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**Stroke Patients' Utilisation of Extrinsic Feedback from Computer-Based Technology in the Home**

**Jack Parker**

**A thesis submitted in partial fulfilment of the requirements of  
Sheffield Hallam University for the degree of Doctor of Philosophy**

**February 2012**

## **Candidate's Statement**

I hereby declare that this thesis, submitted in partial fulfilment of the requirements for the degree of Doctor of Philosophy and entitled 'Stroke Patients' Utilisation of Extrinsic Feedback from Computer-Based Technology in the Home' represents my own work and has not been previously submitted to this or any other institution for any degree, diploma or other qualification.

The work within this thesis is my own unless otherwise stated.

----- Jack Parker.

## **Acknowledgements**

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## **Abstract**

**Background:** Evidence indicates that post-stroke rehabilitation improves function, independence and quality of life. A key aspect of rehabilitation is the provision of appropriate information and feedback to the learner.

Advances in information technology (IT) have allowed for the development of various systems to complement stroke rehabilitation that could be used in the home setting. In the near future these systems may increase the provision of rehabilitation a stroke survivor receives and carries out, as well as providing a learning platform that facilitates long-term self-management.

**Aim:** To explore the utilisation of extrinsic feedback from computer-based technology to facilitate post-stroke upper-limb rehabilitation in the home.

**Method:** Using the principles of realistic evaluation, this study explored the context of utilising computer feedback for upper limb stroke rehabilitation in the home setting; the underpinning theory-driven mechanisms of the intervention and how these impacted on theoretical outcomes. Focus groups with Community Stroke Teams were followed by initial testing and multi-method case studies before, during and after the use of computer-based equipment. Data were analysed in relation to the hypotheses case by case. This was followed by a synthesis of the findings to answer the question, *'what works for whom and in what circumstances and respects?'*

**Findings:** Data analysis reveals that in order to achieve desired outcomes through the use of computer technology, key elements of computer-feedback such as; accurate, measurable, rewarding, adaptable, and knowledge of results feedback are required to trigger the mechanisms underpinning the intervention. In addition, the pre-existing context and the personal and environmental contexts such as; previous experiences of service delivery, personal goals, trust in technology, social circumstances and practicalities may also enable or constrain the underpinning theory-driven mechanisms.

**Discussion:** This research has explored the implications of the paradigm shift from therapist led rehabilitation where feedback is provided face-to-face to a more patient led model of rehabilitation where feedback is provided by a computer in the absence of a therapist. Findings suggest that the delivery of feedback in clinical practice is led by their empirical knowledge and understanding of the therapists. However, this model of delivery may not be conducive to motor learning and self-management and may also influence the personal context of users.

The theory-driven mechanisms underpinning the utilisation of feedback from computer-based technology for home-based upper-limb post-stroke rehabilitation are dependent on key elements of computer feedback and the personal and environmental context. The discovery of these elements may therefore result in the development of technology; therapy education and the subsequent adoption of technology and a self-management paradigm; long-term self-managed rehabilitation; and importantly, improvements in the physical and psychosocial aspects of recovery. Further work is required to; develop the technology so that it incorporates the elements of feedback highlighted by this research; ensure the technology is robust, reliable and accurate; investigate the clinical utility of technology for home-based stroke rehabilitation, and the extent to which it might encourage utilisation by the end user.

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# **Introduction and the Realistic Evaluation Framework used**

## **Throughout the Thesis**

### **Introduction**

Strokes are a global problem and as a result of rising risk factors such as, an aging population, obesity and hypertension, the global incidence of stroke is set to escalate from 15.3 million to 23 million by 2030 (Strong *et al*, 2007). In the UK, strokes are the largest single cause of disability (Department of Health (DoH), 2007) resulting in a cost to the economy of £8.9 billion a year (Saka *et al*, 2009). The decrease in mortality and rise in morbidity means that there are more stroke survivors living with the profound and unique sequelae of stroke, placing an increasing demand on stroke services (NAO 2010).

Evidence indicates that post-stroke rehabilitation improves function, independence and quality of life (Kwakkel *et al*, 2004; Pollock *et al*, 2007) providing that it is long-term, intense, task-specific, goal-orientated, variable, environmentally enriched and includes feedback on performance (Kalra and Ratan 2007; Krakauer 2006; Barker and Brauer 2005; Langhorne *et al*, 2009). Initiatives such as the Quality, Innovation, Productivity and Prevention (QIPP) programme provide a continued focus on delivering stroke services that: are cost-efficient; provide the best quality of care; involves patient choice; allows for care to continue beyond the acute period; maximises recovery; and is delivered closer to home (DoH 2007; 2008; 2010). Indeed, over recent years there has been a contextual shift in service delivery from hospital-based rehabilitation to the community. However, due to the increasing demand on services and financial constraints, service needs cannot be met, therefore, there needs to be further consideration for the delivery of new, innovative service models to increase the amount of time patients spend in therapy within the context of home-based rehabilitation (DoH 2010).

Radical innovation is now considered to be an essential way of delivering the changes that are required to meet the challenges faced in healthcare (DoH 2010; 2011). Therefore, initiatives that focus on patient-centered care that involves contemporary ways of promoting long-term self-management for chronic conditions remain at the forefront of service redesign (DoH 2010; Bunt and Harris 2009; Jones 2006). Recent technological advances have prompted the development of robotic, virtual reality, and

inertial tracking systems that have the potential to provide consistent, detailed, individually adapted rehabilitation in the absence of the therapist (Intercollegiate Stroke Working Party 2008). Furthermore, these systems may also have the potential to promote a model of rehabilitation that encourages self-managed rehabilitation over the longer term.

Much of the evidence supporting conventional post-stroke rehabilitation suggests that feedback is provided verbally face-to-face by a therapist and typically involves hands-on therapy (Ballinger *et al*, 1999; DeJong *et al*, 2004; Hartvelt and Hegarty 1996; Wohlin Wottrich *et al*, 2004). However, the drive towards the use of new technologies and the promotion of self-care exposes unanswered questions regarding the reliance that a stroke survivor can have upon a therapist for both, motor learning skills (Magill 2007) and the self-management of the resultant long-term disability (Jones 2006). Therefore, further exploration is required to investigate the use of feedback provided by technology in the absence of a therapist.

This research explores the shift from receiving face-to-face feedback to receiving feedback provided by computer technology within the context of the user's home in the absence of a therapist. Using a novel methodological approach, this thesis therefore contributes original knowledge by evaluating how the context of using computer-based feedback for upper-limb post-stroke rehabilitation impacts on the theory-driven mechanisms underpinning the intervention resulting in context-mechanism-outcome configuration theory refinement.

## **The Methodological Framework**

The methodological framework used in this thesis was based on the principles of realistic evaluation (Pawson and Tilley 1997). This gave an important innovative dimension to the research study since this methodology has not been used in the development and evaluation of technology for rehabilitation. This methodological approach was essential as the current knowledge base for using technology for post-stroke rehabilitation within the context of the home is limited.

## **Realistic Evaluation**

From an epistemological standpoint, the researcher aimed to explore how the context of the intervention; 'the provision of extrinsic feedback from computer-based technology

for upper-limb post-stroke rehabilitation in the home,' impacts on the underpinning theory-driven mechanisms, leading to variable outcome(s).

With its roots in social science, realistic evaluation (RE) draws on a generative model to explain that an outcome is the result of the interaction between a mechanism and a context. In particular, how a mechanism may lead to differences in outcome if it is added to a different context. For example, the action of lighting gunpowder involves a mechanism (flame) and an outcome (explosion). However, this depends on the context; if the gunpowder is kept in wet conditions, it will not light; if the gunpowder is of poor quality, a smaller explosion will occur. Therefore, if no two contexts are the same, there is a possibility that no two outcomes will be the same. Thus,

*Mechanism + Context = Outcome*

The four elements of Pawson and Tilley's research cycle are Theory, Hypotheses, Observation, and Programme Specification (fig 0-1). The framework begins the evaluation by describing the context (C) in which the intervention is set. This is followed by the initial exploration of the theory underpinning the mechanism(s) and the possible outcomes (O). This is followed by the question, '*what might work for whom in what circumstances*' where the researcher hypothesises what mechanisms of the intervention might work and whom the mechanism is targeted towards. These hypotheses are set out in context-mechanism-outcome configurations (CMOC's).

The next stage involves the 'observation' phase where multiple methods of gathering data are chosen and fieldwork is carried out which then enables the researcher to subject the package of CMOC's to systematic testing<sup>1</sup>, evaluate the findings, and answer the final question, '*what works for whom and in what circumstances and respects.*' The final stage of the cycle involves relating the findings and building on existing theory. This RE cycle forms the framework for this thesis.

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<sup>1</sup> This term is used by Pawson and Tilley (2004) to describe the process of systematically observing the CMOCs using multiple methods of gathering data.

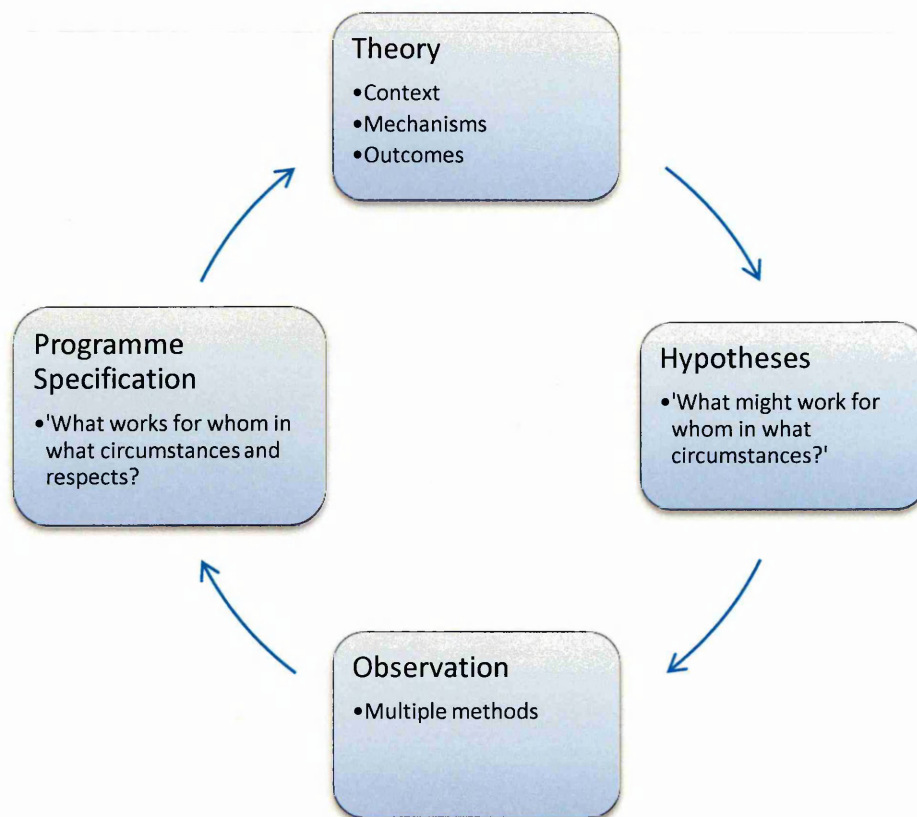


Fig 0-1: The realistic evaluation framework used in this research (Pawson and Tilley 1997 p.58).

### **Programmes<sup>2</sup>**

Programmes (interventions) are a set of theories incarnate that are active and embedded in an open system. In other words, they are pieced together through underlying theoretical assumptions based on evidence. They are also active in that they are open to human volition and decision making in a given context (Pawson and Tilley 2004). The ‘intervention’ in this study is the provision of feedback through computer technology for upper-limb post-stroke rehabilitation in the home.

### **Mechanisms**

Mechanisms are the workings of an intervention that bring about change. Mechanisms are theory-driven in that they form the often hidden components of the intervention that enables subjects to make choices and decisions of their behaviour (Pawson and Tilley 1997). Astbury and Leeuw (2010) suggest that there are three key elements in that mechanisms are; usually hidden, sensitive to variations in context, and able to generate outcomes. The mechanisms in this study describe the process of how participants act

<sup>2</sup> This thesis refers to the ‘programme’ as the ‘intervention’.

upon the intervention stratagem to enable the underpinning theories to work. For example, how receiving feedback from computer-based technology might encourage independent, self-evaluation and self-monitoring of recovery.

### **Context**

The ‘context’ refers to the features of the conditions in which interventions are embedded that are relevant to the intervention mechanisms. Essentially, they address the ‘for whom’ and ‘in what circumstances’ (Pawson and Tilley 2004). Pawson and Tilley (1997) suggest that,

*“The operating condition of mechanisms is always contingent on context; subjects will only act upon the resources and choices offered by an intervention if they are in conducive settings” (p. 216).*

The ‘context’ in this study includes the personal and environmental context of the stroke survivor and their carer, current service delivery, and the impact of rehabilitating in the home.

### **Outcome Pattern**

The outcome pattern is the result of the context enabling or constraining mechanisms in a given context. They therefore, vary according to the variations in contexts. In other words, outcome patterns are the intended or unintended consequences of mechanisms working in contexts. Therefore, because contexts may vary, the outcome of mechanisms working within them may also vary. For example, in this study, a possible outcome may involve a participant adopting and developing a self-management approach to rehabilitation as a result of receiving feedback from computer technology. However, if the context is not conducive, a variation of this outcome may occur.

### **Context Mechanism Outcome Pattern Configurations (CMOCs)**

The interaction between the context, mechanism and possible outcomes are central to the evaluation. This enables the researcher to establish how an intervention embedded in a variable context has enabled or constrained the underpinning theory-driven mechanisms to work or not work – ‘what works for whom and in what circumstances and respects?’ (Pawson and Tilley 2004).

The following section outlines the research question, the aim and objectives of this study and a description of the structure of this thesis.

## Research Question

How does the context of utilising computer feedback for upper limb stroke rehabilitation in the home setting and the underpinning theory-driven mechanisms of the intervention impact on theoretical outcomes?

## Aim and Objectives:

To explore the utilisation of extrinsic feedback from computer-based technology to facilitate post-stroke upper-limb rehabilitation in the home.

- I. To establish the pre-existing context by exploring the nature of current rehabilitative practice post-stroke.
- II. To establish the underpinning theories of the intervention; *'the provision of extrinsic feedback from computer-based technology for upper-limb post-stroke rehabilitation in the home.'*
- III. To establish working hypotheses as to 'what might work for whom in what circumstances' and develop a CMOC variable book.
- IV. To validate the proposed CMOC's by establishing what current practice and provision of information and extrinsic feedback therapists employ to assist patients to continue with their rehabilitation post hospital discharge.
- V. To initiate the observation phase and subject the CMOC's to a systematic test by obtaining the views of stroke survivors and their carers of one form of computer-based technology for upper limb rehabilitation in the home.
- VI. To continue the observation phase and investigate how a number of stroke survivors respond to using this computer-based technology over an extended period of time unsupervised in their home.
- VII. To establish how the underpinning theory-driven mechanisms and the contextual factors help or hinder the underpinning mechanisms of the intervention and in what respects.
- VIII. To establish 'what works for whom and in what circumstances and respects' following the delivery of the intervention.
- IX. To provide recommendations for intervention specification.

## The Structure of this Thesis

This thesis follows the RE cycle illustrated in fig 0-1. The first section of this thesis sets out the theoretical framework to firstly; describe the context of service delivery and how this is changing; secondly, describe the mechanisms underpinning the use of the SMART Rehabilitation Technology System; thirdly, detail the underpinning theories of the intervention and set out the theoretical outcomes of utilising the feedback from the SMART system; and finally, the hypotheses – ‘*what might work for whom and why*’ are set out in context-mechanism-outcome configurations (CMOCs).

The second section provides an overview of the methods used in this research and a validation of the embryonic hypotheses by exploring the professional perspectives of the delivery of feedback in clinical practice. Initial testing of home-based upper-limb post-stroke rehabilitation using the SMART Rehabilitation Technology System is then described. A number of case studies detail the exploration of the use of one form of computer technology to facilitate upper-limb post-stroke rehabilitation over an extended period of time unsupervised in the user’s home. This involves the use of multiple methods of data collection including, observations, interviews, and an extended activity of daily living scale.

The third section begins with a synthesis of the findings to answer the question, ‘*what works for whom and in what circumstances and respects?*’ An overall discussion of the findings of this research is then provided as well as the limitations of the study and recommendations for future research. Final conclusions are then presented.

The final section of this thesis contains the references and appendices.

## Section 1: Theory

### 1. Chapter 1: Context

#### 1.1 Introduction

The initial stage of the evaluation cycle involves eliciting and formalising the context-mechanisms-outcome configurations (CMOC's) to be tested (fig 1-1). This process includes; describing the context such as; the personal and environmental context of the stroke survivor and their carer, current service delivery, the impact of rehabilitating in the context of the home, and the limitations of this model of service delivery.

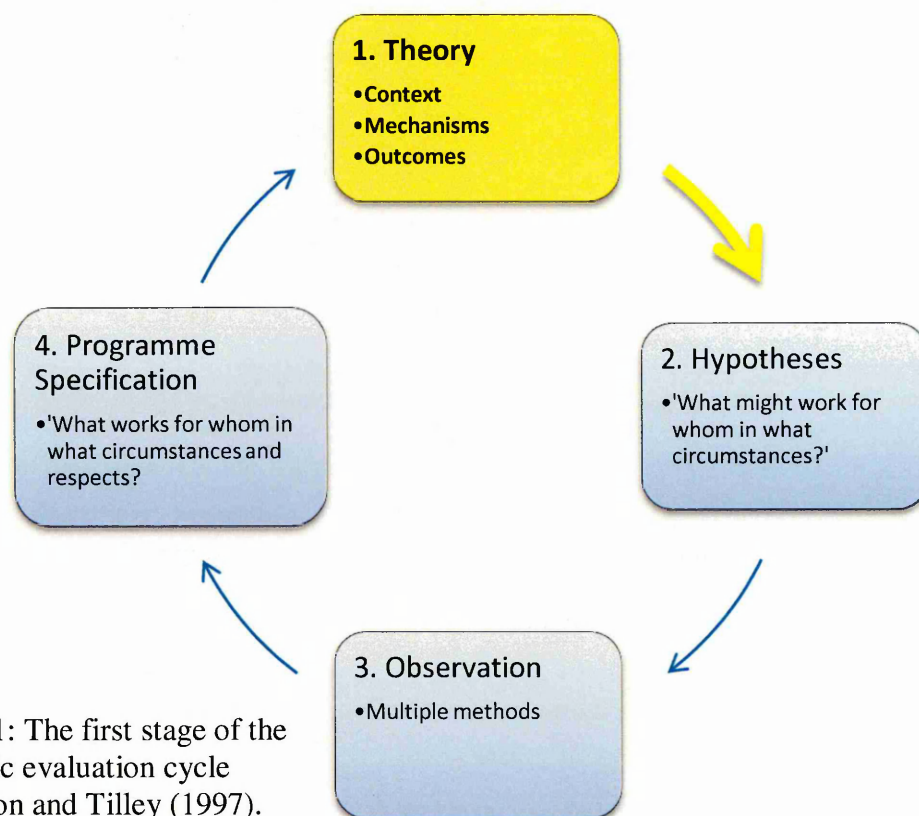


Fig 1-1: The first stage of the realistic evaluation cycle (Pawson and Tilley (1997)).

Therefore, this chapter will firstly; describe the pre-existing context of stroke including the pathology and epidemiology; secondly, consider the impact of stroke on the survivor and their carer's context; thirdly, discuss the context of current and future models of service delivery which embrace moving care into the community; and finally discuss the limitations of this model of delivery.

#### 1.2 Pathology: 'what is a stroke?'

The World Health Organisation (WHO) define stroke as,



*“Rapidly developed signs of focal (or global) disturbance of cerebral function lasting longer than 24 hours (unless interrupted by death) with no apparent nonvascular cause” (Hatano 1976).*

Strokes are caused by a disturbance of blood supply to the brain as a result of ischemia or haemorrhage (Baer and Durward 2004). The damage that occurs from this disrupted blood supply leads to a non-selective loss of cells and importantly, the unique size and location of this cellular death determines the subsequent long-term functional deficits that follow (Sims and Muyderman 2009).

Although the natural clinical course of stroke recovery still remains uncertain (Kreisel *et al*, 2006); observed improvements involve the ability of the neuronal network to plastically adapt to injury (Hallett 2001; Rossini *et al*, 2003). The mechanisms underpinning plasticity and post-stroke recovery are discussed in chapter two.

### **1.3 Epidemiology: Strokes are an Increasing Problem**

Strokes are a worldwide problem and as a result of rising risk factors such as, an aging population, obesity and hypertension, the global incidence of stroke is set to escalate from 15.3 million to 23 million by 2030 (Strong *et al*, 2007) making it the second leading cause of death globally behind ischemic heart disease (WHO 2008). In Europe the incidence is estimated to increase by 30% between 2000 and 2025 (Truelson *et al*, 2006).

The world population in 1990 aged 60 and over was 488 million; this is projected to reach 1,363 million in 2030; a 180% increase (World Population Prospects 2004). Age is one of the most substantiated risk factors for stroke (DoH 2001); therefore, as the population ages, and the mortality rate of stroke decreases (Carroll 2001) more patients are likely to need rehabilitation to improve function, participation and HRQoL which will place an ever-increasing strain on healthcare.

