction are not translated into abilities in "real life", and that the benefits of system use are not then experienced once the system is no longer available, or once the client tires of the system.

Previous researchers have addressed this issue in a number of ways, and an analysis of case-studies presented in Chapters 6 and 7 has provided a limited amount of additional knowledge which is relevant to this topic. One of the most common orientations towards translating abilities into real-life is to ignore the issue. The vast majority of papers that present trials of rehabilitation systems consider systems that present relatively synthetic tasks, and are trialled over durations of use measured in hours, days weeks or, occasionally, months. However, case-studies presented by Bobath [49] indicate that rehabilitation often takes years of effort, so such trials are never likely to consider a rehabilitation process from beginning to end. Instead, trials often involve a carefully-selected cohort who satisfy a set of inclusion and exclusion criteria, and feature the use of a variety of measures to assess changes in abilities in particular movements. Success is then inferred from the statistical analysis of changes in those abilities. Although valuable, statistical improvements in carefully-selected measures of ability do not necessarily transfer into real-world abilities, and a substantial body of stroke survivors may be excluded by the criteria used for selection.

There are a limited number of studies have considered the transference to normal life of abilities regained through interactions with systems. Todorov, Shadmehr and Bizzi [24], for example, present a virtual reality training system that attempts to teach the movements required to hit a ball with a virtual table-tennis bat, and then provide statistical proof for enhanced abilities in hitting real balls with real bats. This at least demonstrates the potential for re-learning a real-world skill through interacting with such a system, although the task itself is still relatively synthetic, in that it considers an extremely limited movement within the repertoire of movements required to hit a table-tennis ball.

The key point here is that, whereas movement therapists are trained in providing rehabilitation support that, if maintained over the course of several years, has the potential to take a client from almost no movement to a complete recovery of movement, each of the individual pieces of work around rehabilitation systems has only considered an interaction that lasts for a

short segment of the required rehabilitation period. As such, the author cannot locate any examples of research constructed around the use of interactive rehabilitation systems to provide support for a complete rehabilitation process. Instead, systems only consider particular phases within this process.

If the vision of using such systems to provide cost-effective support on a large-scale is to be realised, then the role of such systems across the entire process needs to be understood. This kind of effort raises a substantial challenge to research, given the relatively short-term nature of research project in comparison to rehabilitation efforts. However, two of the case-studies described in previous chapters at least hint at strategies that might be employed in such a long-term process.

Firstly, in the case of Irene, interviews indicate a progression onto the reading of physical books which occurred naturally, i.e. without any intervention from the author or a movement therapist. This progression suggests that a real-world activity had been regained through interaction with rehabilitation system. For this participant, the chosen tactic had been to provide an activity that was not synthetic, and which was implemented using an artefact whose form factor was relatively similar to a physical book. It may be the case that this system was then close enough in nature to a physical book that such a progression became natural. This then suggests a tactic of focusing on motivational activities that are not synthetic, and on artefacts whose form factor to physical artefacts whose purpose is related.

Secondly, in the case of Joan, a rapid progression onto real-world exercise occurred, following only three uses of the system. Reflection on design notes suggests that the major limiting factor for Joan was a lack of understanding in relation to relevant rehabilitation exercises, and a lack of confidence in the value of exercise in relation to recovery. As such, we can hypothesise that the system, as deployed, raised knowledge and confidence sufficiently to allow this participant to integrate exercise directly into her life. Although confirmation of this hypothesis was not possible, due to Joan experiencing a third stroke before further detailed interviewing could be conducted, this case-study suggests a tactic of designing for activities whose trajectory naturally leads away from system use, rather than activities which retain dependence upon system use, as is the case for much of the research which has been reviewed. We can hypothesise that these activities might embed elements of learning, or explicit prompts to move beyond system use.

8.3 Considering technologies that resolve contentions in the meaning and understanding of rehabilitation

A topic which has not been found in the literature around technologies to support rehabilitation, but which is potentially important to understand, is that of contention. This is a topic which has featured in at least two of the case-studies featured in previous chapters, and which has implications for the design of future systems. Here, contention refers to a variety of different issues, including different ways in which systems are understood by different individuals, and differences of opinion in the ways in which they should be used. Understanding the situations where contentions have emerged in the case-studies presented in previous chapters is important, in that it has the potential to reveal insights into the design of future systems that take contentions into account.

A number of interesting examples of contention can be found in the case study featuring Irene. Here, contention between Irene and her partner emerged early in the process of design, and continued throughout the deployment process. This contention then had the potential to influence the impact of the system on this particular situation. Concretely, the following are examples of contention during this process:

- Irene's partner saw the tablet PC as a prototype for a general-purpose communication device. As such, he advocated using it to access a wide variety of content, including electronic newspapers and web-site. In contrast, Irene was scared by computers, and wanted to see it as an electronic replacement for a physical book. Analysis of material collected during this case-study suggests that the simplicity of purpose of the final design, which only provided access to electronic books, assisted the success of this intervention. A final design which attempted to make a much wider volume of material available may have appeared much more like a computer, and may have limited the potential for engagement.

- Interviews collected during the deployment phase suggest that Irene's partner clearly wanted to see the end product as a device intended to support exercise. His personal orientation to exercise was then as an

activity which took place every day, at a fixed time. In contrast, Irene primarily saw the device as an artefact which gave access to reading material. As such, she was motivated to use it when she wanted to read. Irene described pressure that was placed on her by her partner to use the device on a regular basis; this might be understood as him applying pressure to understood the device as he did, rather than as she wanted to.

In the second example, such pressure may well have been counter-productive to rehabilitation; using a device when tired or de-motivated risks leading to poor-quality movements, which are understood as counter-productive within approaches to therapy such as Bobath [49]. In addition, to create pressure to use a device in this way may damage motivation to use it in the long-term, and reduce its effectiveness.

A different, and potentially more ambiguous example of contention is provided by the case-study involving Sophie. Early in the process of design, Sophie stated that she was coming to terms with losing full movement in her left arm, and that just using her right was going to be quicker. In contrast, Sophie's parents believed that she should aim to recover full movement in this arm, and were paying for a very large number of private physiotherapy sessions for her. At various points during the process of design, we wondered whether motivation to engage in rehabilitation was being provided by Sophie's mother, rather than herself, based upon comments that she made about finding physiotherapy dull and pointless. Towards the end of the deployment, Sophie broke off contact with the study team, and hence no exit interview was recorded. We wondered if this reflected a general dissatisfaction with the process of therapy on her behalf.

More broadly, contention is an issue which has been discussed in the therapeutic literature. Maclean et al [55], for example, discuss the issue of motivation of recovery on the part of patients, and suggest that therapists should attempt to understand the ways in which each individual patients is motivated, and tailor the rehabilitation programs that they design towards these specific understandings of motivation, rather than trying to impose their own beliefs around motivation on the client. A similar approach can be found in the person-centred approach to Psychotherapy, as defined by Rogers. Here, example texts include [172]. Within the person-centred approach, the emphasis is on a therapist who uses empathy and exhibitions of positive regard

towards a client to create a setting in which the client can explore their own feelings and beliefs, rather than being explicitly directed by the therapist to do so. Together, these observations around the work of professional therapists imply an approach which avoids contention between therapist and client by emphasising a role for the therapist that requires them to understand the beliefs and values of the client, and adjust accordingly.

How to design interactive systems that support therapy, but which avoid contention by not imposing meanings onto clients is an open question, which seems important to raise, but which cannot be answered in this thesis. However, prior research work which considers ambiguity as an important resource for design may be relevant in future investigations. Gaver, Beaver and Benford [173] have positioned the use of ambiguity as a tactic which can "encourage close personal engagement with a system". They then describe how:

> "By impelling people to interpret situations for themselves, it encourages them to start grappling conceptually with systems and their contexts, and thus to establish deeper and more personal relations with the meanings offered by those systems"

Rehabilitation systems that present elements of ambiguity in use might then encourage users to reflect on their own abilities, and to find novel and personal ways to integrate them into their own lives. These might then have a beneficial impact on rehabilitation.

8.4 A process-orientated conceptual model to support a more cost-effective deployment of tailored rehabilitation technologies

The introduction of this thesis motivated the need to construct rehabilitation systems that are tailored to the specific needs of individual survivors of stroke. In 2010, Alankus et al [25] discussed the issue of tailoring, and described it as an open research question, which is yet to be sufficiently addressed. Tailoring is particularly important because of the extreme variability in disabilities that can be caused by stroke. Chapter 5 has discussed the extreme dynamic range in the abilities of stroke survivors (concept 5.3), which means that, if systems

do not match very closely to the patterns of change in individuals then they may become unworkable.

Chapters 6 and 7 have then presented four systems that have been tailored to the needs of individuals. This tailoring has been produced by a design process that focussed directly on the needs of individuals, and which involved three or four design sessions per individual. This is then an infeasibly expensive process to roll out on a larger scale, and raises the question of how to deploy tailored rehabilitation systems in a more cost-effective way. One approach to supporting cost-effective deployments might be to provide a toolkit of technologies from which a particular deployment can be assembled. This approach has recently been advocated by a number of authors, including Balaam et al [27], in 2011.

A *system-centric* perspective to designing such a toolkit might focus on the software and hardware components required in such a toolkit. Drawing on material collected during the workshop described in Chapter 5, and on a review of the literature, the author has already published a paper [35] which attempts to identify these; one example is a component who purpose is the initiation of interaction with a user, and which can be configured with different policies depending upon the needs of the client, and the professional expertise of the person deploying the system. This paper is outside the scope of this thesis, so is not considered in any further detail here. A diagram from this paper is included in Figure 8.1 below.