Financially, stroke consumes 2-4% of total global healthcare costs. In the United States, the total direct and indirect cost for 2008 was estimated at \$65.5 billion. The direct costs (direct care) account for 67% and the indirect costs (loss of productivity) 33%. In the European Union (EU), the total annual cost is estimated at 27 billion Euros. 68.5% are direct costs and 31.5% indirect. In the UK, strokes are the largest single cause of disability (DoH 2007) with overall total societal costs of £8.9 billion a year. The direct

costs account for £4.4 billion, which represents 5.5% of the total UK national health expenditure (Saka *et al*, 2009).

However, of greater cost to the stroke survivor and those who care for them, the resultant sequelae of stroke is a sudden and often traumatic life changing event where the unique complex of physical, psychological and social problems can be devastating (Burton 2000).

#### **1.4 The Sequelae of Stroke: The Impact on Survivors and Caregivers**

The impact of stroke upon both survivors and caregivers have been described as a 'loss' in terms of having reduced; functional ability, independence (O'Connell *et al*, 2001), personal characteristics, personal identity (Ellis-Hill *et al*, 2000) and emotional and social loss (Pound *et al*, 1998). Survivors also face the challenge of accepting that their relationship with themselves and others may change. Socially, their roles and identity may differ as a result of the perceived and/or actual loss of functional independence as well as cognitive deficits (Trigg and Wood 1999).

It is estimated that following a stroke, 70-85% of first strokes are accompanied by hemiplegia (Nakayama *et al*, 1994; Somerfield *et al*, 2004). Of these, 65% will demonstrate some degree of lower extremity motor recovery and only 15% will gain complete recovery both for the upper and lower extremities (Hendricks *et al*, 2002). In addition, longitudinal studies suggest that only 50% of stroke survivors with upper limb paresis are likely to regain some useful function (Broeks 1999) and only 12% of stroke survivors regain full use of their arm and hand (Kwakkel *et al*, 2003).

Stroke survivors are invariably left with physical changes that can profoundly affect their functional ability (Ones *et al*, 2005); independence (O'Connell *et al*, 2001) and social participation (Cott *et al*, 2007; Desrosiers *et al*, 2006; Mayo *et al*, 2002; Rochette *et al*, 2007). In addition, stroke may also impact on their psychological status. For example, studies reveal strokes can result in having reduced personal characteristics and personal identity (Clarke and Black 2005; Ellis-Hill *et al*, 2000). Furthermore, stroke survivors can also experience emotional and social loss for both the stroke survivor and those who care for them (Bakas 2009; Pound *et al*, 1998).

### **1.4.1 The Impact of Caring**

Caring for a stroke survivor can lead to lifestyle changes for both the survivor and their carer (Periard and Ames 1993) due to physical and emotional changes, a feeling of inadequacy (Kerr and Smith 2001; Brereton and Nolan 2000; Field *et al*, 1983) and financial constraints (Periard and Ames 1993). It is estimated that up to three quarters of stroke survivors are discharged home under the care of family members (Dewey *et al*, 2002; Dorsey and Vaca 1998) and evidence suggests that caregivers are at risk of depression, psychological impairments, and even mortality as a result of providing care (Baert *et al*, 2008; Bakas 2009). In addition, carers often feel they do not have the skills and knowledge to care for a stroke survivor at home. They also reported that they find it wearying to motivate survivors to participate in activities rather than letting them ‘just sit there all day’ (Smith *et al*, 2004).

A stroke has a profound yet unique effect on an individual and their family. Indeed, the holistic context not only includes the stroke survivor’s personal and physical environment but also others that maybe involved and may therefore have some influence on the stroke survivor and/or the environment they live in. Therefore, the recovery process following stroke necessitates a model of rehabilitation that considers the individual stroke survivor’s personal and environmental contextual factors as well as their needs.

## **1.5 Stroke Services: Current Service Delivery**

Over recent years service provision has shifted from the context of hospital-based rehabilitation to rehabilitation in the community. Therefore, in order to establish the pre-existing context of post-stroke rehabilitation for this evaluation, the following section will describe current service provision and how this is changing.

In the UK, the National Service Framework (NSF) for older people (DoH 2001) highlighted the need to promote older people’s health and independence by reducing the incidence of stroke and ensuring prompt access to integrated stroke care services. This resulted in the National Clinical Guidelines for Stroke first published in 2000 which aimed to provide explicit recommendations for practitioners, managers and service users about the management of stroke and transient ischaemic attacks (Intercollegiate Stroke Working Party 2000; 2004; 2008). However, a lack of service provision and quality was highlighted in November 2005 by the National Audit Office (NAO) who

published the hard-hitting report '*Reducing brain damage: faster access to better stroke care.*' This criticised current service delivery and highlighted the need for the management of stroke to become a government priority (NAO 2005).

The government responded to this through the consultation paper, '*A New Ambition for Stroke: A consultation on national strategy*' (DoH 2007) which identified recommendations for the latest National Stroke Strategy (DoH 2007). In addition, the National Sentinel Audit of Stroke involves a closer inspection of the quality of services using the evidenced-based standards set out in the National Clinical Guidelines (Royal College of Physicians 2010).

This highlights continued government ambition for better, more organised stroke care. In addition, further consideration for the delivery of new service models to deliver personalised rehabilitation programs that not only reflect the varying pathological condition of the service user but also the context in which they live (DoH 2006; 2006a; 2006b).

### **1.5.1 Stroke Pathways: Taking Care into the Community**

Stroke pathways aim to deliver the necessary and appropriate treatment and care required to stroke survivors and their families in the most efficient, effective, equitable, and humane manner possible from emergency care to community rehabilitation (Langhorne and Rudd 2009).

The identified stroke pathway consists of emergency care followed by, intensive acute hospital care preferably in a stroke unit and then community rehabilitation. However, there has been a significant move over recent years to move rehabilitation into the community through early supported discharge (ESD) and for on-going support (fig 1-2 overleaf).

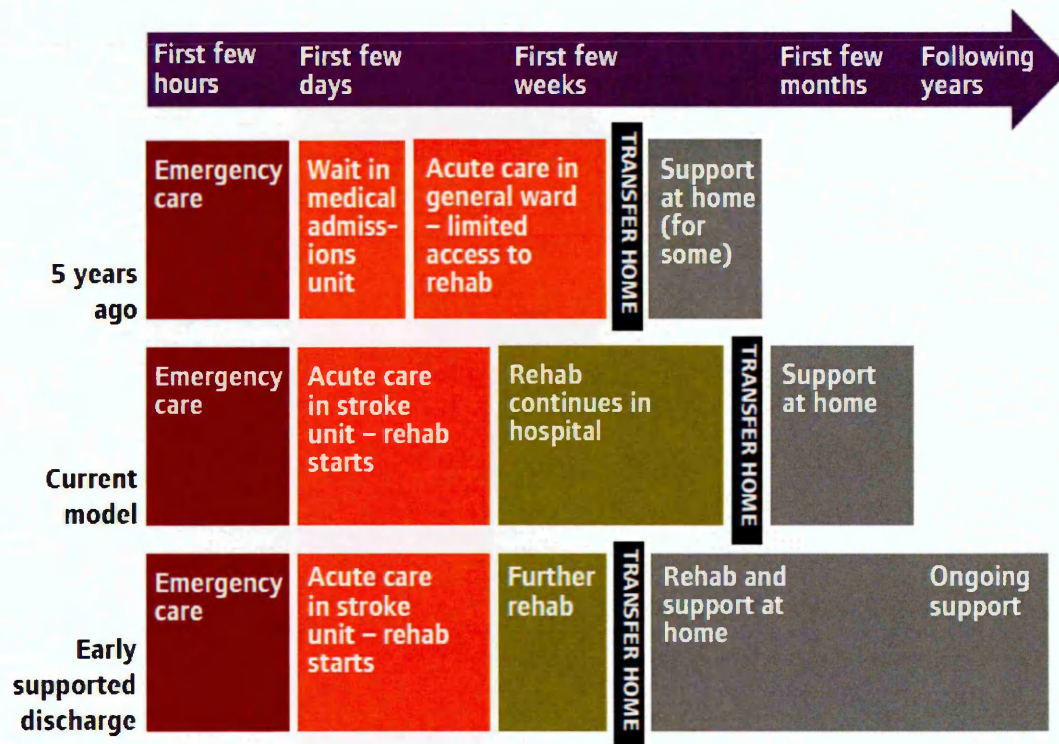


Fig 1-2: Stroke Care Pathway (CQC 2011 p.9).

There is high level evidence to suggest that stroke specialist discharge and community neuro-rehabilitation teams reduce length of stay, admission to full-time care settings and longer levels of dependency, particularly for those with mild to moderate disability if appropriately resourced (Early Supported Discharge Trialists 2005; Intercollegiate Stroke Working Party 2004; DoH 2001; Langhorne *et al*, 2005).

It has also been reported that early supported discharge services are more economical when comparing the number of bed days saved to the costs of the early supported discharge service (NAO 2010; Larsen *et al*, 2006; Teng *et al*, 2003; Von Koch *et al*, 2001). The increasing evidence for early supported discharge schemes and the drive for cost-effective healthcare and providing care closer to home has led the number of districts in England with an early supported discharge team to rise from 22% in 2002 to 36% in 2009 (Royal College of Physicians 2010; NAO 2010). The NAO (2010) suggest that increasing the availability of Early Supported Discharge from its current level – equating to around 20% – to a more optimal level of 43% of patients, with all stroke units providing Early Supported Discharge, would be cost-effective over a ten-year time-frame.

However, it has been a concern that an early supported discharge service places more stress on caregivers due to amount of care necessary for patients in the early stages

following stroke (Anderson *et al*, 2000; Grant *et al*, 2004; Carers UK 2004). However, many of these studies have involved patients with on-going medical needs or those with a progressive deterioration in health.

A randomised controlled trial by Teng *et al*, (2003) found that the caregivers of the early supported discharge service group scored consistently lower on the Burden Index (Zarit *et al*, 1980) compared to caregivers of those receiving conventional care which, it has been suggested, may have been due to the effects of empowering the family and patient to take charge of their rehabilitation (Teng *et al*, 2003). In addition, once the stroke survivor has returned home, they and their family members are able to evaluate the impact stroke has had (Pringle *et al*, 2008).

However, the stroke survivors were well supported by a multidisciplinary team of health professionals. This may suggest providing the caregiver is able to call upon adequate support, they may feel that meeting the needs of the person they care is less demanding. Therefore, if stroke survivors are to be discharged early, it is essential that they do not place more strain on carers by enabling rehabilitation to be carried out with perceived adequate support. Furthermore, any redesign of service provision should also account for the carers' needs and perspectives.

## **1.6 Rehabilitation in the Home: A Change in Context**

Home-based community rehabilitation following a stroke is now regarded as a viable alternative to hospital-based rehabilitation (Geddes and Chamberlain 2001). Evidence indicates that home-based rehabilitation is effective as it allows patients to practice skills in a familiar environment and encourages independence by allowing ownership of their rehabilitation, as well as being cost-effective (Anderson *et al*, 2000; Disler and Wade 2003).

The SMART Rehabilitation Technology System used in this research was specifically designed to be used in the context of the home-setting. Therefore, the next section will discuss the context of home-based rehabilitation; how this impacts on rehabilitation; and the limitations of this model of delivery.

### **1.6.1 The Context of Home-Based Rehabilitation**

Von Koch *et al*, (1998) observed differences in the behaviour of the patient and therapist and their roles when comparing home versus hospital rehabilitation. In their

qualitative case study, they explored the differences in therapy sessions in the home environment versus the hospital. Their analysis describes how there were distinct differences in the roles of the patient/therapist in that the hospital provided more of a disempowering environment for the recipient with less involvement in the planning and goal-setting process. One participant described how;

*“The hospital is like a sheltered workshop” (Von Koch et al, 1998 p370).*

Conversely, in the home environment, they observed how patients took the initiative and expressed particular needs and goals in their treatment.

These findings are supported by Wohlin Wottrich *et al*, (2004) and Ada *et al*, (2006) who found that the physical environment of a hospital made it difficult for patients to regain function and reconvene societal roles and the therapy area did not to provide a physical challenge and failed to facilitate unsupervised practice of rehabilitation exercises (Ada *et al*, 2006).

However, Wade (2000) suggests that in the hospital environment patients may expect to be cared for. Additionally, the anxiety and emotional reactions following stroke may also influence the rehabilitative process whereby patients may become more reliant on others to make decisions, particularly if therapists are perceived as being ‘experts’ to the recovery process (Fure *et al*, 2006).

### **1.6.2 Perspectives of Home-Based Rehabilitation**

Wohlin Wottrich *et al*, (2007) explored the perspectives of home-based post-stroke rehabilitation by a multidisciplinary team consisting of five Physical Therapists, five Occupational Therapists, two Speech and Language Therapists, and one Social Worker. The team described how:

- Supporting continuity from the hospital to home reduced feelings of anxiety and insecurity for both the patient and therapist.
- Therapists were able to see how patients would function in their home environment.
- Therapists were able to promote functional activities more naturally by using known utensils, climbing well known stairs, and walking familiar routes.
- Therapists were able to take a more passive role and allow the patient to problem-solve.

Similar findings have been reported in other studies that have examined the content and context of multidisciplinary home-based rehabilitation (Lincoln *et al*, 2004; Hale and Piggot 2005; Ljungberg *et al*, 2001). An evaluation by Hale and Piggot (2005) described how therapists aimed to gain optimal independent function by building patients' confidence, self-responsibility, and problem-solving skills while ensuring safety.

These findings are supported by the randomised controlled trial by Lincoln *et al*, (2004), where they found; the patients in the specialist community stroke team group were significantly more satisfied with the emotional support they had received; carers were under significantly less strain, were more satisfied with their knowledge of stroke and were more satisfied overall when compared to the control group who received conventional community rehabilitation. However, this model of service delivery is resource intensive and may be unsustainable as the demand for post-stroke rehabilitation increases (Truelson *et al*, 2006).

Robinson-Smith *et al*, (2000) examined self-care and self-efficacy at one month and six months post-stroke. They discovered a direct correlation between self-care, self-efficacy, quality of life and depression.

This suggests that by aiming to improve a patient's self-confidence, expectations of self-care and through this, self-efficacy behaviours; better quality of life and improved mental health may result. Cott *et al*, (2007) suggest that more efforts need to be taken to move away from acute care models of delivery that focus on curative aspects of rehabilitation to longer term care models that make best use of service users' autonomy and decision making throughout the rehabilitation process.

So far this chapter has described the importance of the context of service delivery and how this impacts on rehabilitation following stroke. However, this has highlighted a number of limitations.

### **1.6.3 Home-Based Service Limitations**

#### **1.6.3.1 The Demand for Services Outweighs Supply**

Current service models involve community rehabilitation that lasts on average 12 weeks following discharge from hospital (NAO 2010); in that time therapists and commissioners strive for the best outcomes possible for service users. However,



resources and cost-containment continue to limit the amount of face-to-face contact with therapists and there is a need to improve the clinical and cost effectiveness of therapy in the management of older people following a stroke (Forster and Young 2002; Teng *et al*, 2003).

In 2009 The Stroke Association in collaboration with the Chartered Society of Physiotherapy surveyed 663 stroke survivors in England (< two years post-stroke) about their experiences of community-based Physiotherapy. They also surveyed 497 Physiotherapists (to gain their opinion of the patient experience from their professional perspective) (The Stroke Association 2010). The survey found that:

- 21% of stroke survivors who felt they needed Physiotherapy did not receive any.
- 25% of stroke survivors had to wait longer than one month for their first session.
- 83% of Physiotherapists believe that the process of transfer of care into the community could be improved.
- Over half (52%) of Physiotherapy staff indicated that treatment outcomes could be improved if there was greater personalisation of services. In addition, 74% of Physiotherapists indicated that personalisation of services could not be achieved within current resources.

The subsequent report, '*Moving on*' has suggested four key areas for improvement: 1) community therapy should be available for all stroke survivors that need it; 2) there must be an end to fragmented transitions into community care; 3) stroke survivors should receive services that are tailored to their needs; and 4) the vital role of carers should be recognised and valued throughout the rehabilitation journey (The Stroke Association 2010).

Therefore, more efforts need to be taken to improve the transition into the community following discharge (Cott *et al*, 2007). In particular, there is a need to move away from acute care models of delivery that focus on curative aspects of rehabilitation to longer term care models that make best use of service users' autonomy and decision making throughout the rehabilitation process. Furthermore, if service demands are not being met, there is a need for newer forms of service delivery that has the potential to provide long-term independent rehabilitation that can be individualised to the user.

### **1.6.3.2 Stroke Survivors May Not Make Best Use of Non-Therapy Time**

Current service models involve community rehabilitation that lasts on average 12 weeks following discharge from hospital (NAO 2010). UK community services are 12 weeks and there is significant variation of face-to-face contact hours (NAO 2010). A study evaluating an Early Supported Discharge, found that on average a 14 week programme consisted of 12 home visits (mean), a median time consumption of 23 hours 20 minutes of which only 54 per cent was actual face-to-face contact with the therapist (Von Koch *et al*, 2000). These findings suggest that although more intense interventions improve functional outcomes (Kwakkel *et al*, 2004; Kwakkel 2006), very little time is spent undertaking therapeutic activities for both in-patients and those in community. Significantly, stroke survivors may not therefore make best use of their non-therapy time. Therefore the introduction of technology that can be used in the absence of a therapist may increase the amount of time spent rehabilitating without increasing the demand on services.

### **1.6.3.3 The Current Provision of Instructions and Feedback May Not be Conducive to Autonomous Home-Based Rehabilitation**

In order to facilitate home-based rehabilitation when not in face-to-face contact with the therapist; patients may be provided with exercise sheets to help them and/or their carer remember what exercises to do, how to perform them and how often to do them; which may, in some cases, limit home exercise interventions (Smith *et al*, 2005). For example, a third of stroke survivors experience aphasia (Pederson *et al*, 1995). Therefore, the understanding of written exercise sheets may be limited.

A Cochrane review has shown that the passive provision of information (such as leaflets) is not associated with improved outcomes, whereas an educational approach (such as tutoring) might be effective (Forster *et al*, 2001). However, a later Cochrane review by the same authors suggests that providing information may still; increase the knowledge the patient and carers has about stroke; increase patient satisfaction and reduce depression scores (Smith *et al*, 2008). Therefore, if current resources available to facilitate autonomous activity practice (when not in face-to-face contact) may not be conducive to autonomous home-based rehabilitation because of physical and/or cognitive limitations, such as, not being able to read or understand the exercise sheet provided by their therapist (Hoffman and McKenna 2006), other forms of delivering instruction/feedback are required. In addition, although the provision of feedback is a

key aspect of rehabilitation and motor learning (Subramanian *et al*, 2010; Parker *et al*, 2011); currently, stroke survivors may not receive any feedback during non-contact time and may indeed rely on other family members to comment on their performance.

## **1.7 A Shift in Service Delivery is Required**

Health services in the next decade are faced with: reduced finances; ever higher patient expectations; an ageing population; advances in technology and the growing information technology age; the reduction in mortality and a subsequent rise in morbidity due to advances in treatments, and a changing workforce. Therefore, the predicted need to release £15 – £20 billion through efficiency savings from 2011 to 2014 whilst keeping quality as the organising principle presents a challenge to service providers (NAO 2010; DoH 2010).

Community stroke rehabilitation is fast becoming the preferred choice of rehabilitation settings (Langhorne and Rudd 2009) and the mean length of hospital stay has fallen by 10.6 days (Royal College of Physicians 2010). However, although the number of early supported discharge services has risen; in contrast, there have been significant improvements in acute care but the provision of high quality; integrated services for stroke survivors after they leave acute care have not progressed at the same rate. It has long been recognised that effective management of long term conditions moves beyond the acute onset of disability. As the NAO (2010) succinctly state,

*“Stroke patients may spend several days or weeks in hospital, but it is in the months and years after discharge that they, their families and carers’ experience the full impact of stroke” (NAO 2010 p.31).*

In addition, The WHO (2002) pointed out that whilst there is a clear need to continue improving acute care, this will ultimately lead to a rise in costs without necessarily benefitting the long term health.

*“As long as the acute care model dominates healthcare systems, healthcare expenditures will continue to escalate, but improvements in populations’ health status will not” (WHO 2002 p6).*

Therefore there is continued focus on delivering stroke services that: are cost-efficient; provide the best quality of care; involves patient choice; allows for care to continue beyond the acute period; maximises recovery; and is delivered closer to home (DoH

2007; 2008; 2010). However, service needs cannot be met, therefore, there needs to be further consideration for the delivery of new, innovative service models to increase the amount of time patients spend in therapy within the context of home-based rehabilitation (DoH 2010).

## **1.8 Summary**

This chapter has described the global context of stroke and highlighted how strokes are an increasing worldwide problem and there are more stroke survivors living with the sequelae of stroke, placing an increasing financially unsustainable demand on stroke services (NAO 2010).

Following a stroke the stroke survivor and their close family's personal, environmental and social context may change. Stroke survivors are invariably left with physical and psychological changes that can profoundly affect their physical and functional ability (Pound *et al*, 1998; Ones *et al*, 2005) personal identity (Clarke & Black 2005), their relationship with others (Dowswell *et al*, 2000), and their participation in society (Cott *et al*, 2007; Desrosiers *et al*, 2006; Mayo *et al*, 2002; Rochette *et al*, 2007). As a result of upper-limb impairment, patients describe problems with personal activities of daily living (PADL's), such as, washing, dressing and feeding, and more extended activities of daily living (ADL's), such as, making meals and household chores (Pound *et al*, 1998). As a result, 50% of stroke survivors need a full time carer at home (Mayo *et al*, 2002).

Over recent years there has been a contextual shift in service delivery from hospital-based rehabilitation to the community where stroke survivors are given labour intensive, therapist led rehabilitation. However, service needs cannot be met, therefore, there needs to be further consideration for the delivery of new, innovative service models to increase the amount of time patients spend in therapy within the context of home-based rehabilitation (DoH 2010).

The following chapter continues the evaluation by describing the mechanisms underpinning the intervention. The use of technology for post-stroke rehabilitation; the SMART Rehabilitation Technology System used in this research; and the theory-driven mechanisms underpinning the intervention and the theoretical outcomes.

## **2. Chapter 2: Mechanisms, Theoretical Outcomes and CMO Generation**

### **2.1 Introduction**

The previous chapter described the pre-existing context of post-stroke rehabilitation (the ‘C’ within the CMO configurations). This described the context for this study. Chapter one highlighted how although rehabilitation is essential for stroke recovery, there is a lack of resources to provide this and therefore, new innovative models of delivery and paradigms need to be explored such as the use of technology.

The next stage of the evaluation involves unpicking the key components of the intervention that bring about change (the mechanisms; the ‘M’ within the CMO configurations) using the principles of realist synthesis. This involves identifying concepts and intervention theories (Rycroft-Malone *et al*, 2010).

The mechanisms to consider include; firstly, the use of technology for upper-limb rehabilitation; secondly, the SMART system itself, how this was developed and finally, the theoretical components underpinning the SMART system. This is followed by setting out the proposed theoretical outcomes of the utilisation of feedback that is delivered through computer technology for upper-limb post-stroke rehabilitation.

This chapter will therefore describe the drive towards the use of technology; current technology systems being developed; the work carried out by the SMART consortium and how the study which is the topic of this thesis builds on the research carried out by Mountain *et al*, (2006; 2010). Theoretical outcomes are then described and set out in CMO form.

### **2.2 Using Technology for Post-Stroke Rehabilitation**

The shift in service delivery described previously, highlighted how service provision involves rehabilitation that is led by the therapist and therefore continues to be labour intensive and costly, against the backdrop of an ever demanding and increasing need for stroke services (NAO 2010).

The DoH announced a call for Healthcare Technology Co-operatives (HTC) in 2006, where a collaboration of clinicians, patients, academia and industry acts as a focus for a ‘technology pull’ into the NHS. The aim of the HTC is to harness the potential impact

that technology (both simple and complex) might play in reducing morbidity and improving the quality of life for large numbers of patients such as those who have had a stroke (The Royal Society 2006). The 'Innovation Nation' White paper (Department for Innovation, Universities and Skills 2008) set out a continued drive towards improving the nation's technological capabilities. This includes the cooperation of independent organisations such as, the National Endowment for Science, Technology and the Arts (NESTA) who provide investment in early-stage companies, inform and shape policy, and deliver practical interventions to enhance the integration and development of technology (NESTA 2009).

More recently, in a report published by the Department of Health entitled, *'Innovation, Health and Wealth: accelerating adoption and diffusion in the NHS'* (DoH 2011) sets out an integrated set of measures and a delivery agenda that will support the adoption and diffusion of innovation across the NHS by developing partnerships between academia and industry through the establishment of Academic Health Science Networks (AHSNs).

Therefore, the establishment of the Invention for Innovation (2006), the Quality, Innovation, Productivity and Prevention (QIPP) programme (2009) and the AHSNs (2012/13), provide a continued focus on delivering stroke services that: are innovative; cost-efficient; provide the best quality of care; involve patient choice; allow for care to continue beyond the acute period; maximise recovery; and is delivered closer to home (DoH 2007; 2008; 2010; 2011).

Advances in information technology (IT) have allowed for the development of tools to complement direct efforts by therapists and may in the future even act as surrogates (Liebermann *et al*, 2006). Significantly, these developments may play a vital role in improving the NHS, health economy and patients' care (DoH 2008). Therefore, advances in technology, the growing information technology age; the reduction in mortality and subsequent rise in morbidity due to advances in acute medical care; the use of technology is regarded as a viable (although under investigated) concept in post-stroke rehabilitation (DoH 2010).

A number of potential advantages for using technology in post-stroke rehabilitation have been proposed, such as:

- **An economic case:** Technology may have the capacity to reduce the amount of labour intensive face-to-face contact between the therapist and patient whilst maintaining therapeutic input.
- **Maintaining intensive therapy:** Technology systems may enable patients to carry out repetitive exercise and movement patterns necessary for neuroplasticity whilst reducing therapist fatigue.
- **Safety:** Some forms of technology such as virtual reality, may allow patients to carry out activities that if carried out unsupervised, could be considered otherwise dangerous. For example, crossing roads or climbing stairs.
- **Facilitating motor learning:** Some systems may facilitate a learning environment by allowing the user to engage in rehabilitative exercise that involves repetition and progression in the absence of a therapist.
- **Objective measures:** The use of technology may allow users and therapists to quantify measures of improvement. For example, a system may take range of movement and speed of movement measures or display the trajectory of movement.
- **Fun and engaging:** From the user's perspective, using technology to rehabilitate may make intense repetitive exercise more fun and engaging as well as allowing for personalisation. For example, an avatar may be made to look like the user similar to the Wii Me ([www.nintendo.com](http://www.nintendo.com)).
- **Facilitating autonomy and self-management principles:** Enabling the user to engage in independent rehabilitation (in the absence of a therapist) may allow for problem-solving, decision-making, resource utilisation and taking action throughout the rehabilitation process.

(Jones 2006; Siekierka *et al*, 2007; Stein *et al*, 2009).

Whilst there are a number of possible advantages for using technology, many technological systems are still under development and/or testing therefore, the full extent of possible advantages and limitations are yet to be explored.

### **2.2.1 Technology Systems for Upper-Limb Post-Stroke Rehabilitation**

Over the last decade, a number of technological systems have been developed which may have the potential to provide consistent, detailed and individualised feedback (Intercollegiate Stroke Working Party 2008), such as, Robot-Assisted Movement Therapy (Kwakkel *et al*, 2008), Virtual Reality Technology (Henderson *et al*, 2007) and

Inertial Tracking Devices (Mountain *et al*, 2006; 2010; Parker *et al*, 2010). Crucially, systematic reviews by Subramanian *et al*, (2010) and Parker *et al*, (2011) suggest that stroke survivors can utilise feedback from various sources such as, videotape (Gilmore and Spaulding 2007), virtual environments (Piron *et al*, 2007), robotics (Coote *et al*, 2008), and computer technology (Mountain *et al*, 2010; Parker *et al*, 2010).

In addition, there is growing evidence from controlled trials of efficacy in post-stroke upper-limb rehabilitation (Kwakkel *et al*, 2008; Stein *et al*, 2009; Timmermans *et al*, 2009). The following section will describe these systems and their limitations.

Robot systems have the potential to offer therapy that augments a therapist by enabling the user to carry out repetitive manually intensive therapy. In addition, these systems are able to provide precise repeatable force feedback in a virtual environment and may even be able to deliver complex therapies that are difficult for therapists to sustain over longer periods (Loureiro *et al*, 2010).

Virtual reality in rehabilitation involves the use of computer-generated, interactive, multisensory real-time simulation of a real world activity in an immersive or non-immersive environment (Adamovich *et al*, 2009).

To date trials using robot therapy and virtual reality have involved testing in a clinical or laboratory setting only. This highlights potential limitations for the use of technology for upper-limb stroke rehabilitation, for example, systems are currently cumbersome, expensive and require the therapist to be present at the time of use, which may limit their future use in home-based rehabilitation (Liebermann *et al*, 2006; Crosbie *et al*, 2007; Henderson *et al*, 2007). To add, if current systems comprise of large frames that involve intricate technology requiring specialist operators, consequently stroke survivors may have limited access for use. However, it has been suggested that these systems may be used in a suite in a hospital or community setting where one therapist may be able to operate a number of systems at once (Loureiro 2010 pers comm.). Nevertheless, because this proposal has yet to be explored, a number of usability and clinical utility questions remain unanswered.

Therefore, if stroke survivors are to carry out intense rehabilitation using technology, it is essential that technology is freely available for them to use and that contextual factors have been explored. Furthermore, if users are to accept the use of technology and engage with the feedback it provides, a user-centred design approach is essential (Nasr



*et al*, 2010). By taking a bottom-up approach, this allows the development and subsequent use of technology systems to meet the needs of the end-users.

### **2.2.2 User Opinions of the Use of Comparable Technology to the SMART Rehabilitation Technology System**

Central to this research is gaining user opinions (usability issues) for the use of technology within the context of use. The author of this thesis systematically identified and evaluated comparable technology systems to The SMART System used in this research (see appendix 1 for a summary of the papers p.306). Part of this evaluation included exploring the opinions of participants using the comparable technology. The following section will describe these.

Only two of the five technology systems identified in the review included the opinions of stroke survivors during the trial. The study by Broeren *et al*, (2008) involved carrying out semi-structured interviews to gain the participants' opinions of their perception of the system being trialled. The interviews asked the participants if they thought the games were fun and challenging; which games they preferred to play, and how and if they would like to use the virtual reality system in the future if it was available in regular clinical care.

The findings of the interviews found that all of the participants were positive for the use of the system although they felt hesitant to use the system initially. However, they suggested that by the end of the study they would like to continue playing the games. The participants described the games involving more cognitive processing difficult such as playing Simple Simon memory games. Seven of the participants (out of eleven) agreed on having the system to complement their current rehabilitation program and four suggested they would have the system in their home.

Although these interviews go in some way to evaluate user opinions, there are many usability issues omitted. For example, the authors do not describe the physical practicalities of using the equipment such as, the users' ability to physically manipulate the joystick and the time spent on task. In addition, they do not describe whether or not the users were able use the feedback provided to gain some understanding of their performance.

Rand *et al*, (2009) also carried out interviews following the use of the of the VMall virtual reality system. This consisted of 20 open-ended questions to establish user

opinions of their enjoyment, meaning, motor difficulty, and general use of the equipment. Their interview responses revealed that all of the users believed the VMall had helped them improve their affected upper-limb and that they subsequently used it more for everyday activities than before the intervention. A 53 year old male participant suggested,

*“In traditional therapy, one is dependent on a therapist, here [in the VMall], you work on your own... you do the movements independently” (pp118-119).*

The same participant also remarked that following the VMall training he could help his son tie shoe laces and use his zipper.

Another 73 year old male participant remarked,

*“It all seemed more challenging than to sit in therapy or to exercise alone... the virtual environments took my mind off the effort and work. The VMall made me use my hand and I did things I wanted to do and in reality I cannot do. It did the job... it is better than other therapeutic aids that I know” (p119).*

Other studies identified in the review reported user opinions in previous papers. The study by Edmans *et al*, (2009) carried out initial feasibility testing with both therapists and patients and found that only one patient (out of 10 participants) had difficulties interacting with the touch screen computer and often became frustrated with the technology. Others suggested that they enjoyed using it and that the task was easier than in the real-world (Edmans 2004). During the initial development of the equipment, six out of ten Occupational Therapists had expressed a positive interest in using virtual reality as part of their treatment with four others expressing the need for clear usability evaluation and evidence for its effectiveness (Hilton *et al*, 2000; 2002).

A RCT carried out by Yavuzer *et al*, (2008) built upon initial testing by Rand *et al*, (2004; 2008) where they investigated the potential of using a low-cost video-capture virtual reality (VR) platform, the Sony PlayStation II Eye Toy with young healthy adults, older adults, and stroke survivors. Twelve chronic (> 12 months post-stroke) and five sub-acute (1-3 months post-stroke) completed a single forty minute session where they played ‘Kung Foo’ and ‘Wishy Washy’ games. The findings from the results of the Presence Questionnaire, the Berg Scale of Perceived Exertion and the Short Feedback Questionnaire revealed that all of the stroke participants enjoyed playing the games (4.4

– 5 out of 5) however, most found the games too hard to play because it involved quick thinking and physical reaction times. This was particularly evident with the Kung Foo game where they had to fight an enemy; in these games the duration of the task was limited to 12 – 48 seconds. This was also highlighted by their perceived physical exertion scores ranging from 13.7 – 14.1 out of 20.

Although the reported findings of user opinions identified are limited, they may suggest that the participants in these studies perceive upper-limb post-stroke rehabilitation that uses technology to be fun, challenging, and beneficial.

However, users have also reported difficulties relating to the screen display and describe feeling anxious. This concurs with other studies evaluating user opinions for the use of robot technology and sensor technology for upper-limb rehabilitation (Coote and Stokes 2003; Kemna *et al*, 2009; Reinkensmeyer and Housman 2007; Giorgino *et al*, 2009). Although, it must be noted, studies that involve robots or differing system architecture may have unique benefits and challenges for their use.

### **2.2.3 The Evidence in Support of the Use of Feedback from Computer Technology in Post-Stroke Upper-Limb Rehabilitation**

This research focuses on the use of feedback from computer technology in post-stroke upper-limb rehabilitation in the home. More specifically, this research involves extrinsic feedback from a computer system for upper-limb post-stroke rehabilitation that does not provide physical assistance or tactile stimulation and is provided in the absence of a therapist. Therefore, the author of this thesis systematically identified and reviewed the literature to determine the current evidence underpinning the use of feedback from computer technology for upper-limb stroke rehabilitation (see appendix 2 for a summary of the papers p.307).

The review found that although the evidence is scarce, existing findings suggest that extrinsic feedback may improve motor and functional performance. In addition, concurrent feedback, knowledge of performance (KP), knowledge of results (KR) and explicit feedback may be key components in the promotion of improved performance (Parker *et al*, 2011).

However, it should be noted that only one of the studies identified in the review obtained a Critical Appraisal Skills Programme (CASP) for Randomised Controlled

Trials score above five highlighting the need for more robust investigations (www.phru.nhs.uk 2009).

Although the identified studies used visual and/or auditory means to provide feedback, different categories of feedback were employed. This demonstrates that trials that use a similar method of delivery i.e. visual/auditory may not use the same form of feedback i.e. knowledge of performance/knowledge of results. All of the trials used either KP and/or KR to provide feedback. Although it has been suggested that KP is more effective than KR when performing a reaching task (Cirstea *et al*, 2006; Cirstea and Levin 2007), there are a number of additional elements of feedback unaccounted for. For example, how the feedback is presented and what forms of feedback works, for whom and in what circumstances.

Furthermore, the users in the studies identified in both of the reviews were supported by the therapist during use and the system was not used in the context of the home. Therefore, there are unanswered questions as to what elements of feedback impact on the mechanisms underpinning the intervention, how contextual differences influence these mechanisms and subsequently, how this impacts on the outcomes of the intervention.

To summarise the findings of user opinions (2.2.1) and the evidence in support of the use of feedback from computer technology in post-stroke upper-limb rehabilitation (2.2.3):

- Mirror therapy (visual feedback) in addition to conventional therapy may improve the motor and functional recovery of the hand and upper extremity for sub-acute stroke survivors.
- Visual concurrent KP and subsequent KR feedback may improve functional independence for acute stroke survivors.
- The provision of videotape feedback may lead to a greater satisfaction of performance with acute stroke survivors.
- Concurrent auditory KP feedback may improve motor performance.
- User opinions indicate that receiving feedback from computer technology can be fun, challenging and motivating.

- User opinions suggest that using computer technology for upper-limb post-stroke rehabilitation can improve the (perceived) performance of the affected upper-limb leading to an increased ability to carry out ADL's.
- User opinions suggest that some computer activities can be too difficult to complete as they may be too fast or physically demanding.

The following section describes the SMART Rehabilitation Technology System used in this research.

## **2.3 The SMART 1 Project**

The EPSRC funded SMART Consortium ([www.thesmartconsortium.org](http://www.thesmartconsortium.org)) began in 2003 and involved partners from Sheffield Hallam University, University of Bath, University of Essex, University of Ulster, the Stroke Association and Philips Research Scientists. The consortium aimed to develop and test a prototype telerehabilitation device (The SMART Rehabilitation Technology System) for therapeutically prescribed stroke rehabilitation for the upper limb that would enable the user to adopt theories and principles underpinning independent self-managed rehabilitation.

This proof of concept project involved engineers, HCI specialists, clinical researchers, and therapists working closely to establish the system architecture, the decision support interface, and the therapeutic content (Mountain *et al*, 2010). The following section will describe these features of the system.

### **2.3.1 System Architecture**

The first prototype consisted of two MTX (Xsens Dynamics Technologies, The Netherlands) inertial sensors (comprising accelerometers, magnetometer and gyroscope technology) worn on the upper arm and forearm to record kinematic data from the users undertaking a functional activity (Zheng *et al*, 2006) (fig 2-1). User involvement allowed designers to develop garments for the attachment of the sensors to be donned and doffed by the stroke survivor using the affected upper-limb. Additional user requirements were also recognised during this process including the durability of the materials and maintenance (cleaning) (Mountain *et al*, 2006). The garments to house the sensors during use were a neoprene sleeve which had a thumb loop to enable the user to pull the garment into position using the unaffected arm. The neoprene wrist band had an

adjustable Velcro strap to position the sensor on the posterior aspect of the wrist (fig 2-2 & 2-3).

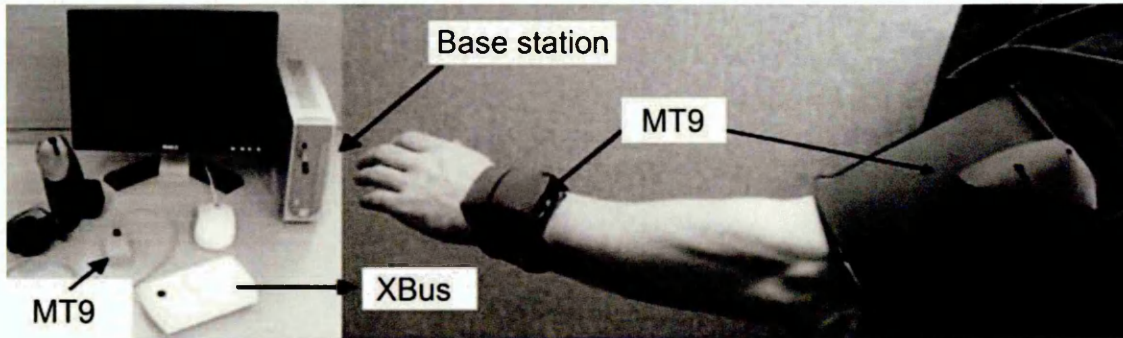


Fig 2-1: Prototype 1.



Fig 2-2: The upper-arm garment.



Fig 2-3: The wrist garment.

### 2.3.2 The Decision Support Interface

The decision support interface was designed to enable the user to observe their own movements using an avatar as representation of their active movements. In addition to recording and playback, the system allowed for comparative analysis of exercises with a reference avatar using a split-screen computer image. This aspect was vital for rehabilitation requirements because it enabled to user to compare their active movements to the ideal in the absence of a therapist (fig 2-4 and 2-5). In addition to visual feedback, quantitative feedback was provided through charts and tabulated data.



Fig 2-4: Screen display of the performed movement and the reference figure.

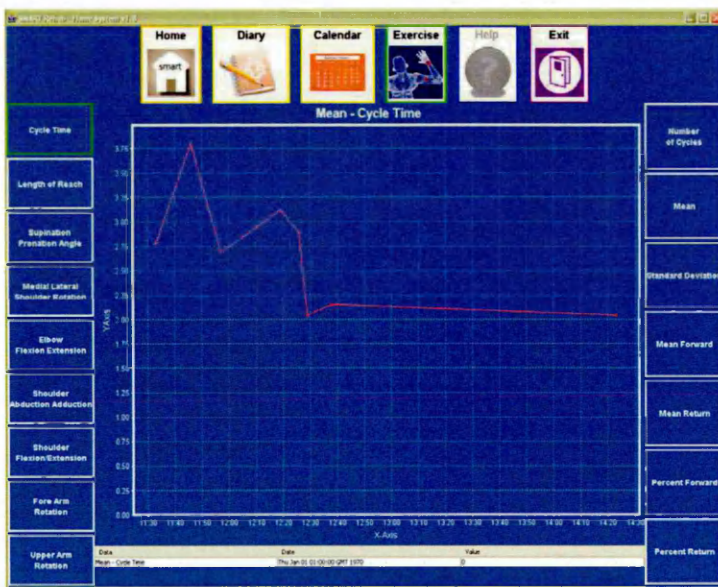


Fig 2-5: Progress chart displaying cycle time and length of reach.

### 2.3.3 Therapeutic Content

Initially seven stroke specialists from two sites participated in a focus group to advise on key rehabilitation interventions. Four key upper-limb functional movements were identified. These included reaching sideways, reaching forwards to grasp an object, hand-to-mouth, and drinking from a cup.

### 2.3.4 Initial Testing

Testing of the first prototype involved focus groups, usability tests with stroke survivors and home visits with stroke survivors and their carers. The focus groups were carried out to gain the opinion of therapists of the sensor attachments and the decision support

interface. In addition, a series of workshops with stroke survivors and carers was also carried out to test the usability of the equipment with end-users.

Participants liked the proposition of receiving quantifiable, objective data about their performance from a system, rather than praise from a physiotherapist (Wilson *et al*, 2007). The usability tests highlighted difficulties using a mouse and keyboard as well as navigation around the screen operations (Wilson *et al*, 2007).