However, in relation to the issue of toolkit design, this chapter has advocated the importance of a *home-centric* and *user-centred* approach, and has presented guidelines and tactics that are in keeping with these orientations. Working from this material, this final section now contributes a small conceptual model to support the future development of a toolkit to support the design and deployment of rehabilitation systems which is rooted in these approaches. This model is focused on the structure of the broader *process* of deploying rehabilitation systems constructed through toolkits, rather than on the technological capabilities of the toolkits themselves. The author has not found any discussions within the existing literature that relates to the process of deploying rehabilitation technologies, and hence this conceptual model represents a novel contribution that can inform future research. Chapter 9 then discusses further research that might be orientated around this model.

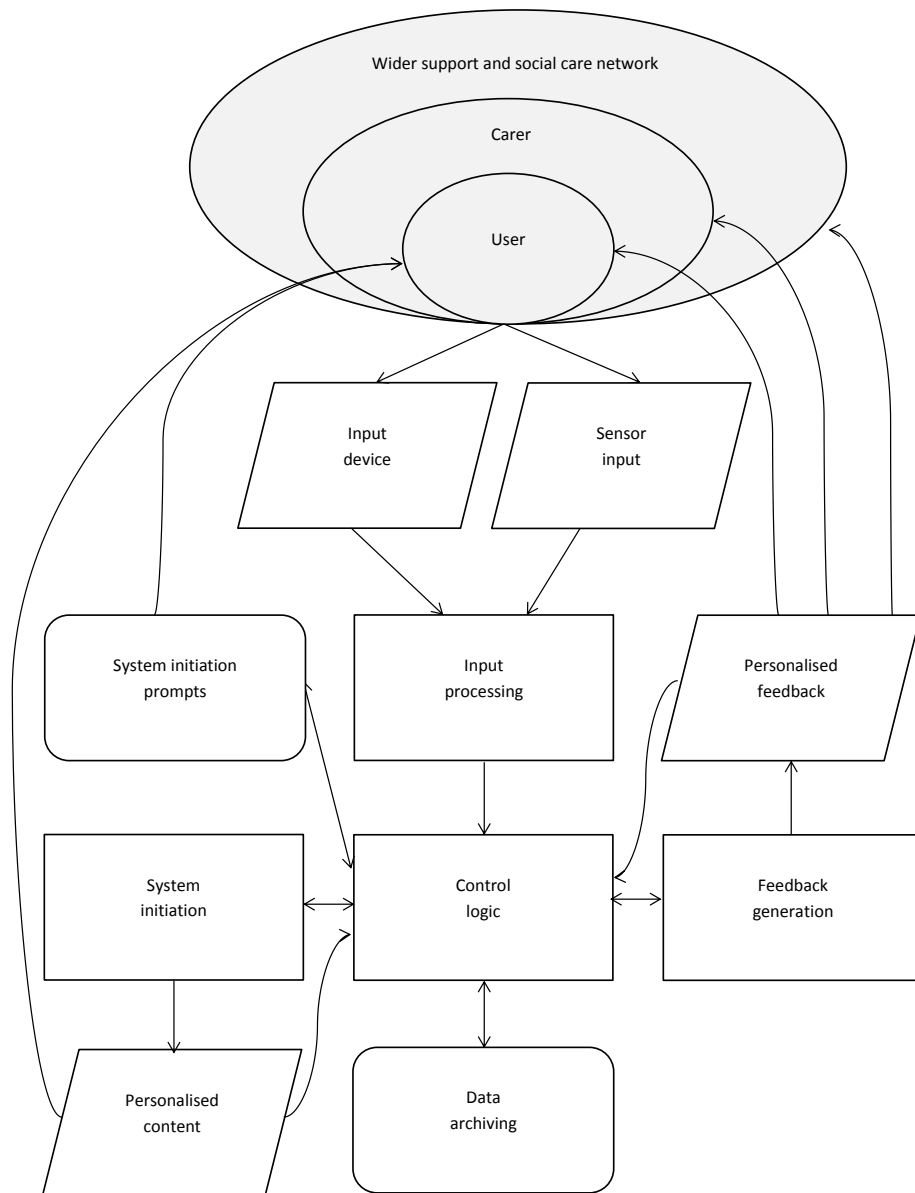Previous work in this thesis has indicated the importance of understanding

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Figure 8.1: A system-centric component model intended to support the development of a toolkit for rehabilitation. Redrawn from [35], previously published by the author.

the context in which a rehabilitation technology will be used, and tailoring aspects of technology to this context. The conceptual model presented below is rooted in the hypothesis that elements of this process can be made more efficient through the use of standardised materials to collect information which is used to inform the assembly of a rehabilitation system from a toolkit of components. This approach is influenced by existing medical practices which involve the design of tools which can systematise the diagnosis of illnesses, and support treatment. Therefore, before presenting the model, the topic of systematisation is briefly introduced.

8.4.1 Systematic materials to support deployments of rehabilitation technologies

An ongoing topic of research within medicine is the systematisation and diagnosis of treatment. Common examples of measures that have emerged from this research process include standardised questionnaires for assessing anxiety and depression (e.g. see [174]), which are often used as an initial assessment step for patients who have just arrived for treatment. Such measures are often presented in a form which is immediately usable by a clinician, such as a questionnaire and an associated marking guide for completed questionnaires. The development of such measures therefore represents one tactic for integrating research knowledge directly into professional practice, and the analysis of data returned through such measures can then support a process of improvement. Ideally, standardised measures would provide an objective assessment of patients which can then help avoid any bias on the part of the practitioner. If designed well, they can also be time-efficient to complete, and can therefore support cost-effective provision of diagnosis and treatment. They can also be administered by individuals who are not experts in the topics that they consider.

The process of design presented in Chapter 6 was mostly not systematic in relation to its orientation to the home. Designers drew on their experience to make observations about the home that seemed important. These observations have then been incorporated into designs, and have proven effective. This chapter has then reflected on this process of design, and provided evidence for the value of:

- Understanding patterns of domestic usage which have been caused by stroke

- Considering the social possibilities of the home

- Respecting the home as a place of living

- Considering the architectural affordances of the home

Some systematic evidence was utilised during this process; designers drew upon data collected through the usage of a diagnostic tool developed by medical specialists specifically for the Motivating Mobility project, and elements of this evidence proved useful, and were integrated into the process of design.

To speed up this process, and to therefore support a more cost-effective approach to tailored rehabilitation systems, then the consideration of some of these issues might then be suited to a more systematised process which integrates the previous experience of designers. For example, material intended to support an understanding of changes in domestic usage might include:

- forms which asked survivors to document any changes in their domestic routine, by drawing on floor-plans

- questionnaires which gathered standardised responses to commonly-encountered issues in the domestic lives of stroke survivors

These could be distributed in advance of any visits focused on deployments, thereby allowing deployment specialists time to consider any issues that were raised by them in advance of deployment, and reducing the time that needs to be allocated to every intervention. The design and validation of these materials is then a topic for future research. The kinds of material collected through this process bears some relation to concepts such as the *cultural probe*, defined by Gaver et al [8], which are packages of material intended to be distributed to future users of systems. However, the concept of a cultural probes is specifically focused on providing inspiration for novel design work. In contrast, the kind of material described above might be more suited to establishing configurations of existing technology. As such, whereas cultural probes are often somewhat impressionistic, encouraging the expression of ideas that might then support the process of designing exciting and novel

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systems, then the kind of material referred to here is likely to be more systematised, intended to fit into a deployment process which is as fast and efficient as possible.

8.4.2 A process-orientated conceptual model

Drawing on these arguments, Figure 8.2 presents a framework highlighting key features of how a more systematised process might work. This illustrates how systematic material might be applied to evaluate the domestic arrangements and the motivations, needs and abilities of someone who is to receive a deployment of technology. It also highlights the potential for providing training to stroke survivors and other relevant social actors, in support of their usage of any technology. Training may include:

- a partner being trained to observe poor quality movements, and to offer suggestions when they are observed

- education which helps establish some of the principles of rehabilitation, allowing stroke survivors and other social actors to make choices with are well-informed

and could itself be delivered through technological mechanisms, which then raises some interesting questions for research.

8.5 Summary and next steps

This chapter has considered a number of issues arising from design and deployment work described in chapters 6 and 7, and presented a process-orientated conceptual model intended to support future research around cost-effective toolkits to support stroke rehabilitation. The final chapter of this thesis now provides a reflection on the entire process of research, with a focus on the question of what it means to tailor a technology.
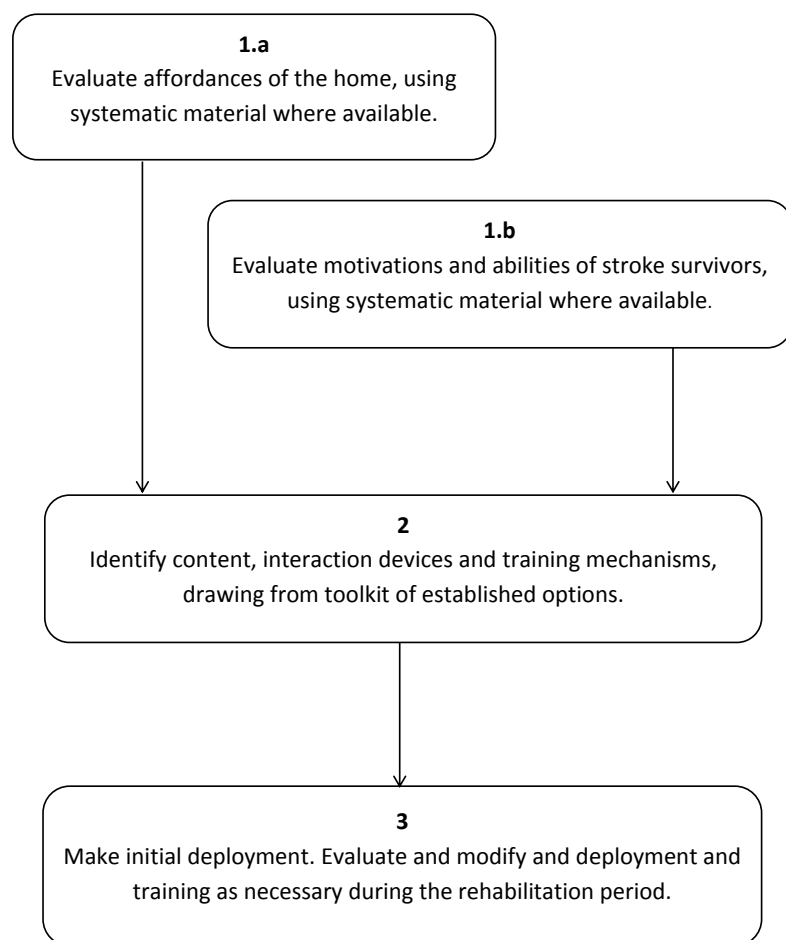
Figure 8.2: A process-orientated model intended to support the development of a toolkit for rehabilitation.

Chapter 9

Reflections and conclusions

This is the concluding chapter of this thesis, and its role is to reflect on the material that has been presented up until this point. These reflections begin with an overview of the structure of the material that has been presented, which considers the contributions that have been made.

Drawing on this material, a discussion is then presented which explores the concept of tailoring, which was introduced early in this thesis. This discussion considers knowledge that has been developed through work presented in the thesis, and integrates a consideration of how to design a technology that is appropriate and sensitive to the homes of survivors of stroke. This discussion also considers the implications of this work for research more broadly, especially in relation to healthcare technologies.

The chapter concludes with some reflections on the process of research itself, which consider the strengths and limitations of the methods that were adopted.

9.1 An overview of the structure and relevance of the contributions

Research into interactive systems to support rehabilitation for stroke has been conducted since at least 1991 [19], and a detailed review of this work has been provided in chapter 3. This thesis has then made contributions in relation to the following topics, as defined in chapter 3.

1. A greater understanding of the implications for technology of the experience of surviving and living with a stroke

2. A greater understanding of how to design rehabilitation technology that are appropriate for the homes of stroke survivors

3. An exploration of the concept of tailoring as it relates to technologies intended to support stroke rehabilitation

4. An exploration of how to design of toolkits capable of catering to the cost-effective deployment of rehabilitation technologies

Contributions in relation to these topics have drawn on data and analysis collected through three studies, each of which has been structured around work that took place during the Motivating Mobility project. These studies are structured as follows:

- Chapter 5 has presented a set of concepts intended to sensitize designers to key features of the experience of living with stroke that are important to understand in the context of designing rehabilitation technologies. It also considers the implications for technology of these concepts.

- Chapter 6 has described the process of tailoring technologies to the needs of four stroke survivors, with a specific focus on the question of how to integrate a specific understanding of individual motivation into the process of tailoring.

- Chapter 7 has presented knowledge gained by deploying working prototypes of these designs into the homes of stroke survivors, for periods ranging from one to seven months.

Chapter 8 has then integrated across these three chapters, to contribute:

- A set of guidelines intended to support the design of rehabilitation technologies that are appropriate for the homes of stroke survivors.

- A discussion which highlights the need to design rehabilitation technologies that support a pathway back to normal activity and which can address contentions in understanding around the nature of rehabilitation.

- A novel, process-orientated conceptual model intended to support the design of a toolkit allowing for a more cost-effective tailoring of rehabilitation technologies to the needs of stroke survivors.

As well as supporting the design of better rehabilitation technologies, work presented in this thesis is more broadly of interest to the research community:

- Stroke can be seen as an exemplar for a variety of illnesses or situations in which the lives of individuals have changed very quickly, and which can then have a profound impact on domestic life.

- How to encourage beneficial change is still an open question in relation to research around persuasive computing [107]. Work presented in this thesis focusses on the question of how to tailor rehabilitational technologies to the nature of individual motivations for recovery, and therefore contributes a greater understanding of how to work with individual motivation as a design tactic.

- The design of technological toolkits for use in particular settings is still a topic of research, especially within Ubiquitous Computing as a research field. The conceptual model presented in chapter 8 focusses on the process of working with a toolkit to tailor a technology, rather than on the design of the toolkit itself. The idea that a process-orientated conceptual model might be relevant to the design of a technological toolkit is then of broader interest to Ubiquitous Computing researchers, or to any researchers who are engaged in toolkit design.

9.2 What does it mean to tailor a technology?

Chapter 1 has provided an argument for why rehabilitation technology might need to be tailored to the individual needs of stroke survivors. Stroke can cause long-term damage to the brain, and because different regions of the brain have specialised functions, then patterns of disability acquired through it are then unique to each individual. The question of how to tailor technologies to these individual patterns of disability has then been raised by Alankus et al in CHI 2010 [25], and is an open question for research.

A number of elements of this thesis can help to understand the question of how this tailoring might take place, but case studies of design presented in Chapter 6 are particularly relevant. A clearer understanding of what it means to tailor a technology might then be relevant to a variety of health conditions in which there is a significant individual variation in experiences, causes, symptoms or outcomes. An example might be research into technologies to support recovery from a variety of common mental health conditions, of which a number of examples have recently emerged in the HCI literature (e.g see [175]). Although individuals with mental health conditions might share recognisable and diagnosable symptoms with each other (such as depression or anxiety), there will be significant differences in the causes of these symptoms; individuals which might then benefit from a careful tailoring of technological interventions to their needs.

As discussed earlier in this chapter, stroke can be seen as an exemplar for a broader range of illnesses or situations in which the life of an individual has changed very quickly, or very severely. Understanding how to tailor technologies for stroke might then help to support an understanding of how to tailor technologies in these situations. Drawing on the work that has been presented in this thesis, a key observation to make is that a broad range of factors beyond acquired patterns of disability need to be considered. An understanding of the range of factors that might be considered is then a contribution that can support future research work.

The table presented in Figure 9.1 considers three specific factors that have emerged through work in this thesis. A detailed discussion of each of these factors is then provided in Sections 9.2.1, 9.2.2 and 9.2.3. Section 9.2.4 then

Factor one: Nature of the home	Technologies might be tailored to affordances of particular homes, and need to be sensitive to the substantial changes that can be caused by stroke.
Factor two: Individual differences in motivation	There are substantial individual differences in the nature of motivation that could be considered in the process of tailoring.
Factor three: Individual differences in understanding	Stroke is a sudden and potentially traumatic occurrence; there may be substantial differences in personal understandings of how to recover which are then important to consider.

Figure 9.1: A three-factor model to guide the process of tailoring.

considers the issue of how the tailoring of a technology might change over time, especially in the context of conditions that can take many years to recovery from. Section 9.2.5 considers the question of who might do the tailoring, especially in the context of broadening the availability of tailored technologies in a cost-effective manner.

9.2.1 Tailoring technologies to the nature of the home

Any sudden or severe illness can cause changes to the home. In any proces of tailoring, an important factor to consider could then be the nature of the changes that have been caused, which then potentially limits the affordances for technology deployment that are available. As noted in concept 5.1 (Chapter 5) stroke can cause significant changes to domestic routines and usage of the home, which might even include the need to move to a more suitable (and often smaller) home, or the re-purposing of the existing environment. Chapter 6 has then provided some interesting examples of the implications of this, including one participant who could no longer use several rooms in her own home for psychological reasons, and two participants who spent a substantial proportion of their time in particular locations in the home that had been set up to be comfortable. Significant changes to life can also cause financial difficulties; in the examples presented in this thesis, one participant described losing freelance work because of his condition. In the extreme case, such changes could ultimately lead to the need for a smaller home. Several

of the participants involved in the work of this thesis were elderly, and described having a relatively fixed division of domestic routines between them and their partner. Their illness then caused significant disruptions to these routines, requiring their partner to adapt by learning new skills. These cumulative changes can then lead to a significant level of existential stress, even several years after the event (concept 5.7, Chapter 5).

What this then suggests is that a careful assessment of the home is needed in any process of tailoring targetted at a situation which has caused a significant disruption. How to do this kind of assessment in a cost-effective manor is then an issue considered in some detail in Chapter 8. This presents a novel process-orientated model for the use of systematic material to tailor an instantiation of a general-purpose toolkit to the needs of an individual. Any assessment might consider affordances for technology in the home as it is now, and also changes in the home that have been caused in the past by the targetted condition. It might be possible to develop material that allows for a systematic assessment that is relatively cost-effective. How to design and integrate this kind of material into a realistic tailoring process is then an interesting question for future research.

9.2.2 Tailoring technologies to individual differences in motivation

A second important factor, which may be broadly more relevant to other applications of health technology, is then the substantial differences in the nature of motivation between individuals, and also the interaction between these and types of exercise required to support rehabilitation. Work relating to this topic can be found in Chapter 6, which presents an exploration of how to tailor technologies to the motivational needs of four participants. Here:

- one participant (Irene) was clearly motivated to regain sufficient ability to engage with specific hobbies, and recovery was supported through some very specific exercises

- one participant (Joan) was more generally motivated to improve her abilities as a whole, and recovery was supported through exercises that sought to engender integration across multiple patterns of movement

- one participant (Solomon) was more generally motivated to improve, but had some very significant localised disabilities that required specific exercises to address

- the parents of one participant (Sophie) were providing a significant amount of motivation for recovery, but it was less clear as to the level of motivation that the participant itself was experiencing

Each of these different styles of motivation and clinical need then lead to a different approach to the tailoring of technologies, and different outcomes from interacting with these technologies. Irene, for example, interacted with her technology for a period of seven months, during which she exhibited a substantial level of improvement in her condition. Joan only used her technology three times, which then gave her sufficient confidence to design her own exercise programme. There was a significant contrast between the technology designed for Irene, which allowed her to return to an existing hobby which she had lost (i.e. reading) and the technology designed for Solomon. The latter appropriated an existing hobby (playing Chess), but actually made engagement with this hobby more difficult when using the supplied technology.