The home testing involved four stroke survivors (aged: 37-73). The home testing revealed a number of issues including:

- Accommodating the equipment in the home; having room in their house for the equipment and where to leave it when not in use.
- Attaching the sensors; only one user was able to don the garments independently.
- Using the computer / keyboard / touch screen / diary; anxiety to use the equipment and explore the system's various components.
- Understanding and using the screen display; difficulties understanding what the screen displays meant, such as, which buttons to press.
- Interpreting screen presentations; different strategies to observe their movements.
- Need for teaching and education; a need for therapists to provide adequate training and support.

### **2.3.5 Prototype Two**

From 2006 this research was carried out in conjunction with Philips R&D in the Netherlands and Germany which led to significant improvements to some aspects of the technological capabilities of the prototype. In addition, the involvement of stroke survivors, family carers and therapists allowed for design specifications throughout all stages of development. A second prototype was developed which included matchbox-sized wireless sensors. Although these removed the need for a wired system, a charger was required to maintain the power (Willmann *et al*, 2007). Further consultation with 28 therapists resulted in a library of seven exercises to be included as well as interface alterations. In addition, a third sensor was introduced to detect trunk movements during use and a laptop computer was used. This was housed in a vest garment to place the sensor at the front of the chest (figs 2-6 and 2-7).





Fig 2-6: The vest garment.

Fig 2-7: User wearing the vest, upper arm and wrist garments and sensors.

### 2.3.6 Testing of Prototype Two

Following this development, the four original subjects who had carried out home testing carried out usability tests of a wireless prototype at the university. The final stage involved four visits as per the first prototype with a further four stroke survivors in their homes ( $n = 4$ , men; aged 59, 68, 74, 80). Similar to the first prototype, the testing and interviews provided insightful accounts with regards to: accommodating the equipment in the home; attaching the sensors; using the computer; interpreting the screen presentation and the overall use of the equipment (Mountain *et al*, 2010).

User feedback on the information provided by the decision support system during these tests found that there was a preference for real-time display as opposed to viewing the practice after the performance. They also requested on-screen comparisons between themselves and the target movement; a method of readily assimilating progress over time and a scoring method which they considered would be motivating. In addition, some expressed their dislike for graphical displays (Mountain *et al*, 2010).

Findings from the home testing of the second prototype highlighted similar findings to the first prototype. However, although a number of developments from the first to the

second prototype had occurred, the second prototype introduced new challenges. These included remembering to charge the sensors after use, placing the sensors in the correct position, and using a mouse pad. In addition, three of the four users were unfamiliar with the equipment which may have affected their confidence to use the technology as well as reduce their tolerance to accommodate it in their home (Mountain *et al*, 2010). However, encouragingly, one of the users was able to compare his movement with the real-time display.

It was reported that inaccurate sensor positioning led to the screen presentation being difficult to comprehend which may have discouraged the user(s) from continuing with their program. In addition, the testing revealed how users considered using the technology for rehabilitation. However, one user suggested that he would not like to use the equipment instead of receiving treatment from a Physiotherapist.

The second round of testing enabled Philips to continue developing the graphical interface and content of the SMART Rehabilitation Technology System. The following section will describe the version used in this research.

## **2.4 The SMART Rehabilitation Technology System Prototype used in this Research**

Key changes from the first to the second round of testing involved the graphical interface (figures 2-8 – 2-12 pp. 49-51) and the library of exercises available.

Initially, each user is added to the system by the therapist. This involves creating a new user account whereby the therapist adds the details of the user; whether the user is left or right side affected; and an account name for the user to recognise. The therapist also prescribes a number of exercises for the user and sets parameters for each of the prescribed exercises. For example, for a forward reach exercise the therapist sets how many degrees of flexion they want the user to carry out. Importantly, these parameters alter the feedback provided by the qualitative chart (fig 2-11 p.51). The bottom of the red zone indicates the lowest parameter and the top of the green zone represents the highest parameter. If the user does not achieve the desired amount of movement (i.e. 60 degrees), they will see their black dots in the red zone; if they achieve above the desired amount, the black dots will enter the green zone. Therefore, the amount of movement entered by the therapist has to accurately reflect the ability of the user or the feedback

provided by the chart may not represent the user's achievement in relation to the therapist's desired outcome.

Following the initial set up the user follows a sequential set of screen questions to determine whether the user is feeling well enough to exercise. During and following prescribed activity; feedback is provided via real-time 3-D images (fig 2-8 – 2-10 pp. 49-51); a qualitative chart (fig 2-11 p. 51) and a summary graph (fig 2-12 p. 51) are displayed on a lap-top computer screen. This allows motion patterns to be identified, analysed and corrected by both the therapist and the patient (Zhou and Hu 2007).

Prior to performing an exercise, the user is able to see a pre-recorded demonstration of the exercise they are about to carry out which can be replayed as many times as the users requires. During performance the user is able to observe their movement on the computer screen (fig 2-8) (not a mirror representation). Once they have carried out the repetitions they are able to then compare their performance to a reference figure (fig 2-9). This includes a zoom function display of a side, frontal or top-down angle of observation (fig 2-10). Users are able to replay their performance as often as they wish.

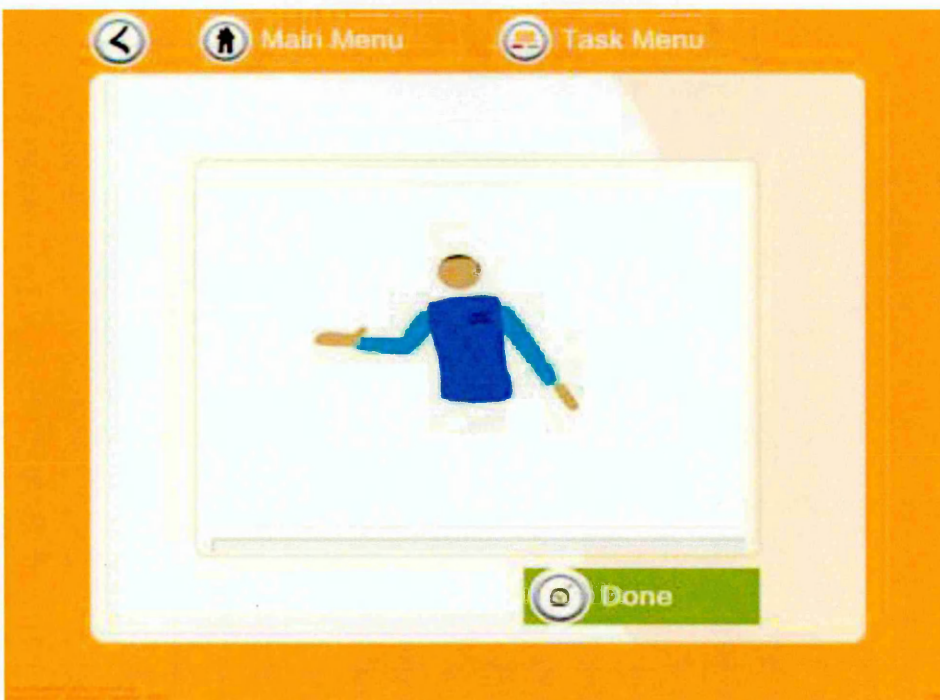


Fig 2-8: On-screen display during exercise. Feedback provided: Visual concurrent; descriptive; visual knowledge of performance; verbal prescriptive parameter feedback.

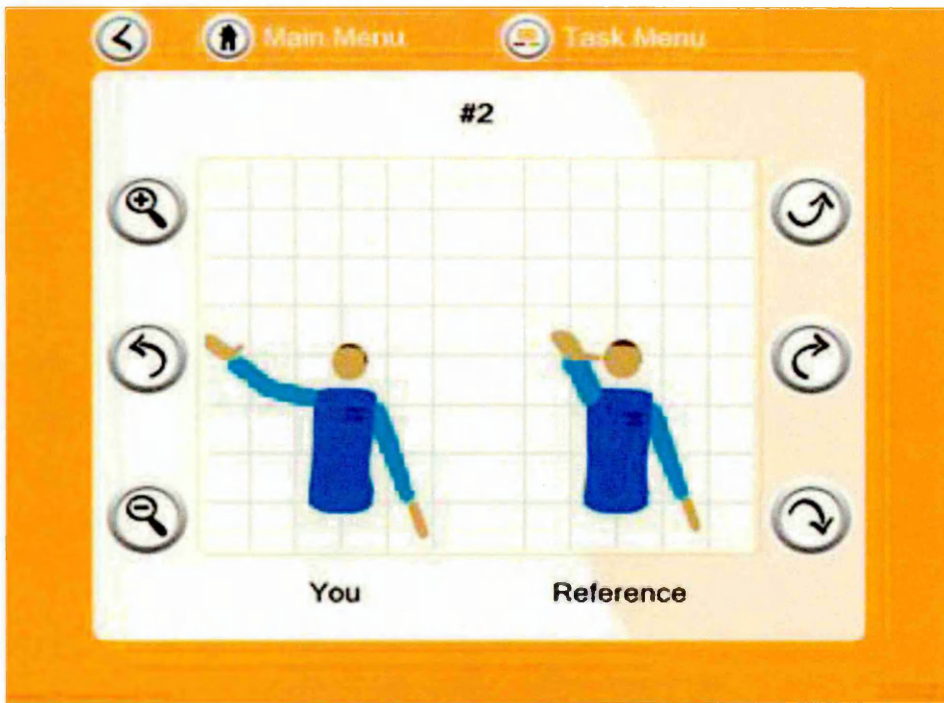


Fig 2-9: On-screen display following exercise (video playback). Feedback provided: Visual terminal prescriptive knowledge of performance and knowledge of results.

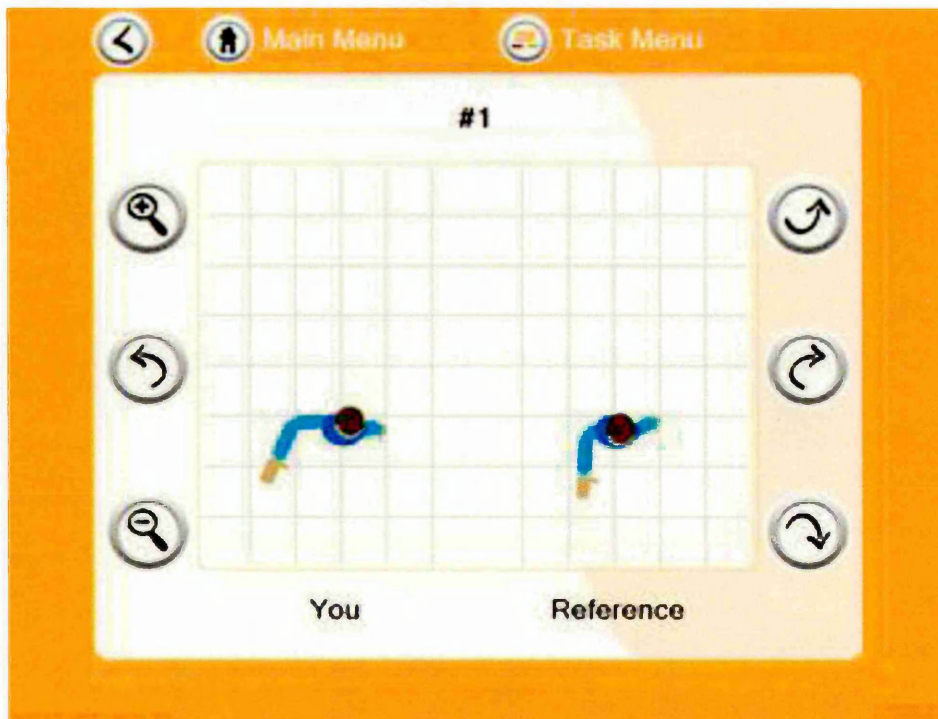


Fig 2-10: Alternative on-screen display (video playback).

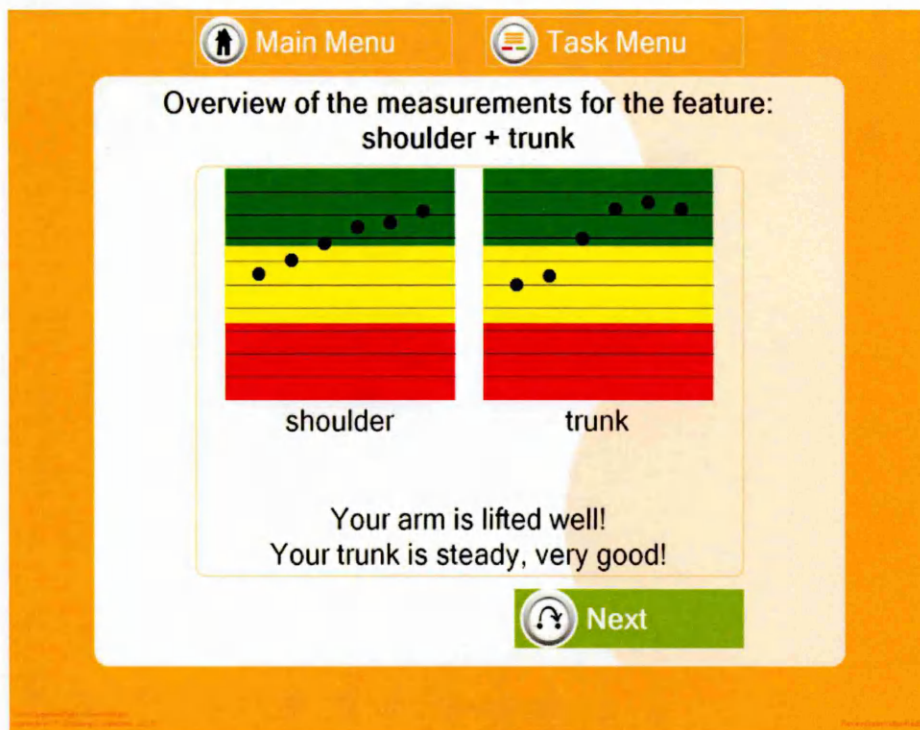


Fig 2-11: Qualitative chart feedback. Feedback provided: Visual qualitative knowledge of results.

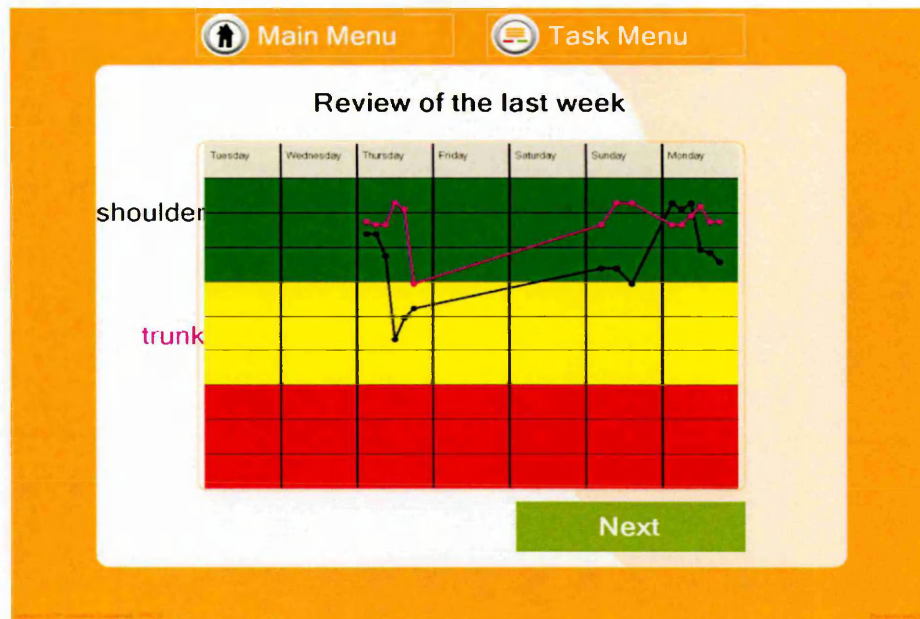


Fig 2-12: Summary feedback. Feedback provided: Visual summary knowledge of results.

During their performance the user is provided with visual concurrent; descriptive; visual knowledge of performance; verbal prescriptive parameter feedback where they are able to see their movements whilst carrying out the exercise(s). The computer program also provides verbal feedback by informing the user of excessive trunk movement. Following the observation of their performance against the reference manikin, a

qualitative chart is displayed (fig 2-11). This provides visual, qualitative, knowledge of results feedback where the user is able to see each repetition (one black dot) within the parameters set out by the therapist. This allows the user to see the results of their performance and receive written feedback. A chart then provides a summary of their results over a week (fig 2-12) where they can compare the results of an earlier performance.

## **2.5 How this PhD Programme Builds on the SMART 1 Project**

The SMART 1 project established that although the use of computer technology for upper-limb rehabilitation in the home was a feasible concept, there were many unanswered questions yet to be explored.

Although future technology systems may have the potential to increase the provision of rehabilitation a stroke survivor receives and carries out, as well as providing a learning platform that facilitates long term self-managed rehabilitation, a key aspect of rehabilitation is the provision of appropriate information and feedback to the learner.

Conventional post-stroke rehabilitation involves hands-on interventions provided by a stroke specialist therapist, and incorporates the provision of extrinsic feedback delivered in person (Ballinger *et al*, 1999; DeJong *et al*, 2004; Hartvelt and Hegarty 1996; Wohlin Wottrich *et al*, 2004). Therapists have empirically relied on their knowledge and expertise to decide which method and form of delivery to provide and when to provide it, on an individual basis with their patient (Hartvelt and Hegarty 1996). However, technological systems are unable to think; they have no emotional connection with the patient; and they are unable to intuitively adapt and change their delivery of rehabilitation and the feedback provided to meet the needs and requirements of each individual patient. Subsequently the user is required to make use of the computer feedback to improve their motor behaviour in the absence of a therapist. This is in contrast to therapist led conventional post-stroke rehabilitation that stroke survivors would receive following discharge from hospital and is indicative of a future anticipated shift to patient led rehabilitation using computer technology.

The research carried out using the SMART system suggests that contextual factors such as personal and environmental influences may impact on utilising this form of technology (Mountain *et al*, 2010; Parker *et al*, 2010). However, there are unanswered questions regarding the reliance that a stroke survivor can have upon a therapist for

both, motor learning skills (Magill 2007) and the self-management of the resultant long-term disability (Jones 2006). Therefore, this research explores the impact personal and environmental contextual factors may have on the underpinning intended mechanisms.

## **2.6 Theoretical Framework: Evidence Review to Propositions**

The process of theory formulation begins with a synthesis of policy and research literature (Pawson and Tilley 2004). Chapter one described the pre-existing context in which stroke rehabilitation is delivered as well as the impact stroke has on the survivor and their carers. The following section will identify the theory-driven mechanisms underpinning the intervention. These are then scrutinised to elicit the key ingredients that may or may not be activated in a given context. This is followed by exploring the theoretical outcomes and the formulation of theoretical propositions presented in CMOOC form.

The theoretical areas underpinning the intervention are:

**Theory Topic 1:** The theoretical approach to post-stroke rehabilitation incorporated within the SMART system.

**Theory Topic 2:** The theories underpinning the use of feedback in post-stroke rehabilitation.

**Theoretical Outcomes:** Self-management and behaviour change.

## **2.7 Rehabilitation and Recovery**

Rehabilitation following stroke is based upon the ability of the neuronal network to plastically adapt and reorganise (Kreisel *et al*, 2007; Kalra and Ratan 2007). Therefore, the following section will describe the neurophysiological and the recovery process associated with neuroplasticity.

The term ‘plasticity’ refers to the brain’s ability to reorganise its structure and function during maturation, learning, environmental challenges and importantly, pathological insult (Lledo *et al*, 2006). Investigations have demonstrated an eclectic mix of reorganisation patterns, suggesting that the process of reorganisation is both dynamic and dependant on the nature of the injury. However, it has been suggested that with a central injury, the neurons that have not lost their function may take on the role of neurons that have lost their function providing their peripheral targets still exist (Lawes 2004). In other words, adjacent areas or contra-lesional areas can take over motor

control (Nudo 2006). These changes involve a number complex processes such as; long-term potentiation (LTP) and long-term depression (LTD) altering the strength and selectivity of synapses and the unmasking of latent synapses (Daffau 2006). Crucially, evidence suggests that neuroplastic changes are driven by repetitive behavioural demand such as carrying out functionally demanding actions (Nudo 2009). These actions are determined by the individual functional deficits of the stroke survivor and form the basis of rehabilitation.

Studies have found that motor recovery for the upper and lower extremities is greatest during the first few months following stroke and gradually plateaus off where recovery is not expected beyond the first six months (Bonita & Beaglehole 1988; Duncan *et al*, 1992; Jørgensen *et al*, 1995a, b, c; Kwakkel *et al*, 2004; 2006; Skilbeck *et al*, 1983; Verheyden *et al*, 2008). However, the concept of a recovery 'plateau' has been criticised for not considering the individual context of the stroke survivor (Demain *et al*, 2006). For example, there is considerable variation in the therapeutic input, the stroke survivor's actions and motivations, and the physical environment in which therapy is delivered. Furthermore, there is also variation in how recovery is measured (Horgan *et al*, 2009).

The concept and perception of 'meaningful recovery' may vary between the commissioner of services, the therapist, the stroke survivor, and their close family. This has implications for the continuation of rehabilitation beyond the recovery 'plateau.' For example, service providers may consider discharging a stroke survivor from services once significant motor and functional milestones have been achieved whereas the stroke survivor and their close family may have desires to continue rehabilitation to achieve further functional and participatory gains (Robison *et al*, 2009). Furthermore, a feeling of self-efficacy and being in control of their recovery have also been found to be important markers of long-term recovery (Jones *et al*, 2008).