In common with discussion around how to cost-effectively tailor technology to the nature of the home, systematic material could be developed to help understand the nature of individual motivations when tailoring technologies. Such material could integrate a well-developed understanding of the nature of motivation as present in both the psychological and movement therapy literatures (e.g. see [55, 56]).

9.2.3 Tailoring technologies to individual differences in understanding of a health condition

In contrast with health conditions that develop slowly, stroke is a condition that occurs suddenly, and which can therefore lead to sudden and potentially traumatic changes in to individual abilities. Post-stroke, there can be substantial differences in the level of treatment received - Chapter 5, for example, highlights some very poor experiences in hospital, and one participant in Chapter 6 described discharging herself from hospital because she disliked the environment so much. These conditions are then likely to lead

to a substantial variation in the understanding of stroke across those who survive it. Given that the home is a social space, then this variation might be considered in the context of others that share it. These differences in understanding are likely to be present in relation to other conditions that develop quickly, or which have severe consequences.

These differences in understanding are then manifest in a variety of elements of work presented in this thesis. Irene's deployment, as described in Chapter 7 provides an interesting example, in that it caused arguments between her and her husband, which were grounded in a differing understanding of the nature of rehabilitation. Arguably, Joan's own rehabilitation had been held back by a lack of knowledge about how to improve, and the three interactions that she made with her technology helped to break down a barrier that was holding her back.

These observations then suggest a model in which the process of tailoring a technology includes an element of education, potentially targeted at resolving contentions in the understanding of rehabilitation between people who share a home. A discussion orientated around this issue is provided in Chapter 8. How to design technology that educates people about their health condition could then be a topic for future research. This could then be relevant across a broad variety of health conditions. Such technology might need to be tailored to the current state of knowledge of particular users, and its mode of presentation may need to take into account a variety of issues that are specific to the relevant condition, c.f. cognitive deficits caused by a stroke.

9.2.4 Tailoring over lengthy time-scales

Recovery from disability acquired through stroke can take many years, and technological support could conceivably be required throughout much of this period. This then raises a question of when tailoring occurs, and some evidence in relation to this question is provided in work presented in this thesis. Given that her deployment lasted for seven months, the most relevant evidence is provided in work with Irene. Here, a single book was used as a motivator for engagement with a technology that required multiple squeezes of a switch. These squeezes were then intended to help regain some strength in her wrist and fingers.

The key issue in this context was that, in making exercise dependent upon

a single book, variation in enjoyment of the book then lead to substantial variations in the level of exertion that were engendered. An interview with Irene suggested that she found one particular part of the book dull, and hence did very little exercise here. A better technology might have used a variety of content to support motivation, which could then have ameliorated these effects. Towards the end of the deployment period, Irene started to regain the ability to hold a book herself. This effectively ended the deployment by removing the purpose of the technology, even though Irene's recovery was not fully complete. At this point, a substantial update to the deployment could have supported an ongoing engagement.

What this example points to is that if engagement with a technology is to last for several years, there are then likely to be substantial changes in motivation and ability over this time, which then means that the tailoring of any technology would need to be regularly updated to match the needs of an individual. This length of longitudinal study is often difficult for research to engage with; how to produce technology that can be tailored over this kind of timescale is, however, an interesting question, and one that could be explored in future research.

9.2.5 Who does the tailoring?

As a piece of Research through Design (see Chapter 4), tailoring in the context of this thesis was essentially lead by a designer, with support from a professional therapist. This is then an expensive process, which can be justified as a piece of research, but which does not scale to the very large group of individuals who are living with the consequences of stroke. Chapter 8 has presented a model for a toolkit which might lead to a more cost-effective deployment of tailored technologies, but there is an open question of who the users of this toolkit might be.

One possibility is that an initial tailoring at least might be conducted by a professional trained in the process, or a small team of professionals. Following the argument provided above, such a professional might need the capacity to assess the home, the motivational needs and the current understanding of a stroke survivor, and would need sufficient technological expertise to be able to select and deploy technological components. This level of expertise is expensive to develop, and this model may only be practical if subsequent

engagements were very infrequent. Especially where engagement with a technology is maintained over several years, then this raises the possibility of users themselves becoming involved in the process of tailoring. How to design interfaces to support this is then an interesting question that could be addressed through future research.

A possible danger is that the process of deploying and maintaining technologies could become as expensive as reasonably regular visits from a professional therapist. Technology, however, can offer direct day-to-day support in a manner that could not be replicated by a therapist, and is not therefore a directly-comparable medium. A number of charities (e.g. [176]) already provide reconditioned computing equipment for free; if interventions were designed to work on older technology, a similar model could make the larger scale deployment of cost-effective rehabilitation technologies possible.

9.3 A reflection on the process of research

Research work presented in this thesis has been structured around three discrete studies, presented in Chapters 5, 6 and 7. Data presented in these studies was collected through the author's involvement in the Motivating Mobility project, with a significant amount of analytical work taking place after the conclusion of the project, with the author working as a staff candidate for a PhD. This section presents a reflection on this process, which briefly considers its strengths and limitations, and makes a set of recommendations to other researchers. It is considers each of the three core studies seperately, and also considers the experience of writing a PhD thesis as a Staff Candidate.

9.3.1 Study one: Initial engagement with survivors of stroke and their partners

Chapter 5 describes an initial process of engagement, which took place over a four-hour period. The purpose of this engagement was to learn more about the experience of living with disabilities acquired through a stroke, and to obtain some feedback on a set of rudimentary prototypes. Data collection began with the audio-recording of discussions in two parallel focus groups -

one with survivors of stroke, the other with their partners. It then concluded with a session in which participants were shown prototype technologies and asked for feedback. Useful data was collected through transcriptions of post-it notes written during this session.

The decision to split participants into two initial focus groups was very deliberate, and very effective. Stroke survivors and their partners described different aspects of the experience of living with a stroke, and were probably more vocal than they would have been if they had stayed together in couples. A third focus group session, with couples brought together, could have produced additional insights. However, there was a significant concern over the levels of fatigue that our participants might experience, as fatigue is known to be a common consequence of stroke. This then led to a decision not to introduce an additional session. On reflection, this was a good choice - participants appeared visibly tired by the end of the four-hour period, although all stated that they were pleased to be involved.

The interview sessions themselves were relativley unstructured, with facilitators being asked to explore the nature of this experience. A subsequent analysis then lead to a set of sensitizing concepts that were broadly spread across the nature of the experience - more tightly structured questions could have been chosen to focus more closely on particular elements of this experience.

In the session in which prototypes were demonstrated, participants were given the freedom to move between different stands, and were asked to write comments onto post-it notes, and also to discuss their thoughts, which were recorded using dictaphone-style audio recorders. Because this session took place in a single room, with little space between stands, then resultant audio-recordings were inaudible. This meant that potentially important data was lost - other researchers engaging with these activities would be advised to experiment with audio capture to protect against this situation.

During this engagement, we learnt that one couple had experienced an uncomfortable experience with other researchers, in that they had taken part in a research study, and had then been completely ignored once data collection had been completed. This coloured their engagment with us, and required delicate and personal treatment to overcome. A conclusion that can be drawn from this is that procedures to keep participants informed about the conduct and outcomes of research are an essential part of ethical practice. Partici-

pants who engaged with the Motivating Mobility project were given regular updates about the process of research, and were sent copies of all publications produced. Irene and Eddie (not their real names) have stayed in regular contact after the conclusion of the project, and will be given a copy of this PhD. Even in just research terms, staying in contact with participants is valuable, as several have since agreed to serve as non-professional referees for a subsequent grant application. The personal value of staying in contact with participants speaks for itself.

9.3.2 Study two: Design of tailored techologies

Study two consisted of a series of design sessions that took place in the homes of stroke survivors, which were facilitated by prototyping activites that took place outside of these sessions. These lead to four designs for tailored rehabilitation technologies, of which prototype implementations were then made. Conducting these sessions in the home, rather than inviting participants to a university, provided substantial benefits in terms of the richness and quality of observations that could be made about the home. Especially in the context of Research through Design (see Chapter 4) conducting these sessions in the home was vital to producing credible results.

On reflection, the time taken to tailor truly individual technologies to the needs of participants was problematic, especially with some participants living near Sheffield and some near Southampton, which therefore contributed a substantial cost. A more focussed tactical approach to the tailoring process might have lead to results that were as interesting, but with less time required. If conducting similar research again, the author would focus on technologies that could be assembled purely from readily available assistive technology products. Rehabilitational benefits would then be provided through a combination of innovative content and a carefully-designed integration with an exercise programme prescribed by a therapist.

This approach worked well for Irene - who was given a technology composed of a squeeze-switch (provided by an assistive technology company) and a generic tablet PC. In contrast, work with Solomon and Sophie was more bespoke, and took substantially more effort. In the case of Solomon, a truly bespoke sensing system was needed to capture his movements, due to his extreme disabilities. This suggests that inclusion and exclusion criteria for

this particular project were not specified as tightly as they might have been. Tailoring technologies using commodity products would also support a long-term desire to support the real-world deployment of tailored rehabilitation technologies on a larger scale.

9.3.3 Study three: Deployment of robust prototypes

Study three involved the deployment of prototype implementations of the four prior designs, into the homes of our four participants. A variety of data was collected around these deployments, including system logs and interviews (some conducted in person and some by telephone). Both were vital in understanding the reality of the experience of using these systems. In the case of Joan, system logs provided an additional layer of information that clarified Joan's degree of usage of the system, which would have been misunderstood if interviews alone had been used.