Evidence indicates that the process of plasticity and recovery can be enhanced with interventions that provide intense, task-specific, goal-orientated, variable and environmentally enriched rehabilitation (Kalra and Ratan 2007; Krakauer 2006; Barker and Brauer 2005; Richards *et al*, 2008). A key aspect of rehabilitation is the provision of appropriate extrinsic feedback to the learner (Van Vliet and Wulf 2006; Langhorne *et al*, 2009). Feedback is also an essential element for maximising experience-dependent plasticity and learning (Subramanian *et al*, 2010). Furthermore, the goal of the



intervention should be to enable the stroke survivor to engage in activities that are meaningful to them (Shumway-Cook 2007). However, the application and content of post-stroke rehabilitation varies across services and therapists (Pollock *et al*, 2007).

## **2.8 The Theoretical Approach to Post-Stroke Rehabilitation Incorporated within the SMART System**

Although a number of theoretical approaches have been espoused (Plant 1998), the SMART system incorporates the principles of a motor re-learning, task-oriented paradigm whereby users are encouraged to carry out intense, repetitive, self-directed rehabilitation that enables them to ‘learn’ and actively problem-solve.

### **2.8.1 The Motor Relearning Approach**

Carr and Shepherd (1998) questioned the neurodevelopmental theory and developed a motor learning theory incorporating musculoskeletal and motor learning principles into neurological therapy. The drive for change stemmed around concerns regarding the carryover of treatment sessions to functional tasks in everyday life and the belief that was an overemphasis on impairments (body function and structures) rather than on functional tasks (activities) (Lennon 2004). This concept focuses on motor learning and biomechanics (Lennon 2004). Carr and Shepherd proposed that applying a cognitive task-oriented approach would lead to an improved ability to carry out that task and the learning requirement of the task would increase the functional carryover of activity. Applying the concept of neuroplasticity they proposed that specific motor tasks, in the appropriate environment with the correct sensory input will increase and reinforce synaptic efficiency (Carr and Shepherd 1998).

### **2.8.2 Task-Orientated Training**

Task-orientated training has recently emerged as the dominant approach to motor restoration in recent years (Winstein and Wolf 2009). Based on motor learning principles, it is concerned with the restoration of activity limitations rather than specific movement kinematics (i.e. body structures and functions). Furthermore, it takes into account contextual factors such as the environment, the task itself and the individual personal attributes and context of living of the individual. It sees the individual as an active problem solver and the acquisition of skills being through meaningful and relevant tasks or ‘goals’.

Task-oriented training has active ingredients that are based on the practice of problem solving with tasks that are challenging, progressive, optimally adapted to the learner and involves active participation. In addition, principles of motor control and learning underpin the concept as identified by Kleim and Jones (2008):

- **Use it or lose it** – any intervention that encourages more use of the affected limb, the better (such as constraint induced movement therapy, bi-lateral arm training).
- **Use it and improve it** – neural adaptation is promoted as skill and motor control improves.
- **Specificity** – the exercise must match the task.
- **Repetition matters** – in order to drive plasticity.
- **Intensity matters** – the dose, frequency, and duration of training are important consideration when designing task-orientated training programs.
- **Time matters** – early rehabilitation leads to better outcomes.
- **Salience matters** – the tasks must have relevance to the learner.
- **Age matters** – younger survivors are more likely to have better outcomes.
- **Transference** – plasticity in response to task-orientated training can enhance the acquisition of similar behaviour(s).
- **Interference** – plasticity in response to task-orientated training can be detrimental to the acquisition of similar behaviour(s) i.e. learning bad habits. (Kleim and Jones 2008).

However, little is known as to which environment is conducive, and more specifically, how the context may facilitate or impede the mechanisms underpinning the motor re-learning and task-orientated approach to rehabilitation.

### **2.8.3 Which Theoretical Approach Should be Used?**

In the UK, most therapists in stroke management treat stroke survivors based on the principles of a neurodevelopment (neurophysiological) training (NDT) approach (Lennon and Ashburn 2000; Lennon *et al*, 2001; Lennon 2003). This is also comparable to that of clinicians in Sweden (Nilsson and Nordholm 1992), Australia (Carr *et al*, 1994) and the Netherlands (Hafsteinsdottir *et al*, 2005). However, there is no evidence to support the use of one approach over another.

This concept focuses on the facilitation of the hierarchical neurodevelopment sequence. Normalisation of tone is central, along with the use of facilitatory/inhibitory techniques, postural sets and key points (Plant 1998). Lennon (1996) describes this approach as a '*re-education of normal movement by manipulation of a variety of afferent inputs*' (Lennon 1996 p35). This uses manual facilitation of normal movement and control where the therapist leads the patient's rehabilitation (Plant 1998).

In clinical practice, therapists who adopt an NDT approach are concerned with patients practicing independently and carrying out exercise without the therapist's handling because this may hinder correct movement patterns and may even encourage abnormal patterns which may in turn create maladaptive plasticity (Lennon 2004). However, this approach is resource intensive and places a great demand on the therapist.

A recent systematic review by Kollen *et al*, (2009) investigated the effects of the Bobath Concept for the treatment of sensorimotor control of upper and lower limb; sitting and standing, balance control, and dexterity; mobility; activities of daily living; health-related quality of life; and cost-effectiveness (16 RCT's; n=813 patients). The findings suggest that the Bobath concept is not superior to other approaches and go on to suggest that evidence-based guidelines should serve as a framework from which therapists should identify the most effective treatment rather than therapist preference. Luke *et al*, (2004) systematically reviewed the literature to determine the effectiveness of the Bobath concept at reducing upper-limb impairments, activity limitations and participation restrictions after stroke. From the eight studies that met their inclusion criteria (5 RCT's), they found that the Bobath concept approaches are not superior over the other at improving upper limb impairment, activity or participation.

However, these reviews highlight a number of limitations within the included trials included such as; poor randomisation techniques; a lack of blinding; and heterogeneity of the approach used within the trial, the outcome measures used, and the small sample sizes. In addition, these reviews do not consider the context, and stage of rehabilitation, such as; whether the rehabilitation is delivered in a hospital setting, in a community day centre, or in the home environment as well as whether the stroke survivor is in the acute, sub-acute or chronic stage of recovery. Importantly, they do not account for the influence of the therapist.

As discussed in chapter one, the context of rehabilitation may influence the type of intervention delivered. For example, the literature describes a clear difference between

the contextual approaches adopted within community settings which may involve treatment that is aimed at improving activities and participation as opposed to in-patient rehabilitation aimed at establishing medical stability and impairments. Therefore, the ‘eclectic’ approach described by Pollock and colleagues (2007) which suggests that different approaches are required to provide the most effective treatment for different patients and different settings, may highlight the need to adopt different approaches based on the setting and the stage of recovery.

Although in the context of independent home-based rehabilitation, the incorporation of a motor re-learning, task-oriented paradigm is indicated for the SMART system, there are unanswered questions as to the extent to which stroke survivors can carry out aspects of their rehabilitation that do not require the presence of a therapist. In other words, do the principles underpinning the motor re-learning and task-orientated approach work in the context of home-based, independent rehabilitation where feedback is provided by a computer in the absence of a therapist?

## **2.9 Feedback in Post-Stroke Rehabilitation**

The SMART system used in this study provides various forms of feedback to the user that is delivered both visually and verbally. The following section will describe these.

Feedback has been classified as either ‘intrinsic’ or ‘extrinsic’. Intrinsic refers to the individual’s sensory-perceptual information such as, visual, auditory, proprioceptive and tactile information, whereas, extrinsic refers to feedback from an external source such as verbal instruction from a therapist (Magill 2007; Schmidt and Wrisberg 2008). Although the term ‘extrinsic’ and ‘augmented’ have been used synonymously in various texts, they describe differing properties. Extrinsic feedback describes the source of the feedback whereas augmented describes the role in which the feedback is being used. In this case, augmented feedback is used to add to or enhance intrinsic feedback.

To fully understand these components, feedback can be divided into its basic methods (fig 2-13 p. 59) (Magill 2007). However, there is additional complexity when various forms of application are added (fig 2-14 p. 60) (Magill 2007; Schmidt and Wrisberg 2008) (see table 2-1 for a description of terms p. 61).

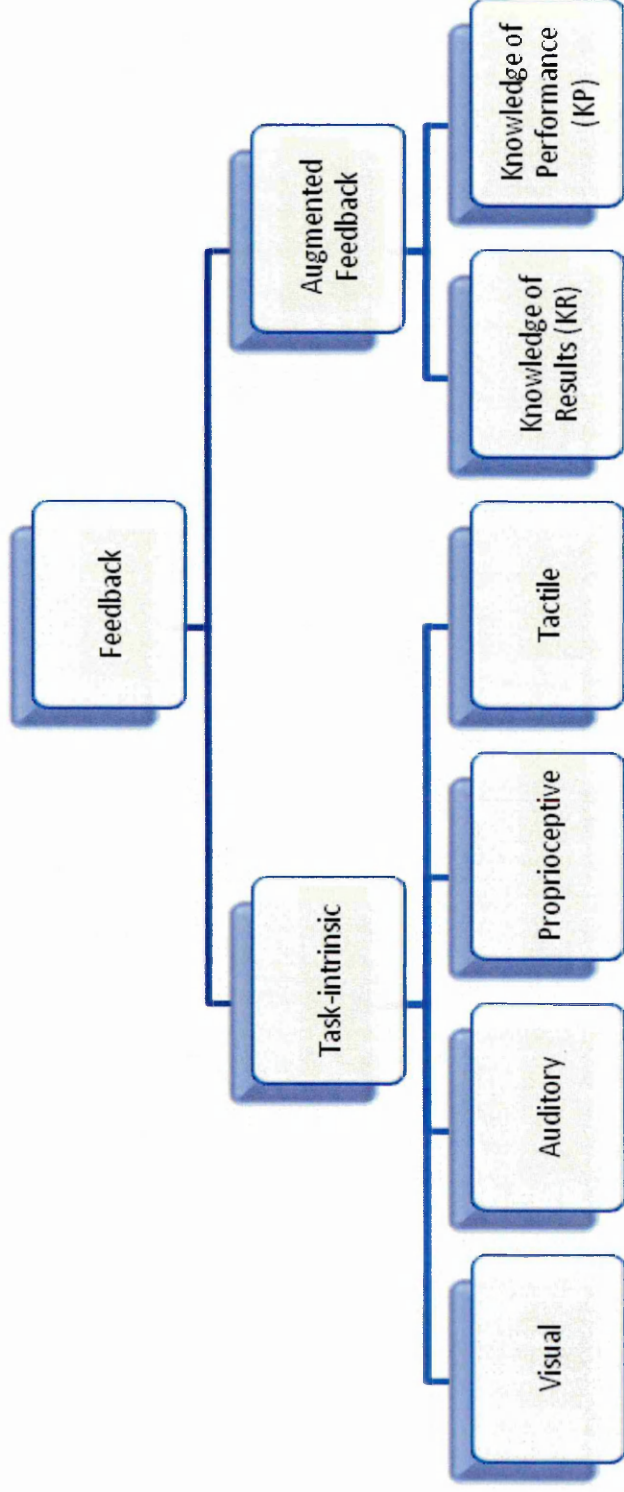


Fig 2-13: An illustration of different types of feedback family that are related to learning and performing motor skills (Magill 2007 p333).

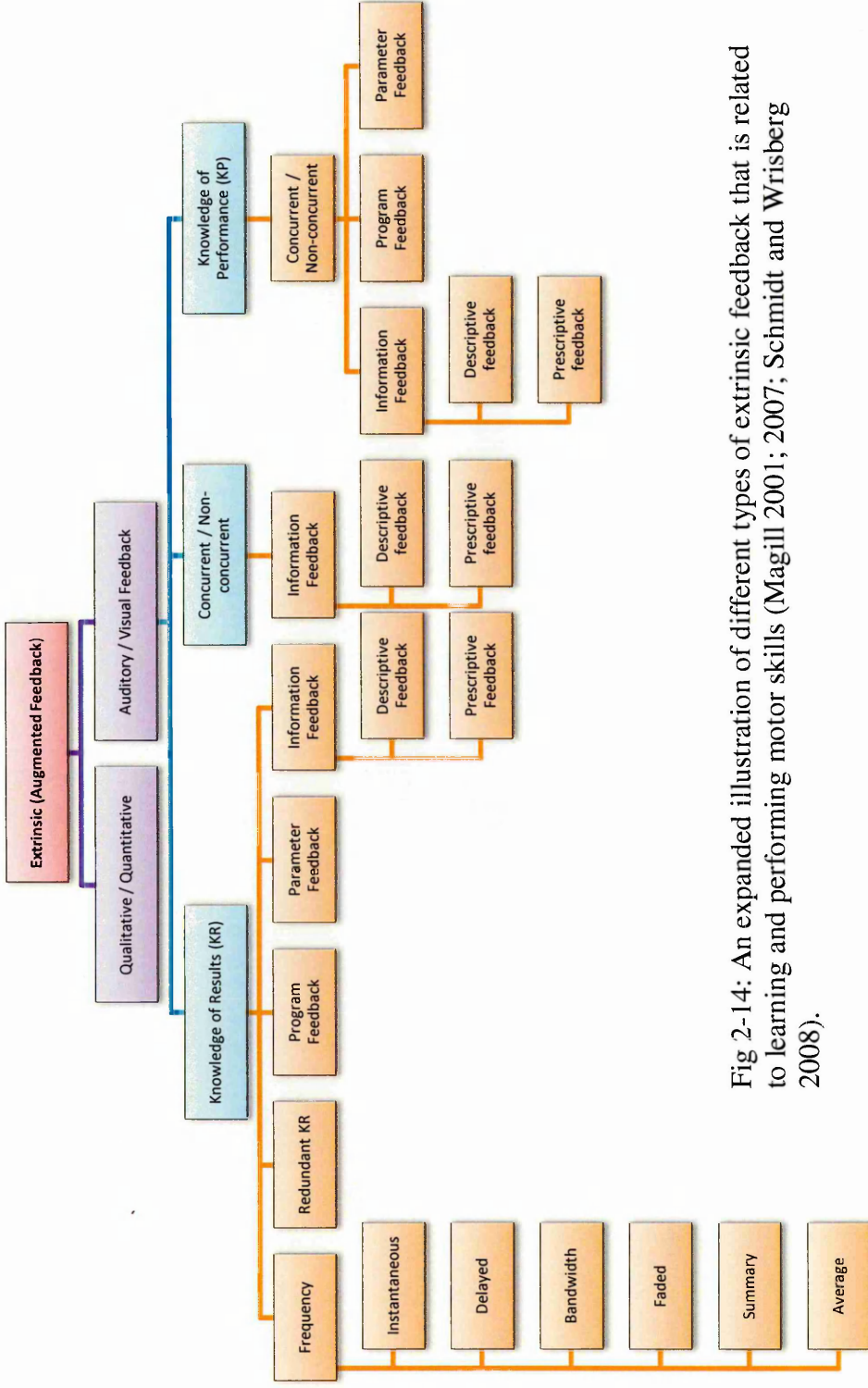


Fig 2-14: An expanded illustration of different types of extrinsic feedback that is related to learning and performing motor skills (Magill 2001; 2007; Schmidt and Wrisberg 2008).

**Table 2-1: Forms of feedback classifications.**

<b>Extrinsic Feedback Variable</b>	<b>Definition</b>
<b>Knowledge of results (KR)</b>	Information about the outcome of performing a skill or about achieving the goal of performance.
<b>Redundant KR</b>	KR that contains the same information as intrinsic feedback. i.e. 'you have spilt the milk'
<b>Knowledge of performance (KP)</b>	Information about the movement characteristics that led to a performance outcome.
<b>Concurrent Feedback</b>	Feedback given during performance.
<b>Descriptive Feedback</b>	Describes the errors made during the performance of a skill.
<b>Prescriptive Feedback</b>	Describes the errors made during the performance of a skill and provides some information as to how to correct it.
<b>Intervention Feedback</b>	Feedback that provides error information about the fundamental pattern of movement.
<b>Parameter Feedback</b>	Feedback that provides error information about the changeable surface features of movements to increase the precision of the skill.
<b>Instantaneous Feedback</b>	Feedback provided immediately following movement completion.
<b>Delayed Feedback</b>	Feedback provided several seconds or more following movement completion.
<b>Bandwidth Feedback</b>	Feedback that is only provided when errors exceed a tolerance level.
<b>Faded Feedback</b>	A schedule for providing extrinsic feedback where the frequency is high to begin with and is then gradually withdrawn.
<b>Summary Feedback</b>	Feedback provided after a series of performances attempts that informs learners about each of the attempts in the series.
<b>Average Feedback</b>	Feedback provided after a series of practice attempts that informs learners about their average performance.
<b>External Focus Feedback</b>	Externally focused - environmental effect.
<b>Internal Focus Feedback</b>	Internally focused - physical movement effect.

(Magill 2007).

### **2.9.1 Stroke Survivors May Rely on Extrinsic Feedback if Their Intrinsic System is Compromised**

It has been reported that up to 65% of stroke survivors have somatosensory impairment and upper-limb proprioceptive deficits following stroke (Winward *et al*, 2007; Niessen *et al*, 2008). Therefore, because intrinsic feedback systems may be compromised, extrinsic feedback may be even more important (Van Vliet and Wulf 2006). This was demonstrated by Stenneken *et al*, (2006) who observed the differences between the finger tapping of two deafferented<sup>3</sup> patients against two age-matched controls when given auditory and visual extrinsic feedback and not. They found that the deafferented subjects were strongly influenced by extrinsic feedback. Nevertheless, if some intrinsic feedback systems are intact, compensation for the reduction of this afferent information may be possible through extrinsic feedback (Kreisel *et al*, 2007). This supports the view that sensory information plays a crucial role in the anticipatory timing of movements and if these systems are compromised learners will rely more heavily on external feedback. However, motor learning involves the internalisation of an external source.

Therefore, if motor learning is to occur, the external feedback must match the internal (proprioceptive) feedback (Majsak 1996). This has implications for this research in that the feedback provided by the SMART system, which is generated without human intuition, must be perceived by the user as matching what they feel they have performed.

### **2.9.2 Extrinsic Feedback is Essential for Motor Learning**

The SMART system used in this study incorporates the principles of motor re-learning (described previously). Motor learning has been divided into implicit and explicit learning systems. The SMART system requires the user to learn implicitly (trial and error) and augment this with explicit, external feedback, independently.

Studies have examined the effects of implicit and explicit learning following stroke in relation to; implicit learning capabilities (Pohl *et al*, 2001; Boyd and Winstein 2001); the impact of the lesion location (Boyd & Winstein 2003; 2004a; 2004b); lateralization (Vakil *et al*, 2000) and explicit/implicit interactions (Boyd and Winstein 2003; 2004a; 2006). Evidence suggests that stroke survivors maintain a degree of implicit learning

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<sup>3</sup> The elimination or interruption of afferent nerve impulses.



capability; although, in comparison to neurologically intact control subjects, their speed of response to the stimuli is diminished (Boyd *et al*, 2007). The literature also suggests that the severity of the stroke may influence the magnitude of implicit learning as well as the task itself (Boyd *et al*, 2007). However, in order to counteract a loss in implicit learning capability, stroke survivors augment this with explicit sources of information. In short, although stroke survivors are maintain an implicit learning capability, more severely affected stroke survivors may require more explicit knowledge (such as extrinsic feedback) to supplement their reduced implicit capabilities.

The study by Mount *et al*, (2007) involved a randomised crossover trial to compare the effectiveness of errorless learning (EL) where the participant is prevented from making errors while learning a task versus trial and error learning (TEL) where the participant is encouraged to try to guess or figure out the correct response and learn from any errors made. They investigated whether EL versus TEL would influence the amount of instructional sessions it would take to learn a functional task.

They found that although there was no statistically significant difference in EL versus TEL, they did find better retention using TEL. This concurs with evidence suggesting that by allowing the subject to make errors and *learn* how to correct them, they are more likely to be able to reproduce the task (Ezekiel 2001). However, Maxwell *et al*, (2001) suggest that by reducing the amount of errors made during initial learning encourages the use of implicit processes. In other words, reducing the parameters of error reduces the explicit, attention-demanding resources required for correct performance which in turn encourages implicit learning.

However, these studies involve experimental designs in controlled laboratory settings where ‘experts’ are on hand to interpret the results. Therefore, there are questions regarding the learning capabilities in varying, uncontrolled conditions where the user is required to evaluate their performance in the absence of a therapist.

### **2.9.3 The Delivery of Extrinsic Feedback as a Mechanism for Change**

This research involves a computer system that provides visual and auditory feedback. Therefore the following section will explore the use of visual and/or auditory feedback. This is followed by the motor-learning theories underpinning feedback, such as, the content, influence on motor control and performance, and timing of feedback.

### 2.9.3.1 Visual Feedback

The visual system is the most significant and dominant senses of the human body. This is verified by the fact that approximately half of the human cortex is devoted to visual processing (Schiffman 2001). The visual system therefore, plays an important part in the provision of extrinsic feedback and stroke survivors may rely more heavily on visual feedback if their somatosensory feedback is compromised (Kreisel *et al*, 2007).

The effect of visual demonstration was highlighted in a study by Ertelt *et al*, (2007) who investigated the concept of ‘action observation’ where stroke survivors watched a functional task on a TV screen that involved movements with varying complexity and then immediately copied the actions. Results demonstrated improvements in function and fMRI analysis compared to a control group immediately after an intensive four week intervention. This study demonstrated the effects of visual feedback on brain activity in that results found a significant rise in activity in the bilateral ventral premotor cortex, bilateral superior temporal gyrus, the supplementary motor area (SMA) and the contralateral supramarginal gyrus compared to the control group.