Chapter 7 is the shortest chapter of this thesis. This was because participants other than Irene and Eddie struggled to reflect on their experience in much detail during the interviewing process. A hypothesis is that this was related to cognitive difficulties causes by either stroke or changes associated with age. On reflection, interviewing, especially over the telephone, was a choice with a limited capability as a research method in this context. Alternatives are not fully clear, but would need to be explored in detail in a similar project.

9.3.4 Writing a PhD as a Staff Candidate

A substantial proportion of the work of this thesis took place after the conclusion of the Motivating Mobility project, whilst the author was working as a Staff Candidate for the submission of a PhD thesis. This is an unusual and relatively rare route to a PhD at the University of Nottingham. For the author, it has been incredibly beneficial, in that it allowed for a substantial reflection on an interesting and valuable topic which will then lead to additional research papers. On this project, the author made a contribution to the Motivating Mobility that was above and beyond the requirements of the research, which has then enabled a sufficiently individual strand of work to be produced for a PhD to be awarded. On many projects, it would be difficult for an individual strand of work to be seperated, which then makes

the Staff Candidate route difficult to access for some researchers.

New staff candidates at the University of Nottingham can no longer submit PhD theses, and instead must obtain their PhD by submitting publications. This seems a shame - in writing a thesis, rather than submitting a set of papers, the author has gained a substantial amount of experience which will then be beneficial in supervising research students, which would not have been acquired through the submission of papers alone.

9.4   Final words

This thesis has presented a body of work structured around the design of interactive systems to support rehabilitation. It has been presented with the intention of having a positive impact on the conduct of this research in the future, and with a genuine desire to support the design of technology that can improve the health of the population.

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Appendix A

Original application for submission of a thesis

This is the original application that was made to the Teaching and Learning Committe at the University of Nottingham in March 2010.

Thesis justification

Stroke is the largest single cause of disability in the developed world (World Health Organisation, 2004), and is a significant burden on health services of many countries (World Health Organisation, 2004). Stroke is a disease which disproportionally affects older people, and, due to demographic change in industrialised nations, the incidence of stroke is likely to increase in future years (Willmann et al, 2007). In the UK at least, stroke services are already changing to reflect this reality, and an emphasis is being placed on providing support for stroke survivors who wish to remain at home, minimizing the amount of time that they need to spend in the hospital system (Department of Health, 2007). This mode of care is often referred to as self-management (Department of Health, 2007), and support for self-management is an ongoing topic of research within the healthcare community.

Stroke is a chronic illness, and ongoing disabilities caused by stroke can be severe; these can include sensory, perceptual, cognitive and motor deficits which, in physical terms, can often affect the whole of one side of the body, which tends to be referred to as the hemiplegic side. There is good evidence that recovery in physical movement can be supported by regular physiother-

apy (Pomeroy and Tallis, 2002), and many survivors, in the UK at least, receive short-term therapy, before discharge from hospital. Such therapy tends to focus on recovery from disability in the lower-limb (Broeks et al, 1999), with the aim of increasing quality of life by recovering mobility as rapidly as possible. Many survivors are therefore discharged with little ability in their upper limb, on their hemiplegic side, and unless they can afford to pay for private physiotherapy, may struggle to regain much of their former ability by themselves. Given existing constraints on the health service budget, and given the likely increase in the stroke population, there is a clear need for approaches that can support the self-management of rehabilitation in stroke survivors, potentially for many years post-stroke. This is an open area of research, and one in which the author of this thesis has been involved, through an ongoing project called Motivating Mobility: Interactive systems to promote physical activity and leisure for people with limited mobility (EPSRC grant: EP/F00382X/1). The aim of Motivating Mobility has been to investigate whether computer systems have the potential to assist in the self-management of stroke rehabilitation in the upper limb, and our methodology has focused on designing, deploying and evaluating a number of rehabilitation systems for stroke survivors who have been recruited by the project. This thesis will be constructed around the individual contribution that the author has made to this project, and its core contribution would be in the presentation of a design framework, with supporting evidence, which would aim to assist others who wish to design systems to support the self-management of stroke rehabilitation in the future. Design frameworks are an accepted approach within both computing and design research, and a recent example of a thesis constructed around a design framework is provided by Reeves (2008).

In terms of its contents, this thesis will begin by presenting a review of the literature in relation to stroke and the self-management of rehabilitation. This review will then be used to identify the need to learn more about designing individualised systems for stroke survivors, which appears to be an under-researched area of self-management practice. The thesis will then present a series of analyses which have been performed by the author, all of which will lead towards the core of the thesis, which is a novel design framework. The first of these analyses has already been published, in a peer-reviewed conference (Rennick Egglestone et al, 2009), and has been constructed around a series of workshops, with stroke survivors and professionals. It has identi-

fied the necessary components of a system designed to support self-managed rehabilitation. The second analysis will be constructed around existing, but as yet unpublished, participatory design work, carried out with stroke survivors, which has led to the design and deployment of four systems with stroke survivors. It will document this design process, and provide material that contributes towards the final design framework. The third analysis will be of a variety of different types of data produced during these ongoing deployments; it will seek to evaluate their success, and to extract knowledge that could be useful to those who wish to design such systems in the future. The fourth, and final analysis will consist of the design framework itself, which will attempt to integrate and present the knowledge that has been gained through work reported on in this thesis; its final form is yet to be decided, but several candidate structures are emerging. The thesis will then present a discussion of this framework, with a focus on inspiration for future work. The author is currently in the process of applying for a research grant to carry out further work in this area, and it is hoped that the process of constructing this thesis will therefore be of direct benefit to his own future research, as well as benefitting other researchers in a similar position.

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Appendix B

Data gathered through a participatory workshop

This appendix contains the transcribed data that was collected during the workshop described in 5.

Interview transcript: stroke survivors

This is a transcript of an interview with three participants. Interventions from the interviewer have been italicised.

did you have any physio therapy or anything? Did you go into hospital when you had your stroke?

P1: Yes, I went into the northern general first and then across to Halamshire and then back to the northern general which really were horrible I were in months of oh sit in that chair, sit in that chair, dont movie, sit there. That were it all day.

And no therapy?

P1: No

You didnt have a physiotherapist?

P1: No, I did in the halamshire,they got me up

P2:they are very good in halamshire

P1: Yeah they got me walking

And what was your experience like?

P2: Well I was on holiday when I had my stroke and I was taken into Hull infirmary, Royal Infirmary

Yeah

P2:And they transferred me from there to halamshire and uh from there when I got ,you know, as though I could move ab-. Because I couldnt do anything, I was completely paralysed down this side.

Right

P2: and I couldnt, they didnt feed me, you know I was milked(???) by mouth. And once I got a bit of you know energy back they got me out of bed to do a bit of physio at Hull. And then when I came to halimshire they started me on physio there. And I was you know I was

Is that like a stroke unit Or is there more small services there?

P2: Yes at Halimshire they had , yeah they have a special stroke ward

Yeah

Theres men and women there,

So they got you very busy with physio there?

yes

And how about you what was your experience?

P3: well I was very lucky because if youve got to have a stroke have it in your doctors surgery, I was going away on the Wednesday abroad to Portugal and I had to go see her about something I dont to leave(???) on the Monday I got in for 10 oclock and my husband was in the car outside, I did all the driving and I went into the surgery and she said "oh what can I do for you" and I was just about to tell her when I said "oh my head feels , I feel so tired,". Id done seven nights ofcourse so I expected that, so I put my head down on the desk and I had my hand in my pocket and she said "remove your hand" and um then I said "oh um my speech is slurring" I remember it all so clear. She said "well my afraid mrs P3 your going back to the Halimshire, youve had a stroke." But I was a bed manager there, so um. Im crying and making a fuss, I cant be going on holiday so fortunately she didnt send me , this this isnt going to be broadcast right?. She didnt send me to the northern general

because she said " I'm not going to have you lying around in an A and E"
she said "Ive contacted the Halimshire and Neuro medicine have accepted
you" so when I got there they were all very quick and this sort of thing and
then straight up to the uh scan. And the registrar came up with me, he said
"if its a clot they have just started using thrombylitis can I use it?", "oh yes
anything". Well Id had a massive bleed so they said well thats out you know
so it was really touch and go for about 3 weeks I dont remember a lot of that
, I know I went up and down to the scan.

Its good that you got seen quickly though

P3: Well

very good

P3: Well I thank to this day my GP because um well you know who knows?
you know lying around in a busy casualty so anyway um. After the 3 weeks
because I got to know the um liason sisters who barnston there quite well
and she ever day she told me she was coming down to see if I could go up
to the stroke ward and after 3 weeks I did go up there and I started Physio
right away. But even so I was in for 15 weeks altogether and my husband and
I were adiment I wasnt going to go home until I could climb up the stairs to
my bed , which is so unrealistic I was. And semi look after myself and then
it started to dawn on me thats not going to happen so I got the consultant
wouldnt let me go home without a full package and they set that up for me
twice a day carers and I started physio right away but unfortunately that
was only about 4 days a week. I dont know if you found that but we just,
weve got 28 patients

How long did you get of Physio each day?

P3: Oh it was about half an hour

*So just 1 session, about half an hour? Was yours about the same, half an
hour 4 times a week?*

Yes Yes about half an hour, yeah well I think I went every day of the week I
cant remember now. Sometimes it depends on sickness and holidays when I
came, when I came home from the hospital I had uh 3 physios come to get
me home. To come and see me.

And how often did they come?

They came every day for 12 weeks

Thats good

Then I was sent to Netheredge. The Ark at Netheredge which is very good. They um they you get half an hour of physiotherapy and there and you know your encouraged by all the other people that are there, well most of them have had strokes, some of them are MS patients.

So whats the ark is it?

Its a patient center (???). They kept me going there for 12 months.

Yes I went to them, once I learned more about it, they were very good with the physio they got me on my feet, they got me walking along the bars, all this kind of thing but there wasnt the the neurological specialist input into that and I realised that since going to, we go to the same place the Halamshire physio which you know specialises in neurological imparments. and so if only there could have been somebody there could give that input right from the very beginning

Whats the difference of input? What has the difference been?

Well I feel that, well for one thing uh I think they would have worked on my leg and arm at the same time

Right

Its just the constraints of the money and that and everything else but the urgent thing is to get your leg to onto your feet. And get you out there.

So they didnt do anything with your arm?

They didnt do much, Alison who actuall worked with the AFAS machine she um did a few for me down at the, downstairs on the L1 L2 but it wasnt sort of two people working on you at the same time or say you might for a quarter of an hour try and sort your leg out then have 15 mintues on this. So consequently my arm was like that for 2 years, bit over. And then gradually we are getting somewhere with it.

But its harder to do it a long time after your stroke than during the first few months when youve had a stroke. You get more recovery

Yes

But this isnt that, that you got more recovery early on or?

Yeah it worried me in a way that um she didnt do it, uh I was asking the question but I was saying to Maggie, you remember Maggie the senior one she kept on saying to her you know, they are always asking people how are you going to do because you want to do your best and she says well the best recovery and the most recovery is in the 12 months. And because your brains all mixed up your thinking, im no better and 12 months is in 2 weeks Thats another sort of fear that because you cant get on at first your not going to.

How long do you think you went on getting better for?

Hmn well I suppose I was doing a little bit better every week but Ive since learned that theres this plateau that people reach

But how do you feel? Do you feel that you are still getting better?

Oh yes Im still improving

Yes Yess my balance is improving, I mean my balance is improving and im improving Keep positive Keep positive

But if you think maybe like 6 months ago, are there things that you can do now that you couldnt do then?

Yes I couldnt move this arm at all

And how long ago was it you had your stroke?

2 and a half years

So youd say that your still getting some improvement?

Yes I think so yes, but the thing is when I first had my stroke, I had this feeling that I was locked inside myself, I was some else and not me I kept on saying to my husband, I cant believe this has happened to me. I was saying that up to four years

Because you were working?

Yeah I was working full time, I arranged to go part time for my last two years up to sixty five I felt so unwell and I never even got to that.

Did you get high blood pressure or anything like that?

That was what caused it actually, my chalestorol was normal and everything it was just the high blood pressure.

I had high blood pressure for years

And did you take tablets for it and everything?

oh yes

And did you have problems with moving afterwards?

yes down the left side

And yet you had no physiotherapy?

No, no, only there used to be someone at the Ark I had to stick up for myself.
Most I can manage She were mobile quite quickly werent you Yes just sitting
there you get your arm quite

*Is one of your arms stronger than the other now? has your arm recovered
completely?*

Yeah, not completely no. I cant open a jar and the fresh thing for deodorant

So is it the strength in the arm? thats the problem or. is it dexterity

No its my hands

Yes n that *Its doing fine things is it?*

Im trying to knit now

Thats good therapy. Can you knit can you do it?

Well, im doing a big cardigan and im already..

I hope its thick wool

Not lately, Ive made four and believe me I could throw it through the window.
I just cant get the pattern right, mind im doing the daftest thing. Ive got
bottle green wool

Why is that daft?

Well I its very dark green *My - used to put a white knapkin under her knee
when knitting*

For the dark colours then it would show up well uh we went to a meeting
last week or the week before and you can knit for charity but Tom thinks ive
bought all this wool to knit a big cardigan for charity but its only 2 a ball
the wool and I want 32 balls.

How much have you done?... youve got a long way to go then?

I couldnt tell you how many times Ive

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unravelled it

Yep, and keep trying another ball of wool because it will split so

But you enjoy doing it

I was just going to ask that

Well Im swearing up here you know

But do you get satisfaction out of doing it?

Well I shall, well tomorrow, in the light. I, you make me torn knitted(???)

You havent answered my question. Do do it because your husband wants you to or do you do it because you enjoy it because you get something from it

Well I wanted a green big cardigan so I will finish it.

And if you finish it then you will get satisfaction out of it?

And also for this they have a stroke shop in Halamshire, yes they do, and I promised to knit them some dolls cloths and things like that, get my fingers going.

Lovely, but when you had your physiotherapy how was it , were you given exercises to do on your own? did you get things to practice on your own?

Only little bits to do

How were they give, were they written down, or just shown to you?

yes they used to put it on a. they used to give you a printout at the Ark

Yeah What sort of things did you get given to do?

Move your legs, like move one behind the other and um stand on one leg, then she said Im not coming any more, your ok you are.

There were told me to

Id be interested to know about the exercises you did one was putting one leg behind the other

but to stand up by the sink and do exercises yeah

And what sort of exercises when you were standing at the sink

like you know moving along

what about ones for your arm did they give you ones for your arm

they always told me not to move my arm, I think thats why it is like it is now

and did you enjoy doing that

Yes I like exercise, I used to do exercise before I had my stroke, I had a tread machine and an exercise bike aswell

How often did you do those exercises?

I used to do them every morning yes.

So if youd been given exercises would you have done them every day

Yes

P2: to P1:do you swim?

I used to yeah but theyve opened a hydrotherapy pool on Richmond road now and I go to a group called different strokes at Darnah and theyve started to go there this hydrotherapy pool. P2:Its just that we go, Gordon takes me to Bakewell swimming pool and every Thursday afternoon they have a disabled session 2-4, they have got hoists and everything and they charge just 1.25 for me and the carer comes with you and its wonderful exercise ive got a life jacket and I just do it on my back you know but its really good exercise, its the only exercise I feel Im getting. Because you know im conscious of my weight and everything (and my heart and lungs)

You have to exercise to keep fit, for your heart and lungs dont you

Otherwise you sit at home doing

Progress is always slow isnt it, its harder for you to see than everyone else

She says im hard on myself

Did you get physiotherapy exercises to do on your own?

Thinking back I think (hold something in hand and push) (???discribing an exercise???). You see at first your so shattered about this awful thing thats happened your just thinking whats the point. You see your husband and hes not struggling because he was in the navy and hes been taught husbandry so he could iron he could wash he could cook he could clean everything. It was just thinking why are we spending the rest of our lives like this? its terrible at first

Its a bereavement at first isnt it, its such a loss

Yes your grieving yes your grieving for what youve lost and everything. So it takes a little while to get over that but uh Ive tried to stay, both of us, very positive you know and your sometimes say to people I am positive about this, Im going to do it but your thinking to yourself, not really, but it keeps everybody happy, you know.

Whats the FES that you mentioned?

Its a machine that uh its got a battery uh a holder with a battery in it. and its um its got a dial that goes from 1 to 9 you can, you dont have to bother about the numbers too much its just how you feel its doing something for you. theres an electrode that goes under your foot, its in a pad and it goes on your insole in your shoe. And that goes up to this, and it clips into the machine. And then theres 2 pads with electrodes in them again that you put in and one goes on the muscle there. and then you feel up your leg to find the first sort of bumpy bony part and that is the perennial nerve runs over that and you put the second one on there and you just bring that up and clip it into that and then you do a test on it. To see what strength you need it at. And first time I ever tried it I pressed this test button and my foot was like that, my foot was like that, this left one. Up it came and I thought id done very good, because weve worked very hard on exercise on my ankle to try and get it to come up on its own. And then you set it to that and so every time you step on that foot the circuit goes on you see and it helps you to go on to lift your foot. And so two weeks after id started I went to Emma and said this isnt working for me and everybodys trying so hard, it took me a year to get the machine from health service, everybody has tried so hard Stop she says, lets see what your doing. So I was walking forwards like this, she said what are you lifting your leg up for?, I said I uh dont know, isnt that what Im supposed to do?, She said no, she said your toe will come up and just sort of kick your foot through as if your kicking a foot ball and thats all you need to do. And then ofcourse it was much better and so..

But you need the physios touch to get that movement right

Youve gotten used to walking the other way

She says dont you remember how you used to walk? I said no, not really, you cant close your eyes and visualise how to walk

Its something so automatic isnt it

Everything you do, youve got to stop and think first, but you know, I think physios are wonderful. I first got one going through Emma was that Sue Barnston had heard of a botox trial they were doing at the Northern General, would you be interested? I said oh yes anything because everything with my arm and everything. So I was I got the botox and everything in my arm and just one in my leg and there were 3 trials one was with physios 6 weeks, one was with just the botox on its own and one was no botox and the physio. So um. 6 weeks I went and had the physio twice a week by a neuro therapist. And uh my walking improved. You know they did the pattern on the floor to see what my gait was like and they said oh its improved marvellously. And um then when they told me that by the end of it they can tell you, they told me no you havent had the botox and thats when I realised, oh the physio has done it. So then I learned about, you know X physio and booked him there.

Do you think its because you thought it was going to make you better? that gave you confidence in think it was going to, do you think that affected you.

I dont know, you see they give you the injection, the doctor whose giving you the injection says I dont even know if this is botox or not. Its just a number and your in the group. And I did think it might be the botox that was working and I wasnt sure whether it was the physio or the botox or both. So when they told me that It wasnt the botox then I know its the physio

And your own perseverance

Well thats right yeah

The other thing we want to ask you about really is what, the things youve persevered with like that, what makes you keep going with that.