The findings of this study support the mirror neuron hypotheses where it is understood that the observation of actions recruits the same motor representations active during the actual execution of those same actions (Rizzolatti and Craighero 2004; Buccino *et al*, 2004; 2006). The mirror neuron system has also been shown to be involved in imitation (Iacoboni *et al*, 1999) and imitation learning (Buccino *et al*, 2004). However, mirror neurons appear to be biologically tuned, in that they are not active when the action is performed by a robot (Tai *et al*, 2004) or when a tool is used to pick up an object (Rizzolatti and Craighero 2004). In contrast they are most active when the action is observed directly opposite the actor’s hand (mirroring the movement) (Rizzolatti and Craighero 2004).

This neurophysiological discovery has sparked great interest in how it may be applied in neurorehabilitation (Buccino *et al*, 2006; Iacoboni *et al*, 2007). Given that the basic principles involve observing an action with intent to imitate can improve motor function following a stroke; an exciting area of exploration is the use of mirror therapy. In a similar way to the subject being provided with a visual stimuli used in action observation; mirror therapy differs slightly in that it involves the participant observing their own movement whilst they are performing the action therefore providing visual concurrent feedback. The subject observes the movement of the non-paretic limb in a

mirror to give the illusion of the two limbs acting in synchrony (Ramachandran and Altschuler 2009).

However, one factor to take into consideration is the emotional impact of using a mirror on the stroke survivor. This has recently raised an e-discussion amongst Physiotherapists via iCSP ([www.interactivecsp.org.uk](http://www.interactivecsp.org.uk)) (iCSP 2008). The key theme emerging from their discussion is how patients find seeing themselves in a mirror upsetting and/or confusing;

*“Early in my career, I used a mirror for postural feedback and sent this patient to her bed for days, sobbing”.*

*“I feel it is upsetting for patients to see themselves and they often cannot concentrate over the hurdle of how they look”.*

In addition, the therapists thought that the use of mirrors can be confusing either directly as a result of perceptual problems or as a result of being upset by what they see;

*“Those with severe left neglect often don’t respond to using a mirror because they can’t attend to what they are seeing and relate it to their posture” (iCSP 2008).*

This discussion highlights the qualitative nature of using feedback and how research may not reflect the true impact of using a particular type of feedback in a clinical setting.

### **2.9.3.2 Verbal / Auditory Feedback**

Verbal feedback is believed to be used more than visual feedback in clinical practice (Hartveld and Hegarty 1996; Talvitie 2000; Talvitie and Reunanen 2002). Roberts and Bucksey (2007) conducted a study that examined the verbal and non-verbal communication between physical therapists and patients. Their study highlighted the unequal balance of communication previously observed by Talvitie and Reunanen (2002) whereby therapists spent approximately twice as much time talking than the patient. Nevertheless, Roberts and Bucksey (2007) suggest that good communication between the clinician and the patient can lead to better clinical outcome and is therefore considered to be the most important aspect of practice. Importantly, it is believed to enhance the resources of the patient and lead to a positive patient outcome (Lundvik Gyllensten *et al*, 1999). This may suggest that verbal communication that incorporates

feedback is an important element of clinical practice for both the patient and the therapist.

However, this research explores the use of verbal feedback that is provided through computer technology which eliminates any personal communication skills a clinician may adopt to facilitate the rehabilitation process.

#### **2.9.4 The Content of Feedback**

Although a distinction should be made between feedback which is information relating to performance and instruction which is information relating to what should be performed; some forms of feedback may also contain instruction. For example the phrase, 'you lifted your arm much higher that time; this time try and keep your trunk stable,' contains feedback *and* instruction (prescriptive feedback; see table 2-1 for terms p.61). Therefore, the following section will consider the various contents of feedback as well as instruction.

Extrinsic feedback has been divided into knowledge of results (KR) where information is given about the outcome of performing a task, as opposed to knowledge of performance (KP) where information is given about the movement characteristics that led to the performance outcome (figs 2-13 and 2-14 pp. 59-60) (Magill 2007). Studies that have directly compared verbal KR to verbal KP have shown that verbal KP is more effective when performing a reaching task (Cirstea *et al*, 2006; 2007). However, the participants received verbal feedback by a therapist which may therefore suggest that whilst stroke survivors may require extrinsic feedback on the movement characteristics necessary to achieve the required outcome, they may still rely on the therapist to provide the feedback.

Furthermore, KR and KP are relatively broad categories of feedback and can be broken down further (fig 2-14 p. 60). For example, it is possible to give KP that includes descriptive feedback, such as, a video replay of their performance or give KP that includes prescriptive feedback, such as, a video replay followed by text i.e. 'lift your arm higher'. The difference being descriptive feedback provides a description of the errors made during the performance of a skill; whereas prescriptive feedback adds to this by providing some information of how to correct it. Indeed, the systematic review by Parker *et al*, (2011) highlighted this heterogeneity in studies that have explored the use of visual and/or auditory feedback in post-stroke rehabilitation. This suggests that

careful consideration should be made as to what form and method of delivery of feedback is given. In other words the provision of feedback is not a 'one size fits all' component of rehabilitation.

Research with healthy participants has found that prescriptive feedback can provide short term improvements in performance but the learner may become reliant on the provision of the feedback itself (Schmidt and Wrisberg 2008). For example, if the learner is given the answers to the problems, they may not develop the skills to work out the answers for themselves. However, providing prescriptive feedback may be more appropriate during early stages of motor learning and can also reduce the amount of error in subsequent performance (Mount *et al*, 2007). This suggests that prescriptive feedback should be gradually withdrawn as the learner develops their skills.

Another example of variability in the content of instruction was studied by Fasoli *et al*, (2002). Their counterbalanced, repeated-measures design was used to examine the effects of externally focused (environmental effect) versus internally focused (physical movement effect) instructions on movement kinematics during functional reaching tasks: which were (a) removing a can from a shelf and placing it on the table, (b) taking an apple off a shelf and putting it into a basket, and (c) moving an empty coffee mug from the table onto a saucer. The study involved sixteen stroke survivors (mean age 61.19 yrs.; > 6 months post-stroke) who were able to perform the tasks with their affected arm and seventeen age-matched adults (mean age 61.19 yrs.) without neurological impairments. The two forms of instruction were:

- External-focus condition: "Take this can from the shelf and place it on the table with your [right or left] hand. Pay attention to the can: Think about where it is on the shelf and how big or heavy it is."
- Internal-focus condition: "Take this can from the shelf and place it on the table with your [right or left] hand. Pay attention to your arm: Think about how much you straighten your elbow and how your wrist and fingers move."

They found that shorter movement time and greater peak velocity were evident when reaching under the external-focus condition of all tasks than for the internal-focus condition ( $p = < 0.5$ ). This suggests that external focus instruction is more effective than internal focus instruction when performing functional tasks. This is also consistent with Parkinson's disease patients (Landers *et al*, 2005) and healthy subjects who also

perform better when given external focus instructions (Wulf and Prinz 2001). However, a recent multi-method pilot study involving eight Physiotherapists and eight stroke survivors revealed that in practice, therapists predominantly give internal focus instruction and feedback, such as, '*well done! You straightened your elbow more that time, this time try and focus on opening your hand as well*' (Durham *et al*, 2009). This raises questions as to how aware therapists are of the forms of feedback they provide and what form(s) of feedback stroke survivors routinely receive throughout their rehabilitation period. Furthermore, the feedback provided by the SMART system also provides internal focus feedback in that it focuses the user on the physical movement effect which may be detrimental.

### **2.9.5 The Influence of Feedback on Motivation.**

Research in sport psychology indicates that positive reinforcement produces greater improvements than negative reinforcement (Smith 2006). One of the reasons for this is the effect of negative reinforcement on the motivation of the learner (Schmidt and Wrisberg 2008). However, Magill (2001) argues that feedback on errors may be more effective than feedback on correct performance alone. This is because it directs the learner to what changes are needed to improve performance. However, he also agrees that feedback on correct performance is more motivating. Interestingly, Maclean *et al*, (2000) explored the attitudes and beliefs of stroke patients who had been identified by professionals as having high or low motivation. They found those labelled as being highly motivated patients thought that learning the correct execution of exercises was important. This was in contrast to those identified as having low motivation.

Highlighting the correct aspects of performance also involves the provision of praise or reward. This in itself is important for motor learning (Wickens *et al*, 2003). The benefits of rewards appear to be two-fold in that rewards may affect the therapeutic relationship as well as motor learning. Talvitie (2000) highlighted the socio-affective characteristics of patients' and therapists' interaction with regards to extrinsic feedback in a hospital setting. Through a systematic observation of how feedback was communicated to patients with videotape analysis. Observation of the feedback provided was found to be mainly motivating and reinforcing. However, this was on occasion in conflict with performance. Nevertheless, the therapist was able to create a positive environment; thus increasing the patient's confidence.

Nudo (2007) explains how operant conditioning coined by the 1930's psychologist B. F. Skinner, refers to spontaneous behaviour that occurs as a result of positive or negative events. In essence, the provision of a reward; be it a pellet of food in animal studies or functional gains in stroke survivors, has enabled scientists to investigate the neuroanatomical and neurophysiological changes that occur following rehabilitation after stroke (Nudo 2007). Over recent years, studies have investigated reward-related mechanisms in the uninjured brain (Bray *et al*, 2007; Delgado *et al*, 2004; Kapogiannis *et al*, 2008). These studies have identified specific areas of the brain that processes reward-related activity. More importantly, they suggest that rewarding activity may strengthen synaptic connections that are involved in behavioural motor learning. Although these mechanisms have not yet been investigated specifically in stroke; one of the key areas responsible for reward-related behavioural plasticity is the dopamine system which is thought to be stimulated as a result of reward.

A study by Rösser *et al*, (2008) hypothesised that administering the dopamine precursor Levodopa would improve procedural motor learning. This was based on the theory that the levels of dopamine reduces in old age, considering that over 80% of stroke occur in those aged 64 or older (Carroll 2001). Their double-blind, placebo-controlled, randomized crossover trial, involved chronic stroke survivors receiving three doses of Levodopa (100mg of Levodopa plus 25mg of Carbidopa) or a placebo before one session of a procedural motor learning, serial reaction time test. They found that Levodopa significantly improved procedural learning compared to the placebo.

This may suggest that the provision of a reward is important for both the psychological and neurophysiological influences during motor learning. However, during post-stroke rehabilitation the reward is given by a therapist who may have established a therapeutic relationship with their patient. Therefore, if the reward is given through technology, how might this impact on motivation?

### **2.9.6 Providing Feedback less Frequently May Improve Retention**

Optimum levels of feedback frequencies have been extensively investigated in healthy subjects (Schmidt *et al*, 1989; Schmidt *et al*, 1990; Yao *et al*, 1994). Findings suggest that reducing the frequency of feedback to healthy subjects may enhance the learning process (Magill 2007; Schmidt and Wrisberg 2008). However, determining how often feedback should be given appears to depend upon the complexity of the task. For

example, Schmidt *et al*, (1990) compared the effects of giving summary feedback after 1, 5, 10 and 15 attempts during a laboratory test that resembled baseball batting.

They found through a retention test that giving feedback after five attempts appeared to be the optimal amount. Schmidt and Wrisberg (2008) suggest that there is a need to balance how much of the performer's intrinsic feedback requires augmentation and how able they are to detect their own errors. It is apparent following a stroke that the intrinsic feedback systems may be compromised (Winward *et al*, 2007).

Therefore, does a stroke survivor require more frequent extrinsic feedback depending on how severely the intrinsic feedback system has been compromised? Studies that have examined the frequency of feedback with stroke patients have demonstrated that reducing the frequency may increase consistency in performance (Weinstein *et al*, 1999), accuracy (Thomas and Harro 1996) and retention (Saladin *et al*, 1994). This may suggest that reducing the frequency of feedback benefits the learning process which concurs with healthy subjects (Magill 2007; Schmidt and Wrisberg 2008). The SMART system used in this research enables the user to choose when they receive feedback by allowing them to skip feedback delivery i.e. they can skip the video replays.

### **2.9.7 The Timing of Feedback**

Studies have found that in clinical practice, feedback is given concurrently (during performance) (Hartveld and Hegarty 1996; Talvitie 2000; Talvitie and Reunanen 2002). However, Orrell *et al*, (2006) argue that the cognitive deficits that occur as a result of a stroke such as language, orientation, attention and memory may affect the ability to utilise various forms of feedback / information concurrently. In other words, the provision of explicit instructions to perform relatively complex movements at the same time that the patients are asked to perform them may be confusing. For example, a patient may have to think about picking up a cup whilst listening to instructions concurrently which may be detrimental to information processing. Evidence suggests concurrent feedback maybe counterproductive to learning in healthy subjects (Schmidt and Wulf 1997). Wulf (2007) adds to this by suggesting that allowing the learner to control the timing, frequency and presentation of movement demonstrations can enhance learning. She also speculates that self-controlled feedback may influence motivation and independence (Wulf 2007a). However, this is yet to be explored in the context of home-based rehabilitation using computer technology.



This section (2.9) has explored the theories underpinning feedback in post-stroke rehabilitation. Existing findings suggest that extrinsic visual and auditory feedback may improve motor and functional performance. In addition, a number of forms of feedback including; concurrent feedback, knowledge of performance, knowledge of results and explicit feedback may be key components in the promotion of improved performance (Parker *et al*, 2011).

Currently, the provision of feedback involves a therapeutic relationship and careful delivery from the therapist who is able to consider the personal and environmental context of the stroke survivor (chapter 4). However, as described previously, a computer cannot establish a relationship; it has no feelings or emotion; it is unable to change or alter its delivery to a stroke survivor having ‘a good day’ or a ‘bad day.’

Therefore, there are unanswered questions regarding the reliance that a stroke survivor can have upon a therapist for both, motor learning skills and the utilisation of feedback. In particular, there are unanswered questions as to which forms of feedback and methods of delivery work for whom in what circumstances to produce desired outcomes. Nonetheless, providing feedback through technology in the absence of a therapist may crucially provide an opportunity for the stroke survivor to carry out independent self-managed rehabilitation and behaviour change.

## **2.10 Theoretical Outcomes: Behaviour Change and Self-Management**

So far this chapter has described the mechanisms and the essential ingredients underpinning the SMART system. The final part of the first stage of the evaluation involves describing the intended outcomes of the intervention. The SMART system used in this study was designed to encourage a change in behaviour towards self-managed rehabilitation (as an outcome of using the system). This is therefore underpinned by self-management and behaviour change theories. The following section will describe these.

### **2.10.1 Behaviour Change**

Behaviour change theories involve both psychological and physiological processes that affect motor performance (Schmidt and Wrisberg 2008). The approach to rehabilitation in 2.8 (p. 55) described how specific concepts are adopted by the SMART system to produce a change in motor behaviour. These include elements of motor learning and motor control theories (described previously). However, some aspects of motor

performance are volitional. Therefore, without a desire to adopt and implement these concepts, changes in motor behaviour will not occur. This requires stroke survivors to actively plan, initiate, maintain, and promote these mechanisms in order to achieve improvements in motor performance (Nieuwenhuijsen *et al*, 2006).

### 2.10.1.1 Health Behaviour Change

The adoption of health behaviour that leads to health-related gains involves persuading individuals to actively embrace change. As a result of variable context, inadequate knowledge and skills, opportunity, and motivation, this process has proved more difficult than expected (Michie *et al*, 2008). In order to understand behaviour change, a number of health behaviour models and interventions have been espoused. These range from stage theories such as the Transtheoretical Approach (Prochanska and Di Clemente 1984) to the non-stage models such as Social Cognition Theory (Bandura 1997).

Although there has been a proliferation of interventions to test behaviour change theories, the number of high quality evaluations remains scarce and the need for greater understanding of what works for whom and how they work is a continuing requirement (Abraham *et al*, 2009). Abraham *et al*, (2009) discussed the NICE guidance on behaviour change and suggested that in order to incorporate the psychological targets required for behaviour change interventions, a number of theories should be included. These include:

- *Self-regulation theory*: This involves engaging service users in setting their own goals, action planning, and self-monitoring (Abraham *et al*, 2009).
- *Social cognition theories*: This involves the role of motivation to change, self-efficacy, outcome expectations, and feedback reinforcement (Bandura 1997; 1998).
- *Goal theories*: This involves actively planning and implementing graded personal goals in specific contexts (Austin and Vancouver 1996).
- *Operant conditioning*: This approach highlights the need to focus on the benefits and rewards of change and the repetition of rewarding behaviour(s). This also involves identifying how the environmental context can trigger or reinforce behaviour (Skinner 1974).

## 2.10.2 Moving Towards Self-Management

Over recent years there has been a policy shift towards self-management and moreover, empowering service users to take ownership of their conditions. However, this involves a shift away from the established medical model of service delivery to a model that may enable individuals to become less reliant on one-to-one service provision and provide them with the skills to self-manage over the longer-term.

In the UK, the Expert Patient Programme set out to take a new approach towards the management of long-term chronic disease. Research and observations by health professionals demonstrated that patients with chronic diseases need not be just recipients of care but actively involved in the decision-making process (DoH 2001). By allowing and indeed encouraging patients to use their knowledge and experience, they may have increased responsibility which may lead to improved confidence, resourcefulness and self-efficacy.

The white paper '*Our Health Our Care Our Say*' set out to put service users at the forefront of healthcare and prioritise self-management of long term conditions (DoH 2006). In addition, the NHS Operating Framework 2009/10 also puts informed choice, a greater access to services and services that enable service users to manage their condition at the heart of delivery (DoH 2008a). More specific to stroke, the National Stroke Strategy (DoH 2007) states that more needs to be done by professionals to empower individuals with the skills to set personal targets, and manage symptoms and their functional progress in the longer term. In addition, there is increasing emphasis towards 'working together' with service users as opposed to just providing a service (DoH 2009). Ham (2010) suggests that greater attention is required to support people with long-term conditions to care for themselves. In particular, two of the ten characteristics required for high performing chronic care systems such as stroke services state that; priority should be given to people self-managing with support from family and carers and a system should exploit the potential benefits of information technology (Ham 2010).

The sequelae of stroke continue long after service input has ceased (Lincoln *et al*, 2000). Providing stroke survivors with the ability to continue their care without the need for specialist service input is essential if they are to retain and even improve their levels of activity and participation following discharge. Therefore, facilitating independence

and autonomy following stroke is an integral part of long-term recovery (Intercollegiate Stroke Working Party 2008).

There is a clear move towards patient empowerment and moreover, establishing services that have greater service user involvement. Moving care closer to the context of the patient is essential for this process to be successful (DoH 2006). The shift in service delivery from hospital-based rehabilitation to the community and placing more emphasis on self-management can allow stroke survivors to be treated closer to home whilst enabling them to be more involved in their recovery.

### **2.10.3 Self-Management**

To date, there has been minimal research on self-management interventions for stroke and it is unclear what self-management should actually involve (Jones and Riazi 2011). Nevertheless, efforts are being made to identify components of self-management (Lorig and Holman 2003; Jones 2006) as well as integrate self-management principles into therapeutic approaches for stroke rehabilitation (Johnston *et al*, 2007; Jones *et al*, 2009; Kendall *et al*, 2007). In addition, new methods of carrying out post stroke rehabilitation that specifically incorporate self-management strategies are also being investigated such as the use of technology (Huijbregts *et al*, 2009; Mountain *et al*, 2010). Therefore, exploring models of service delivery that enable the mechanisms underpinning self-management to work effectively are essential.

Barlow and colleagues (2002) suggest that,

*'Self-management refers to the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and life style changes inherent in living with a chronic condition'* (Barlow *et al*, 2002 p.178).

Lorig and Holman (2003) identified five core self-management skills: problem-solving, decision-making, resource utilisation, forming a partnership between the patient, and healthcare provider and taking action. They also suggest that it is essential that healthcare practitioners involve patients in the practice of self-management in order to enable patients to cope with chronic disease and long-term disability.

The self-management of chronic conditions is often based on the social cognition theory (Bandura 1986, 1997) where,

*'Behaviour is influenced directly by goals and self-efficacy expectations and indirectly by self-efficacy, outcome expectations and sociostructural factors'* (Serlachius and Sutton 2009 p. 50).

### **2.10.3.1 Goals**

Goals serve to determine the direction of behaviour intended and provide a way of measuring meaningful change and outcome. Currently, goal-setting is one of the established methods of involving stroke survivors and their family in the management of their condition (Mastos *et al*, 2007). It is well recognised that the sequelae of stroke can impact on rehabilitation outcomes; such as, post-stroke depression (Spalletta and Caltagirone 2009), fatigue (Michael 2009), and motivation (McClellan *et al*, 2002). Therefore, in order to promote behavioural change, one of the key recommendations proposed by the National Clinical Guidelines for Stroke (Intercollegiate Stroke Working Party 2008) involves setting personalised goals with the patient. In particular these recommendations state that these goals need to:

- Be meaningful and relevant to the patient
- Be challenging but achievable
- Include both short-term (days/weeks) and long-term (weeks/months) targets
- Include both single clinicians and also the whole team
- Be documented, with specified, time-bound measurable outcomes
- Have achievement evaluated using goal attainment
- Include family members where appropriate
- Be used to guide and inform therapy and treatment.

(Intercollegiate Stroke Working Party 2008 p37).

Levack *et al*, (2006) suggest that four major purposes of goal planning are indicated. These are: 1) to improve patient outcomes 2) to enhance patient autonomy 3) to evaluate outcomes and finally, 4) to respond to contractual, legislative or professional requirements. However, goal-setting has been criticised for being driven by non-negotiable therapist led outcomes and only lasting over the short-term (Playford *et al*, 2009). Indeed, evidence suggests that goals are often set by the therapist and may therefore not allow stroke survivors the opportunity to practice some of the key elements of self-management, such as, decision-making. Therefore, exploring models of service delivery that enables the mechanisms of self-management to work effectively is essential (Jones 2006).

### 2.10.3.2 Self-Efficacy

Self-efficacy is one of the major constructs of SCT and refers to the,

*'Beliefs in one's capabilities to organize and execute the courses and actions required to produce given attainments'* (Bandura 1997 p.3).

In other words, self-efficacy involves the level of confidence an individual has that they will achieve certain behaviours or psychological states. Further, it involves the individual's judgement of their potential ability and skills to carry out tasks even when faced with challenges and difficulties (Jones 2006). This suggests that there is a level of cognitive appraisal whereby the individual may draw on previous experience and resources they have to undertake a task. Crucially, evidence from observational studies indicates that self-efficacy expectations consistently predict behaviour (Luszczynska and Schwarzer 2005). Following a stroke, individuals are faced with new challenges and are guided through a process of rehabilitation which is intended to provide them with the skills to accomplish functional and participatory everyday tasks. Therefore, if new behaviours and challenges are to be achieved, the essential elements of SCT and in particular, self-efficacy are adopted within self-management interventions.

Sources of self-efficacy are obtained directly from the information and feedback they receive from the performance of a task (Jones and Riazi 2011). Four key sources of self-efficacy have been identified within the literature. These are;

- *Mastery experiences* – gaining confidence in achieving and accomplishing tasks.
- *Modelling* – the observation of similar individuals achieving and accomplishing tasks through direct observation or through written and visual material.
- *Interpreting physiological signs* – having the ability and confidence to interpret symptoms and changes in symptoms such as, pain, weakness, stiffness, and fatigue.
- *Feedback and persuasion* – The provision of some recognition of their performance and progress from personal achievement as well as significant other i.e. family members.

(Lorig and Holman 2003; Jones 2006; Jones and Riazi 2011).

There is growing evidence that self-efficacy is associated with positive outcomes such as; quality of life, depression, activities of daily living and function. However, the way

in which self-management interventions should be most effectively delivered remains unclear (Jones and Riazi 2011).

For example, the RCT by Kendall *et al*, (2007) explored the role of a self-management education intervention with 100 stroke survivors (n = 58 in the intervention group). The intervention group received self-management education over a six-week period (2hrs per week). They found that in contrast with the control group, the intervention group did not follow the same functional decline. However, although the self-efficacy was consistently higher than the controls, it did not change over time for either group. This suggests that an education intervention alone may not be enough or indeed have the ingredients necessary to enable change. In other words, in order to change self-efficacy, there may need to be a practical element whereby stroke survivors are able to physically achieve and ‘master’ tasks; they are given the opportunity to observe examples of behaviour and interpret physiological signs, and finally, they have the opportunity to receive feedback that may reinforce their efforts and subsequent behaviour.

Although there is emerging evidence that self-management interventions that include an educational element as well as a practical element show improved levels of self-efficacy, the lack of methodological rigour highlights the need for further research to establish an optimal format for delivering self-management interventions (Jones and Riazi 2011). Furthermore, there are unanswered questions as to what and how self-management interventions delivered in various contexts enable or constrain the underpinning theories. For example, it has been proposed that home-based rehabilitation is an environment that may facilitate self-management strategies (Jones and Riazi 2011). However, how this environment impacts on a stroke survivor’s ability to adopt self-management and self-efficacy principles remains unknown.

So far this research programme has explored the key theories underpinning the intervention ‘the provision of extrinsic feedback from computer-based technology for upper-limb post-stroke rehabilitation in the home’ and the expected outcomes (self-managed rehabilitation and behaviour change). The second stage of the realistic evaluation cycle (fig 2-15 overleaf) involves generating CMOC’s.

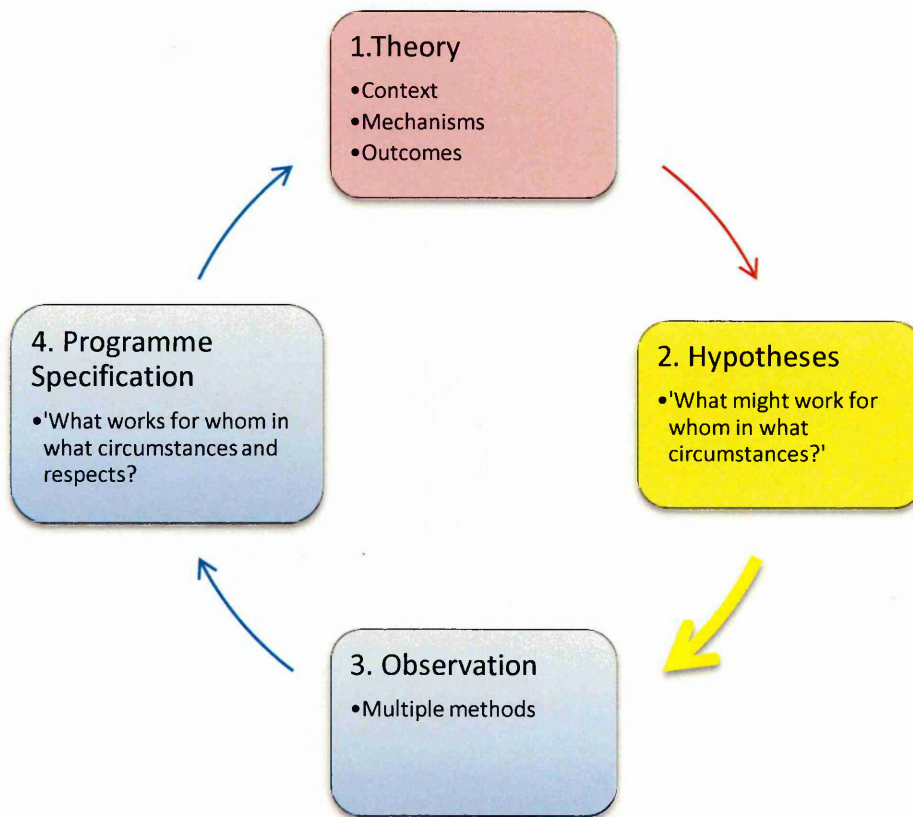
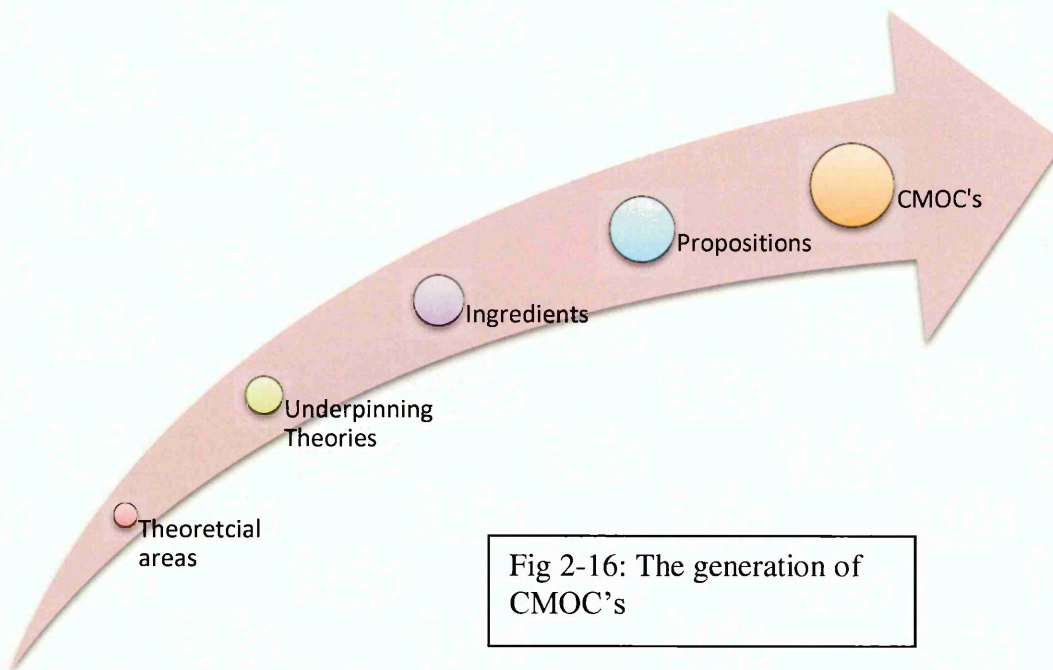


Fig 2-15: The second stage of the realistic evaluation cycle (Pawson and Tilley (1997)).

## 2.11 The Generation of CMOC's

The process of exploring the underpinning theory has highlighted a number of theoretical 'ingredients' that underpin the propositions and CMOC's as to how the intervention might work and in particular, how the utilisation of feedback from computer-based technology may lead to outcome(s). The following figure illustrates this process (fig 2-16 overleaf).





The following section will describe the theoretical ‘ingredients’ that are drawn from the theories and how the feedback from the SMART system incorporates these ingredients (table 2-2 p. 80). The resultant propositions are then set as mechanisms to describe the *process* of how users of the SMART system act upon the intervention stratagem to make them work. These are then set as context-mechanism-outcome configurations (CMOC’s). The final part of developing the CMOC’s involves describing possible outcomes (table 2-3 p. 82).

**Table 2-2: The incorporation of theory-driven ingredients within the SMART system.**

Theory Topic	Theories	Ingredients	How the feedback from the SMART system incorporates these.
<b>Theory Topic 1: The theoretical approach to post-stroke rehabilitation incorporated within the SMART system.</b>	<b>Underpinning Theories: Neuroplasticity; Motor-learning</b>	Independent practice	Used in the absence of a therapist.
		Intensity	Increased rehabilitation activity.
		Problem solving	Self-monitoring, self-interpretation, overcoming problems encountered in the absence of a therapist.
		Goal setting	Choosing which exercises to perform.
		Specificity	Matched movement patterns.
		Repetition	Increased rehabilitation activity.
		Salience	Relevant (meaningful) feedback.
		Motor learning	The SMART system provides an opportunity to learn implicitly and explicitly through trial and error and explicit feedback.
<b>Theory Topic 2: Feedback in Post-Stroke Rehabilitation.</b>	<b>Underpinning Theories: Motivation; Operant Conditioning; Motor-learning</b>	Feedback content	The SMART system provides KP, KR, verbal and visual feedback. It also provides prescriptive feedback (in part).
		Feedback schedule	The SMART system provides feedback concurrently, terminally, after each performance and in summary.
		Rewards	The SMART system provides the user with the rewards of good performance through a red, amber, green chart and through scores (depending on exercise).
<b>Theoretical Outcome: Behaviour change and Self-management.</b>	<b>Underpinning Theories: Self-regulation, Social cognition, and goal-setting theories; Self-efficacy.</b>	Goal-setting	The user is able to set specific, measurable, realistic, and time specified goals (targets) to achieve that are confirmed by the computer feedback.
		Action planning	The user can choose when to use the system and how many sets / repetitions they do.
		Self-monitoring	The user is able to monitor performance(s) independently.
		Reinforcement	The SMART system provides the user with positive feedback (depending on performance). Others are able to observe results.
		Self-management	The SMART system provides the user with an opportunity to problem-solve, make decisions, utilise resources, collaborate with others, and take action depending on their interpretation of the feedback provided.
		Self-efficacy	The SMART system provides the user with an opportunity to evaluate achievement(s), observe demonstrations (the avatar), interpret performance(s) and changes in physical and emotional feelings as a result of usage, and receive feedback which may include verbal persuasion from significant others.

## 2.12 Propositions

- Feedback provided by the system will encourage independent rehabilitation, self-evaluation and self-monitoring of recovery.
- Feedback provided by the system will increase the user's confidence to carry out self-managed rehabilitation, self-evaluation and self-monitoring of their condition.
- Feedback provided by the system will encourage the user(s) to problem-solve by providing them with an opportunity to interpret their performance and change their movements to improve subsequent performance(s).
- Feedback provided by the system will encourage the user(s) to self-manage their condition by providing them with an opportunity to make decisions, utilise resources, and take action.
- Feedback provided by the system will provide the user(s) with an opportunity to collaborate with significant others such as, the therapist and carer.
- The feedback provided encourages the user(s) to set specific, measurable, realistic, and time specified goals (targets) to achieve.
- The use of the SMART system will encourage the user(s) to problem-solve by overcoming technical problems encountered that impact on the feedback provided.
- Receiving positive feedback will encourage the user(s) to use the SMART system.
- Through intense, repetitive, specific, salient practice, with confirmation of performance, users will learn motor skills.
- Through repetitive practice, users will increase their confidence and usage of their affected upper-limb.
- The delivery of (extrinsic) computer feedback will enable users to learn implicitly through trial and error.

## 2.13 Context-Mechanism-Outcome Configurations (CMOC's)

CMOC's are propositions and comprise models indicating how the intervention may activate the mechanisms for whom and in what circumstances. This leads to the creation of a *variable book* which sets out hypotheses to describe 'what might work for whom

and in what circumstances’ (Pawson and Tilley 1997). Therefore the following section will set out the CMOC’s.

### 2.13.1 CMOC’s: ‘What Might Work for Whom and Why’

For clarity, the following table is set out to describe what plausible theory-driven mechanisms might work in what context(s) to produce possible outcomes; the ‘*variable book*.’ The variable book is set out as ‘what’ (M) works ‘for whom’ and in ‘what circumstances’ (C) to produce what possible outcomes (O). How these outcomes are measured is also presented.

<b>CMOC’s</b>	<b>Plausible mechanisms: ‘what’</b>	<b>Contexts: ‘for whom’ and ‘in what circumstances’</b>	<b>Possible outcomes</b>	<b>Measures</b>
CMOC 1	M1: Receiving feedback from the system might improve the user’s confidence by confirming performance.	C1: A system that is accessible (in the home setting) and used by the stroke survivor, independently of the therapist.	O1: Adoption and development of a self-management approach to rehabilitation (behaviour change). - Independent rehabilitation, self-evaluation and self-monitoring of recovery.	Observation of use and avatar replays. User diary. Usage of the system. Interview data.
CMOC 2	M2: By receiving feedback, users might feel confident to be able to interpret their performance and changing their movements to improve subsequent performance(s).	C2: A system that can be used independently by the stroke survivor in the home.	O2: Development of self-management skills. - Problem-solving.	Observation of use and avatar replays. Interview data.
CMOC 3	M3: By receiving feedback, users might feel confident in making decisions, utilising resources, and taking action.	C3: A system that provides feedback to the stroke survivor during and after use.	O3: Users take ownership of their condition. - Making decisions, utilising resources, and taking action.	Observation of use and avatar replays. User diary. Interview data.

CMOC 4	M4: By receiving feedback, users might engage with significant others such as, the therapist and carer.	C4: A system that provides feedback measurements for the stroke survivor.	O4: Users involve others in their rehabilitation through choice. - Collaborate with significant others	Interview data. User diary
CMOC 5	M5: By receiving feedback, users might be motivated to set specific, measurable, realistic, and time specified goals (targets) to achieve that are confirmed by the computer feedback.	C5: A system that allows the stroke survivor to set goals in relation to the feedback provided.	O5: Increased motivation and self-management. - Goal-setting.	Observation of use and avatar replays. User diary. Usage and number of repetitions. Interview data.
CMOC 6	M6: By receiving feedback, users might feel confident to problem-solve by overcoming technical problems encountered that impact on the feedback provided.	C6: An environment where the user is provided with adequate resources and support.	O6: Development of self-efficacy. - Perseverance in adversity.	Observation of use. Interview data.
CMOC 7	M7: By receiving feedback, users might be motivated to use the SMART system as a result of positive reinforcement.	C7: A system that provides positive and rewarding feedback to the stroke survivor which can be described/observed by significant others.	O7: Increased usage of the affected upper-limb, intensity, and repetition.	Observation of use and avatar replays. User diary. Usage and number of repetitions. Interview data.
CMOC 8	M8: By receiving feedback, users might be motivated to carry out intense, repetitive, specific, salient practice.	C8: A system that allows the stroke survivor to carry out repetitive use and provides computer feedback in the home setting.	O8: Improved motor and functional performance.	NEADL Observation of use and avatar replays. Usage and number of repetitions. Interview data.

CMOC 9	M9: By receiving feedback, users might be more confident and motivated to carry out repetitive practice and increase their usage of their affected upper-limb.	C9: A system that encourages the stroke survivor to carry out repetitive use.	O9: Increased use of the affected upper-limb in ADL's and social participation.	NEADL Interview data. Observation of use and avatar replays.
CMOC 10	M10: The delivery of feedback might engage the users.	C10: A system that delivers salient (meaningful) feedback to the user.	O10: Increased repetition through the use of the SMART system.	Usage and number of repetitions. User diary. Interview data.
CMOC 11	M11: The delivery of feedback might engage the users and enable them to learn implicitly through trial and error.	C11: A system that allows the user to observe their performance concurrently.	O11: Improved performance on the computer exercises.	Observation of use and avatar replays. Computer scores.

The CMOC's (listed above) are then tested and refined which enables the researcher to evaluate *'what works for whom and in what circumstances and respects?'*

## 2.14 Summary

This chapter has described the computer technology used in this research and how this research builds on previous investigation. This chapter has also scrutinised the key components of the intervention to reveal the underpinning components of the intervention, the underpinning theories, ingredients, and propositions. This has led to the development and description of mechanisms, contexts and possible outcomes to form CMOC's that can be tested. This has uncovered what particular aspects of each of the theories may be activated under certain contexts leading to proposed outcomes.

In order to explore how the context impacts on the underpinning theories to produce outcomes, this research utilises the principles of realistic evaluation, multiple methods of observation and the systematic testing of CMOC's.

Therefore the following chapter continues the RE cycle by describing the chosen methodology and outlining the methods employed to observe the CMOC's.

## **Section Two: Observations**

### **3. Chapter 3: The Methods Adopted to develop and observe the CMOC's**

#### **3.1 Introduction**

Chapters one and two highlighted that current models of service delivery are unsustainable and that new, innovative service models to increase the amount of time patients spend in therapy within the context of home-based rehabilitation are essential (DoH 2010). This has prompted the development of robotic, virtual reality, and inertial tracking systems that have the potential to provide consistent, detailed, individually adapted rehabilitation in the absence of the therapist (Intercollegiate Stroke Working Party 2008). However, using such technological systems in the home environment presents unique, context specific challenges for the user which can impact on the use of technological systems and erode benefit (Mountain *et al*, 2010; Parker *et al*, 2010).

So far this thesis has detailed the realistic evaluation methodological framework (page 12), followed by the context; the mechanisms underpinning the intervention and the theoretical outcomes; and the CMOC's. The third stage of the evaluation cycle involves the 'observation' phase where multiple methods are used to collect data that will enable the researcher to interrogate the hypotheses (Pawson and Tilley 2004) (fig 3-1 overleaf).

In order to evaluate the complex multi-faceted nature of utilising feedback from computer technology in the home and observe the hypothesised CMOC's described in 2.13.1 (p. 82); this research uses an eclectic mix of research methods. Therefore, this chapter firstly, explores the philosophies underpinning the chosen methodology; secondly, describes the chosen research design; thirdly, outlines the methods employed and finally, describes the steps taken to establish trustworthiness.

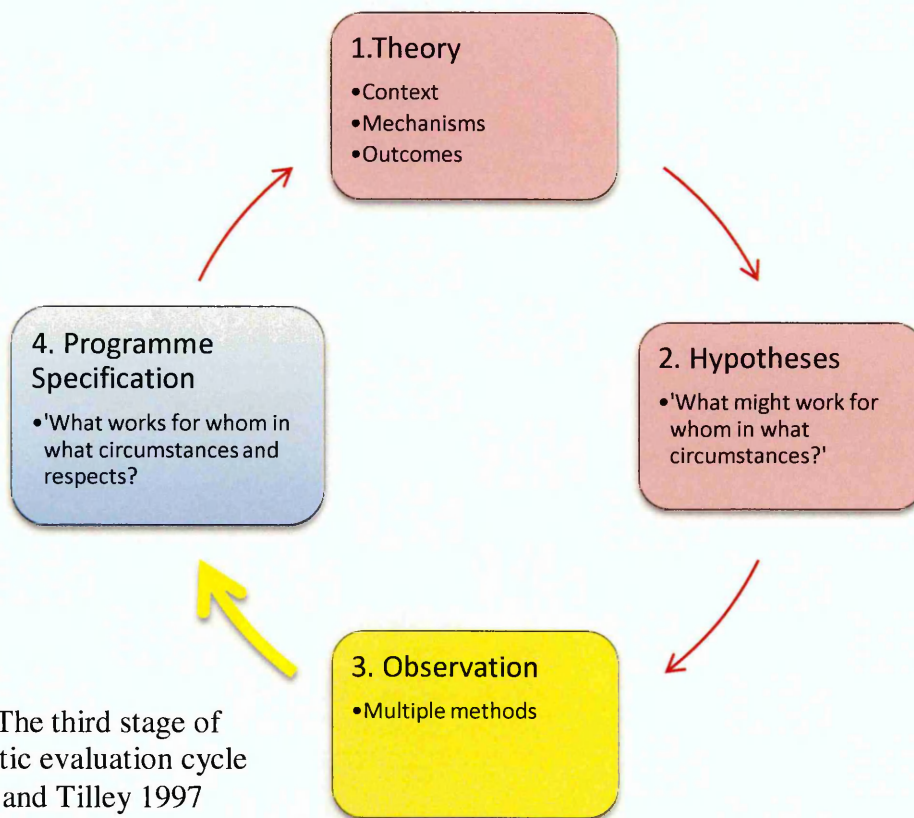


Fig 3-1: The third stage of the realistic evaluation cycle (Pawson and Tilley 1997)

### 3.2 Choosing an Appropriate Methodology

Choosing an appropriate methodology involves drawing on paradigmatic positions to achieve the best possible outcome (Broom and Willis 2007) whilst taking into account the sequential steps of increasing population based evidence for complex interventions<sup>4</sup> (Medical Research Council (MRC) 2000). The sequential framework necessary for embedding interventions into health services are outlined by the MRC. These steps start from the exploration of relevant theory and identification of an appropriate study design, through to; early testing (modelling phase); exploratory experimental design; robust experimental design (RCT); and finally, long-term implementation and monitoring (MRC 2000) (fig 3-2 overleaf).