Well you want, really you want to be more able to do things. You know the feeling of feeling absolutely useless because I said to one group Ive been in I just want to be able to iron and they looked at me as if I was mad. I said well thats my way of being useful, to help my husband, you see I can sit on a chair, and pull out the ironing board and iron with one hand. but theres things like you cant fasten your bra you cant tie up your shoes. You know its that feeling of you know, I mean, Gordon helps me to, we have got a step in shower, so he helps me into that in fact. I cant dry myself, fully.

So what things have you found where you do feel useful?

Have you found things that you do feel useful

Yes I can go around to the doctor (???)

So you really want things in your daily life that you can do, so its part of your daily life So what about you X, what are the sort of things that motivate you?

Well I want to be able to move this arm, my left leg is a lot better, I can do it quite good now, but the physiotherapist said its not quite right yet. But it is going that way

And what makes you, if the physiotherapist gives you something to do, an exercise to do, are some exercises more motivating than others? What is it that makes you feel like you want to do them?

Oh when I can feel that that hands you know looser than it was before I went, sometimes it is and sometimes it isnt

So do you think that some of the things they give you work better

Yes, they do yeah.

So when you see more of a result from doing it, your more motivated to do some more?

Yes.

And do you think it matters if you do things just like as exercises or whether the exercises is part of doing something does that make a difference

yes I think it does yeah, like he tells me not to use a stick, he tells me I can go without a stick now but I keep it because I feel secure with it

But is there some other things that. well tell me about some of the things that youve been given to do to help your arm recover

Well I roll a ball a round with it you know and try to squeeze a small ball and let go because my fingers sometimes tighten up so much that I cant let go of things

And do you sometimes, does the physio say to do things, practical things like you know yeah he says keep going and keep doing your washing up and get your dusting done

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other patient: I think, I dont know how you feel, but I feel that this is a vicious circle, I found my legs getting better and then my arm packs up, and so I do some exercises on the arm and it feels better, its just seems you need to break that somewhere along the line. But um they told me just to do that sort of thing to try and straighten these fingers up you know. Well they are lovely when shes been working on them and they feel very easy when youve had your physio.

It feels more relaxed, and when it feels more relaxed can you use it better. it works better?

Yes, yes

But do you think your knitting helps you

Ive only done about 6 rolls so far and got it right, so tomorrow, starting tomorrow morning we shall be knitting

What does your arm feel like, when you touch it does it feel the same as the other one

yes

I thought I was different from others because I used to think that I couldnt see out, I felt like, have you seen that advert for glasses at spec-savers, theres a sausage? and he has glasses on, thats how I felt for ages, its gone now but thats how I felt. I as inside something and something was tied up here.

What do you think would make the biggest difference to your getting exercises, doing more movement

I always feel as if somebody is at my side, yes you know, Ill be sat in a chair at home and Ill be oh there was someone who sat there (???)

And is that a help or does that hold you back?

I think that holds you back, I just feel that theres always somebody hanging onto my hand.

What would be the biggest help

Well it helps just talking about it, when I used to go to the Ark, thats what we used to do we used to sit around a table, the 6 of us, and we used to talk about you know what we were experiencing.

You pick up tips from what other people are experiencing.

Yeah

And what about you, whats been the biggest help for you? what have you found most helpful

Well really I dont know its just John pushing me on, we have to have a walk every day. And I think thats it and you know. John does a lot of exercises that I dont

Would you like to do some when hes doing his?

Oh I would like to do some, yeah, definetly

Are you able to do things at home, are you able to do any cooking or anything?

I cook the meal every day, and we eat at lunch time, Im telling lies here, because we missed it today, we had sandwitches. But because Tom cant cook, therefore I make it that we have one good meal.

And you cook that?

Oh yeah

And what sort of things do you cook?

well I, well have a nice roast of lamb this you know. On Sunday and that

And you can manage to get the roasting tin out of the oven

Yes but theres only two of us

so its a small tin, your not cooking a turkey for 20 people

No, and then I do potatoes and carrots in the oh you know separately, like 2 tins but I can manage them. Cant get tops off anything

Can you peel vegetables?

oh yeah

What about you, whats been the most useful thing with rehab and motivating you to do things?

Well I think going to Emma and having a GP thats positive and saying that yes you can do it

Its interesting that all 3 of you have said in different ways that its people

Well it is because if youve got somebody who doesnt care .throughout all of

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it its been the fear of falling, its still there in the background so I want to get rid of the damn stick because it is in my way

You also mentioned your stick you said you feel you need it?

I do yes

But they said carry it, but I cant carry it, if its there I have to use it,

and once youre carrying your stick, those hands are out of action arent they

Yeah, and Im beginning to get my balance, Im more confortable about that but uh because we were going through this with Emma thismorning she said right now the goal is when Gordon is out at the front you go out and walk up and down a bit and see if you can.

She still feels as if I need more confidence with the walking

Yes, so confidence is another thing?

Yes, and I think physio is the answer, I cant think of any, even botox that makes that makes that much difference, it does release the tightened up muscles and everything but thats about all, its got to be your own determination.

Ok we need to go next door now, we will certainly get some things out of that, very thought provoking

Interview transcript: partners

This is a transcript of an interview with three participants. Interventions from the interviewer have been italicised.

what were interested in hearing about is what your perspective has been as carers with having a partner having had a stroke. Would one of you like to start talking about the time that you grew up in and some of the key differences for you that you were expected to do and

C1 as I say, I did nothing at home. I and swept up did that type of thing I didnt do very much at all my wife was a full time housewife. I used to come home from work and my tea were ready and that type of thing, so I been retired 7 8 years so when the stroke happened it really hit me that way because I just lost being 75 year old, we been married almost 50 year you get your only little world

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so how long had there just been the two of you at home?

C1: um 10 year. My daughter been married 10 years. You get close together. Thats the only person you got, even if youve got friend etc. Its the home life that it effects. And like most people with a house with upstairs and downstairs, we just couldnt manage well [anon] couldnt get downstairs.

so you couldnt get [anon] downstairs?

C1: no we couldnt get [anon] downstairs when she first had a stroke, she had a serious stroke then,

did she have a stroke at home?

C1: no we were on holiday actually we were at so she went to hospital for six weeks which wasnt bad, weve got a caravan so I just slept in the caravan anyway so that wasnt so bad, Im talking for myself now, that wasnt so bad because I just visited the hospital every day. Then she came to Sheffield, the same thing again, in hospital for 6 weeks. But when she came home, tahts when it started, then its 24/7 caring, and Ive retired, so it dont matter in that respect, but upstairs downstairs the social worker said why dont you have a bed downstairs, but [anon] were dead against that because her mother had a bed downstairs, and once she got in it, she didnt get out so we finished up selling the house and having a flat which is ok, but it did affect me, it affected me a lot actually, I became very withdrawn, plus youve no free time, the only free time I have now is x mornings a week, where the carer comes to get her out of bed, and I go to the gym, four mornings a week, and that the only spare time youre there 24/7 Im very fortunate, because [anon] is walking shes got her wits about her but she cant do anything because her left hands gone. But were alright, were managing but when the wife got out of hosipital got home, I didnt know how to turn the oven on that is a fact I didnt know there were an electric switch in the bottom of the cupboard to turn in on. I had to ring her sister up its silly, but it were things like that and then you had to get into the routine of when you had to do the washing we go out for meals its just as cheap

do you go out for all your meals?

C1: no we dont go out for every meal we got out every other day, and the cost of meals nowadays we, as long as we dont go out to town, its not so bad, it cost just as much to cook your own food. But in general its ok, and as I

said I think that iris is very fortunate because iris is coming on ok, she has got her wits behind her, Im not having to look after her mind, its ok.

so that was 2006?

C1: 2006 yes

and [c2] youve had a more recent experience havent you

C2: youll have to repeat that

[anon] told me you didnt wear your hearing aid. What about you, and [anon] with her stroke? When did [anon] have her stroke?

C2: last October weve enjoyed an average healthy lifetime and that night it happened

was it at home

C2: it was at home. And I was downstairs, [anon] was upstairs, and shes thumping on the bedroom floor, and she collapsed in the bathroom, but she managed to crawl on the landing, into the bedroom, and she got as far as the bathroom door, and thats where I found her. So I managed to get her onto the bed, and then I picjed up the phone, and dialled 999, and they came very quickly, and very efficient, they got here into the hospital, and from there, she was there months in hospital. And then she came home for a period, and then she went back again into the hospital and

why did she go back again

C2: she kept having spasms she got back there and she was in quite a while, and she came out then, and she was going in as an outpatient for a blood test twice a wekk. And then they decided then that this blood test could be done through our local practicioner, and she still goes there now, and its only a short walking distance, and we walk there and back.

is that still twice a week?

C2: generally once a week, but sometimes it gets a bit worse sometimes she gets a bit and she manages to go out for short walks, she went to the hairdressers yesterday, and I walked here there ... I dont know if you know our village, its a bit of a rural thing, but we just walk across, yesterday, we went in a pub and had our lunch. I am a cook in my own way, but not [anon] is a very good cook, and I miss all of that now [anon] was brought up in the country and I was a town boy [anon] came out of the country all girls had

to learn to cook and bake

so what have been the biggest changes for you

C2: well I did used to do the bits and pieces in the house cleaning up, washing the dishes, hanging curtains but when it comes to cooking, Im very basic. [anon] does a bit of the cooking now, but she gets tired has to sit down

so are you learning new skills? How to cook more?

C2: oh yes yes. If a person cant cook his own meals, in desperation, then hes not worth a salt he must have a tin opener, can use a tin opener! And um, washing wise, I had to learn the washing machine but now [anon] does this, but putting the washing onto the line, I do that but my biceps are causing me problems now, with dragging carpets for many years, theyre gone, and theyre very a year last January, I did collapse with this problem, and really jarred it, and I had to have treatment for that, and Im getting old, parts are wearing out

and no ones looking after you, in some ways, its harder for rode to look after you, in some ways, as you get older

C2: Im a poor patient! I wont accept everything

so is it just you and [anon] at home

C2: yes we have one son, hes normally resident in Manchester, but at the momemtn hes resident in Canada hes a computer bod. He got to the top of the ladder, I didnt. He goes to America, he virtually lives in ameraica, put in a nutshell, he goes along and sets up the procedure to automate production sets up production lines he works for breweries and things like that

and do you have anyone from social services helping you

C2: when [anon] first came out of hospital, they used to come in the evening to see if [anon] was still in bed but they used to come about 7 o clock were not late night people, but 7 is out of the question we dispensed with them and we got on she eventually started to go up stairs, and we had another hand rail fitted, and I used to get up behind here, and get her in bed, but now shes very self-supportive. I rigged up an alarm so if she presses a button and Im downstairs its a mobile alarm its a box, with a little button, and whenver the person presses that button, it sounds on the box, and I come

to see whats happening. I can bring it downstairs, and if Im upstairs, she presses the button in the kitchen its a mobile thing.

and how about [third carer]

C3: [anon] was a nurse for 45 years

what kind of nurse

C3: she was a midwife for 33 years. She got moved from Plymouth to the x hospital here in Sheffield. Last 7 years, before she had the stroke, she was bed manager 7 nights on 7 nights off she came down one morning after having down her 70 hours had her breakfast, went to the doctors on a completely unrelated thing, and had a stroke in the doctors office, in front of her I wish it had never happened. Anyway, the doctor lady was switched on, and she made sure she had a neuro bed straight away next she was tied to the wall the consultant woulnt let her out till this care package was put together so her hospital bed was delivered to the house, to the dining room, and a social package was pput out, where the carers would come in twice a day, it was like that for a year, then we had to get rid of the social workers because they werent playing ball, they were turning up when they felt like it, 6 o clock on night to put her to bed. They were supposed to work to 9:30 at night, but they were skiving off, they were doing a tea-time round, and theyd stick us on the end of it we had to pay for this, you know? Anyway, thats it, and since then, weve had a stair lift put in, so I can get her upstairs. She did try it for six weeks, but it was killing her by the time she got back down, she was exhausted. And sometimes she had to come down on her bottom, and that was uncomfortable for her. Anyway, we got the stairlift put in, and Ive done the caring ever since, but I was taught, because I was ex-navy, I was taught husbandry, cooking, sewing, everythihng, so you were self-sufficient, no washing machines in those days, I was fortunate, I could cook, clean and do everything. So Ive looked after her ever since.

and you moved here?

C3: weve been here 20 odd years

and do you have a good social network?

C3: well she does, the nursing world, I dont know anybody

C1: and what that man said about care, that is one of my main bugbears, care. At this moment in time, we are very fortunate, we have a regular carer,

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shes brilliant but other times they did things in their own time, not at times that suited you

C3: theyd come at 10am in the morning to get her out of bed, too late different people. You didnt know who was coming the next day,

C1: our getting up time, Ive said between 9 and 10, but sometimes they come at 8 in the morning two people came from wakefield that day, they walked over the grass verge. I said do you mind taking your shoes off and they said no, and I said youre not coming in my room with shoes like that! She says were not allowed to because of health and safety I said to other people let you come in the house, she says yeah I said well not in my house! So she went out. But thats the kind of service you get. You still get people coming in who wont take their shoes off, but Ive got some of them slip on things [to put over the top]. Youre paying 11 pund an hour for these people.

youre not getting very personal care then, not very respectful of your home

C1: the majority of them have been a waste of space . Youve got a list of their duties, but you feel embarrassed saying you should be cleaning the bathroom out, you should be doing the hovering. Every time, theyre supposed to turn up for an hour, but even [anon], the longest shes been in is 40 minutes, and thats even with a cup of tea.

C3: but you still have to pay for the hour

C1: theres some of them who are in and out in a quarter of an hour so many thgns we want to ask, but one thing in particular, whats your experience of rehabilitation and exercises, and did you get any help in doing rehabilitation and exercises?

C3: when they got her back on her feet, they concentrated on getting her up, but theyve realised since that they should have been working on the arm as well as the leg, at the same time. Now for two years, were running into problems, trying to get it straightened out. We do exercises, about 100 exercises in the morning, but .. also massage, her neck, her arms, her shoulders, her face she does another set of 50 exercises exercising her left arm every day. these are exercises that the physio has talked you through?

C3: yes, [anon],. Shes a senior physio at On average, it works out at twice a week. But thats 50 an hour now [private rates?].

how many years ago now?

C3: 5 years.

so youve been seeing private physio

C3: twice a week. On average, sometimes its less. We had a month off. They work on the arm, because its stiffend up. Now if the arms not working, the leg doesnt want to work. [talks about some kind of rehab machine].

so can I ask a question? So shes very good at doing her exercises?

C3: she wants to do it. She had a course at Barnsley, a weeks solid physiotherapy, with two or three people working on her at the same time, but she came back exhausted. This exercise exhaustion, theres no doubt about it, after that she was really tired

so its an important thing to get a balance between making sure some exercise is done but also making sure that its not too exhausting

C3: thats right too. But the thing is, when she was in hospital, they didnt work on the leg on the arm at the same time, so being up here didnt do any good. They put a splint on it, which has helped, its kept it in that position. You didnt get physio every day, physio Monday to Thursday 3 sessions a week is a waste of time!

if I asked all three of you for your wives, what would be the best goal that they could achieve? What would be the best ting that they would want to achieve

C3: use it again to be able to cook

C1: thats the same for my wife. If she could make a cup of tea, I mean seriously, that would she would like to make a cup of tea, which she cant do

C3: but I can do those things she just wants to be normal shed like to walk like she could walk before something that would help her walking

but cooking seems to be but what about [anon], what would she like to do again?

C2: get back to normal get back to all the domestic chores and her house is her house

Responses to four technology demonstrators

The following are the responses of stroke survivors and their partners to a set of technology demonstrations. Responses were provided on post-it notes. Each item in the list represents a single response. Responses are grouped by the technology demonstrator to which they refer.

Torches

- Could already do it

- Remote control

- More than one focus (??dont think this is the right word but cant read, sorry!)

- How to make sure youre doing the right movements?

- Can angle the torch with wrist without moving arm

- Lights on wall so you get above to help enforce

- Make it go higher tomorrow

- Social function of the carer is enforcing use of the hemi hand

- Constraint study ties in with physio

- Liked this very much

- Didnt actually move her arm to reach the target even when they were widely spaced just re-positioned the angle of the torch so need to think about how we link the game to the movement

- Liked the music

- R uses the internet has her favourite websites. I liked messing about with it likes messing about with anything like that.

- Has enjoyed playing patience on the computer

- I like the mouse more than the keys on the computer

- My nephew Ian does the family history on the internet side splitting s there are so many Foxes

- Wanting to drive, couldnt cope with the steering wheel, infrared and switches

- Music ? other ideas, jokes, pictures, snakes and ladders, ludo

- Jcket to wear interesting to look back and see graphics

- Feedback

- Useful if on own story of difficulty putting jacket on, needed help

- Incentive

- Just wait until read ?something I cant read??   easy to say cant be bothered

- If set up and agree to do twice a day, so having it there and some feedback

- No good doing at 6pm at night on downward slide or after 4pm

- Kept diary

- Think doing fine but see its not with mannequin feedback

- Arm exercises mannequin, you had to follow, visual, graphics, played back and could see differences in arm and self

- Stretching out for 10 times can be exhausting

- After 7 arm wouldnt reach so far

- Content alternative, not just one thing, get bored

- Lighter torch

Google Earth

- Must make it simple

- Solitaire on computer

- History slices (? Wrong word) for lm

- Photographs

- Lots of things needed

- I would like to be able box and see pictures

- Egg cup! Grasp

Chess

- Baking? Keep saying well bake Ill do the pastry you do the finishing touches

- Dont think I could teach anyone

- Finding the time

- T doesnt have any time up 6am til 10pm makes her rest/cuppa

- Could be doing something whilst R resting

- On social side been neglected

- Wants more strength and dexterity

- AR example dancing?

- mother dont be so daft

- stick in the muds

- Dont go to Stroke Clubs usually only second time

- Son says should do shopping on-line

- Better to go to shop as it gets you out

- Younger days, dancing class

- Son/friend plays with people in Australia

- Can speak to them and see them

- Cant think they would use it?

- Son abroad would work but he wouldnt like us watching him

- Not chess, used to play scrabble, checkers, monopoly, solitaire, 5s and 3s card game

- Tried the movement with stick not able to do it

- Angle easier if flat

- Getting shoulder to move (stiff this morning)

- Want to do it yesterday!

- Something like mouse (like audio stick but thicker)

- Like m. bowl (sorry again cant read!)

- Play solitaire

- More interested in gym equipment

- Not competitive either with others or herself

- Would prefer to have the board not the computer screen displaying the game

- Not interested in chess but like scrabble/draughts

- Dont like computers

- Be ok if it was on the TV but I have trouble with my eyes

- Like doing exercises prefer to do it on my own

- Liked knitting/crochet but cant hold the wool

- Suggestion re helping to get hand straight to move over surface

Tapestry

- Getting back to how we were before on holidays

- Not interested in sewing so didnt appeal (but friends who were she thought would be)

- She does like scrabble and dominoes

- Might be tempted to use the non-hemi hand

- Better if the person had strength in the opposite hand to use both hands together

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- Requires artistic talent

- ?? different sizes to hold and activate

- Having to let go of block in order to activate colour as release is a problem

- Get a specific end result (good)

- Would have to lift and not slide might cheat!

- Ball might be better than a block

- Block would need to be shaped to individual hand ability

- Own focus re hobbies is good