<sup>4</sup> Complex interventions: An intervention that involves; a number of interacting components, difficulty in the behaviour change required by participants, a number of groups, variability of outcomes, flexibility in the intervention (Craig *et al*, 2008).



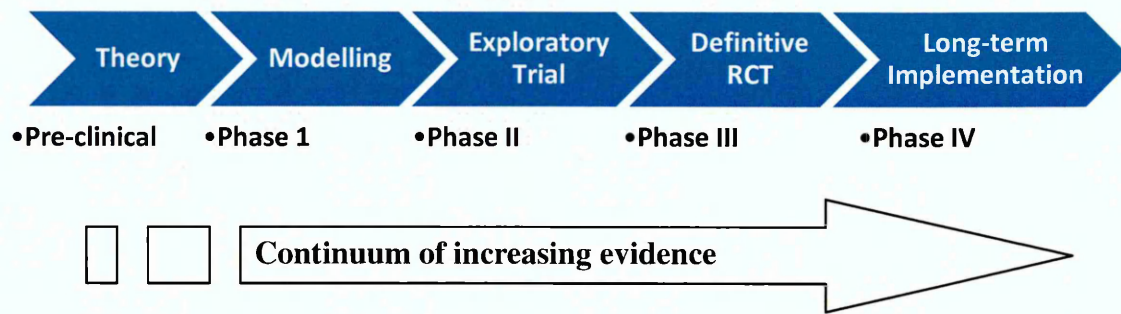


Fig 3-2: The sequential framework of increasing evidence (MRC 2000 p.9).

However, whilst the original framework in 2000 sets out the sequential steps that must be taken (i.e. an RCT cannot be carried out before feasibility testing), it was criticised for being too rigid; needing to place greater attention to the contexts in which interventions take place; and that the process of increasing evidence was too linear (Craig *et al*, 2008), resulting in an updated framework placing greater emphasis on the development, feasibility and evaluation phases (MRC 2008) (fig 3-3).

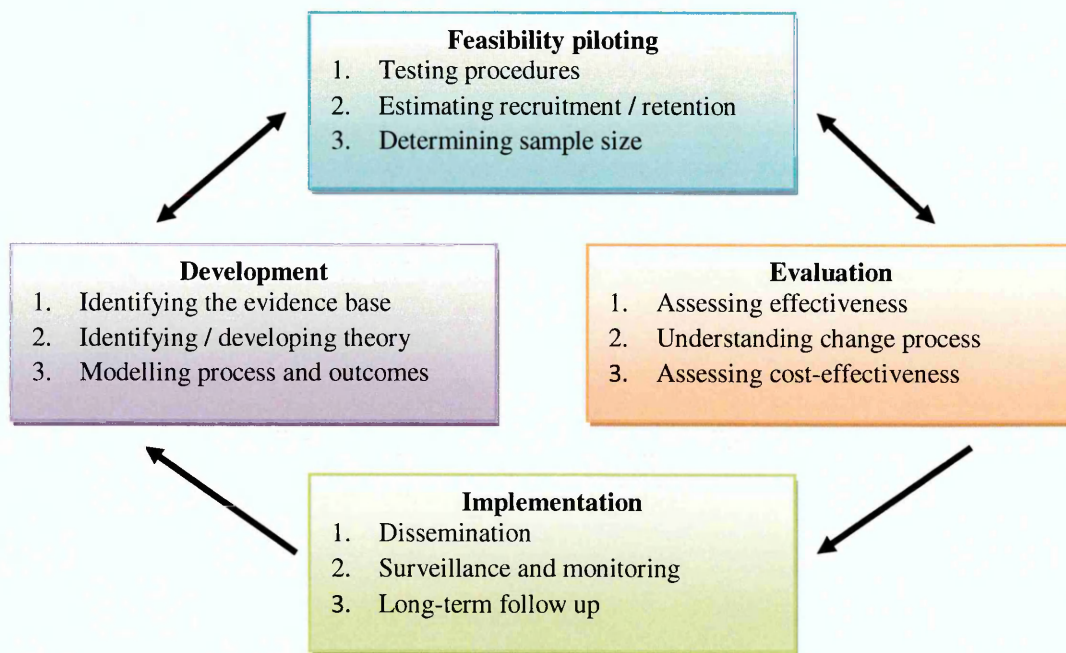


Fig 3-3: The key elements of the development and evaluation process (MRC 2008 p.8).

The relevant element of the new framework for this study is the recognition of early testing and contextual factors. The introduction of radical innovation and potential paradigm shifts in service delivery requires an iterative process of feasibility testing, development, and constant evaluation that includes all stakeholders (NIHR CLAHRC SY 2009). This research involves the exploration of relevant theory and initial testing of

a complex intervention in the context of the home. Therefore, this research is positioned in the early stages of the MRC framework (2000) (fig 3-4).

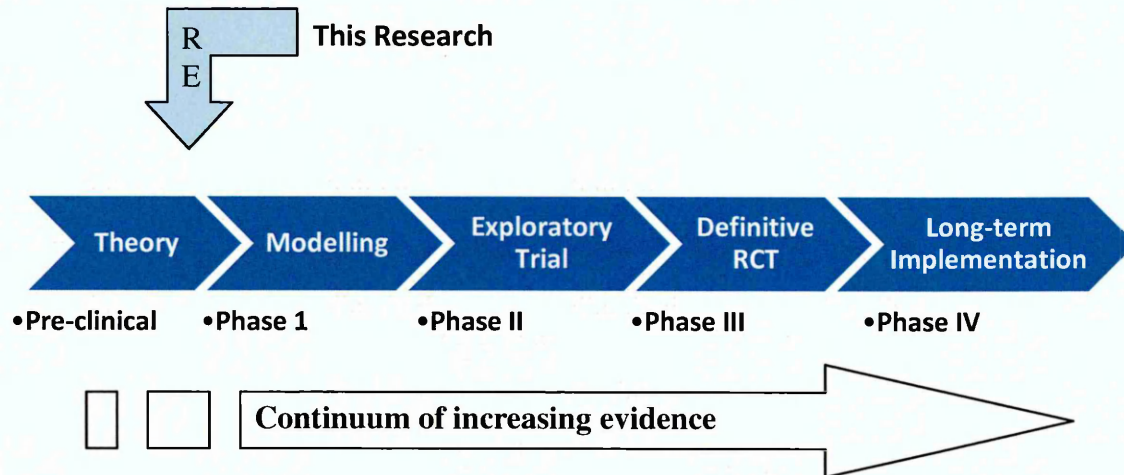


Fig 3-4: The position of this research within the sequential framework of increasing evidence (MRC 2000).

### 3.3 Paradigmatic Approaches

Health researchers vary greatly in the paradigm they adopt to study designs. However, adopting an approach that is the most likely to inform practice and increase knowledge is likely to be the most appropriate (Broom and Willis 2007). These disparities have traditionally varied from a positivist (a deductive, quantitative approach) to an interpretivist (an inductive, qualitative approach).

Positivist, quantitative studies employ experimental, quantitative methods to test hypothetical generalisations; they also emphasise the measurement of causal relationships in controlled conditions. The credibility of this approach depends on instrument construction such as a valid, reliable outcome measure that is responsive to clinically important changes (Bowling 2009). The strength of positivism lies in the quantification of aggregate data, measures to reduce bias and confounding factors, objectivity, reliability through randomisation, and the ability to generalise to the population (Broom and Willis 2007).

In contrast, interpretivist, qualitative research is a method of naturalist enquiry that sets out to explore and interpret an area being studied by collecting naturally occurring data in natural social settings (Denzin and Lincoln 2005). Pope and Mays (2006) describe two distinct characteristics of qualitative research; firstly, it is concerned with *'the meanings people attach to their experiences of the social world and how they make*

*sense of that world'* and secondly, *'it studies people in their natural settings rather than in artificial or experimental ones.'* (Pope and Mays 2006, p4) Put simply, qualitative research aims to answer questions such as, *'what is x and how does x vary between different circumstances rather than how big is x and how many are there?'* (Pope and Mays 2006 p.3).

Historically, positivism has been the dominant paradigm in the evaluation of service provision. However, health researchers are becoming increasingly pragmatic in their approach (Broom and Willis 2007; McEvoy and Richards 2003). The MRC framework (2000; 2008) suggests that early developmental interventions (such as this research) should involve methodological approaches that identify potential confounding factors, limitations, and underlying mechanisms that may influence the reliability of the results for population based studies. Furthermore, if large service intervention trials have not accounted for differences in participants, circumstances, and contextual factors, the intervention or hypothesis under test may not be as significant as the findings suggest (Pawson and Tilley 1997; Rycroft-Malone *et al*, 2010).

Therefore, it is imperative that the early exploration of complex interventions are suitably 'unpicked' and as Broom and Willis (2007) suggest, *'researchers should take a pragmatic approach to research design and data collection'* in *'what could be called 'horses for courses'* (p.28).

This research aimed to explore how the context of utilising computer feedback for upper limb stroke rehabilitation in the home setting and the underpinning theory-driven mechanisms of the intervention impact on theoretical outcomes.

Therefore, in order to observe the CMOC properties in action (described in 2.13.1 p. 82), a mixed-methods approach was chosen using the principles of Pawson and Tilley's realistic evaluative framework (1997) (described on page 16).

### **3.4 Research Setting**

This research specifically explores the impact the context may have on the underpinning mechanisms. Therefore, the home setting would allow the researcher to evaluate the environment in which the SMART system was intended to be used. This includes the interaction of the therapist(s), participant, carer, and the computer technology encapsulated within the context of the participant's home (see fig 3-5 p.91).

By collecting data in the participants' homes, the researcher is able to evaluate what impact the physical environment has as well as other family members on the mechanisms. For example, how the ability to store the equipment may impact on independent use and how carers may (or may not) reinforce behaviour.

### **3.5 Methods of Data Collection used in this Research**

Understanding how new interventions, innovations and policy changes impact on those involved requires a holistic approach. In order to explore the multifaceted phenomenon of utilising extrinsic feedback from computer technology for home-based stroke rehabilitation, a number of research methods were used to gain as full an understanding as possible of the how the context impacts on the mechanisms underpinning the utilisation of feedback from computer technology. Table 2-2 (p.80) details the specific CMOC's in which the methods employed were utilised to measure change (which methods measure which outcomes).

The following section will outline the methods chosen and in used in this research.

#### **3.5.1 Observations through Case Study**

In order to explore the personal, social and environmental context of the users and how this may impact on the mechanisms, the researcher carried out a number of in-depth case studies.

Case studies have been variously described as a strategy of inquiry (Denzin and Lincoln 2005), a methodology (Merriam 1998), or a comprehensive research strategy (Yin 2003). They involve the study of an issue explored through one or more examples of a phenomenon that are considered to be illustrative of a wider process or structure (Cresswell 2007; 2009). Distinct from narrative research where the focus is on the individual (and their stories), case studies focus on the issue within that case by providing an in-depth, contextual understanding within a bounded system. Yin (2003) states that,

*'A case study is an empirical inquiry that investigates a contemporary phenomenon within its real-life context; especially when the boundaries between phenomenon and context are not clearly evident' (p. 13).*

He also suggests that,

“You would use a case study method because you deliberately wanted to cover contextual conditions – believing that they might be highly pertinent to your phenomenon of study” (p. 13).

The researcher can purposely select cases that may show different perspectives of the problem, process or event (Stake 1995). In addition, Yin (2003) suggests that by involving a number of cases, the study can utilise *replication logic*. By replicating the procedures of the intervention (mechanisms), a contrast in findings may allow the researcher to analyse the variation or similarities in the data across the cases. In other words, if the case receives the same intervention as the previous case but leads to a different outcome; does the researcher know anything about that case that might suggest why? In order to provide an in-depth account of the case(s) and uncover the contextual factors, the researcher draws on a number of sources of information such as; interviews, profiles, observations and documents. The use of multiple sources of evidence allows the researcher to explore a broad range of issues that may impact on the main issue under investigation. In addition, any finding(s) or conclusion(s) is likely to be more accurate if it is based on different sources (Yin 2003).

Figure 3-5 illustrates the ‘case’ where the therapist provides a model of delivering feedback that involves face-to-face feedback.

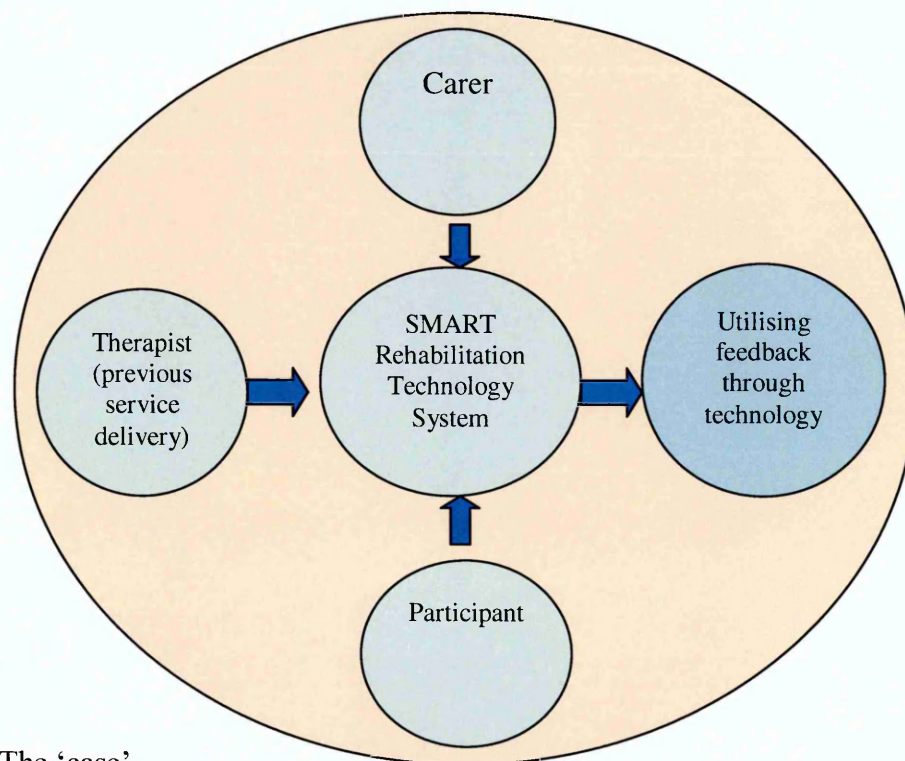


Fig 3-5: The ‘case’.

In short, if the mechanism(s) stays the same (replication) and the only variable is the context, the researcher can explore what aspects of the context may have changed the outcome. The following section describes the methods used to collect data in this research. In common with realistic evaluation, this approach explores the individual contextual factors that impact on the case.

### **3.5.2 Observational Methodology**

In order to explore the interactions and behaviours of the participants and their carers during the use of the SMART Rehabilitation Technology System, observational methods were employed. This specifically enabled the researcher to observe the interaction between the environmental context and the mechanisms leading to an outcome. For example, the researcher was able to observe changes in behaviour such as frequency of use and improvement in performance.

Observation of behaviours, actions, interactions, and activities allows for more understanding than what people say about situations. This method of gathering data can be quantitative or qualitative, structured or unstructured, formal or informal, or participative or non-participative (Bowling 2009).

Qualitative observations allow the researcher to explore the research setting, potential participants, and may also provide some early data. Crucially, in health research, the immersion of the researcher within the research setting allows the researcher to gain some understanding of the interactions between the patient and their environment, as well as the patient and practitioner (Pope and Mays 2006a). However, in order to obtain 'pure' data, the researcher must remain open without any predetermined ideas of which the discrete behaviours may emerge.

The interaction and location of the researcher within the setting can also influence the data collection and even the data itself (Hughes 2007). These are; the researcher as a complete observer, observer as participant, participant as observer, and complete participant (Wallace 2005).

The complete observer does not take part in the setting, and adopts a 'fly on the wall' approach. With this method the researcher does not physically influence the data. However, has been suggested that interactions and behaviours may be influenced by the notion of 'being watched'. To eliminate these reactive effects, some researchers choose to observe through a two-way mirror but this raises ethical questions. For example, the

participant may be unaware of their involvement in the research which may be unethical (Bowling 2009).

The 'observer as participant' approach enables the researcher to marginally engage in the situation. This method advantageously allows the researcher to ask questions, observe behaviours and interactions without actively being part of the workforce (Wallace 2005).

The 'participant as observer' involves the researcher being part of the group under study. For example, observations of a clinical setting may be carried out where the researcher plays a full and active role within it and the other participants are made aware of the research being conducted. The advantage of this is that it allows access to the setting and the researcher is embedded within the research itself. However, the researcher may influence the data and therefore, either consciously or even sub-consciously; this may introduce some bias (Wallace 2005).

The researcher as 'complete participant' involves the researcher taking an insider role and therefore allows for covert observation of the field. However, this method of observation has been questioned ethically as the participants are unaware of the observations taking place. An advantage of this method is that the participants are not influenced by the researcher's presence leading to 'reactive effects' (Wallace 2005).

The researcher's position during the observations of the case studies (chapter 6) moved from 'participant as observer' and 'observer as participant' throughout the period of data collection for each participant (up to five weeks). This was because the researcher was required to initially set up the computer equipment and subsequently train both the participant and their carer to use it and change and adapt the exercises throughout the period. This directly involved the researcher (participant as observer). However, subsequent visits allowed the researcher to step back from the participant and their carer and take the role of 'observer as participant.' The move to and from 'participant as observer' to 'observer as participant' was important as the researcher may have influenced the data by adding interpretation and personal opinion of using the SMART system if an observer as participant approach was maintained. It was also important for the researcher to step back from the participant using the system as the aim of this research was to explore its use 'in the absence of a therapist.'

### 3.5.3 Individual Interviews

In order to explore the interaction between the personal context and the mechanisms leading to an outcome, the researcher gained the opinions and perspectives of the participants and their carers through semi-structured interviews. This enabled the researcher to explore the participant and carer's previous experience of receiving feedback from the community stroke team therapists before using the SMART system; and subsequently their experience of the feedback provided by the computer. Furthermore, the researcher was able to explore how the participant and their carer may have collaborated or if the participant had gained confidence in carrying out independent rehabilitation.

From a philosophical and epistemological perspective, participant interviews aim to gain access to the participant's understanding of the world and give them opportunity give their perspectives and experiences (Taylor 2005). Interviews can be categorised as; structured; semi-structured and unstructured. These subdivisions reflect the flexibility and rigidity of the data collected (Britten 2006).

- Structured interviews are a way of administering set questions to the participant which therefore restrict the response given. They are commonly used in surveys and should be viewed as a quantitative data collection tool (Britten 2006). For example, interviewees may be asked: 'Since your stroke would you describe your treatment as good, fair or poor?'
- Semi-structured interviews are questions that follow a set format or theme that allows for open-ended responses to specific enquiry. This format enables the researcher to gain specific data whilst allowing the interviewee to diverge in order to elaborate on an idea or response (Silverman 2005). For example, interviewees may be asked: 'Since your stroke, what are your views of the treatment you have received?'
- Unstructured interviews allow for in-depth responses from the interviewee. They enable researchers to explore the perceptions, experiences and meaning of particular phenomena whilst allowing for flexibility (Low 2007). For example, interviewees may be asked: 'Can you tell me about your recovery following your stroke?'



Interviewing participants requires a number of skills. These include; the ability to gain trust and mutual respect; being sensitive to the issues being considered and possessing the necessary verbal and non-verbal communication skills (Silverman 2005). Taylor (2005) suggests that the researcher must be able to reflect upon the consequences of power and control, social class and the impact they may have on the respondent.

This form of interview can potentially enlighten research in that it enables the underlying feelings and perspectives of service users to be exposed. In addition, it provides those being interviewed with the opportunity to express their views and in particular how they feel about the treatment they receive.

### **3.5.4 Focus Group Methodology**

In order to explore the professional perspectives of the delivery of feedback in clinical practice two focus groups with the two Community Stroke Teams who had provided rehabilitation in the homes of the participants subsequently recruited to use the SMART Rehabilitation Technology System (described in detail in chapter 4). This would establish what forms of feedback therapists adopt and what the stroke survivors participating in this study had experienced during the rehabilitation period prior to using the SMART system (their pre-existing context). This process also allows the researcher to validate the embryonic hypotheses set out in chapter two.

Focus groups are a qualitative method to obtain in depth information, on a specific topic, from a target audience through the systematic questioning of a group of individuals in a formal or informal setting (Fontana and Frey 2000). This form of group interview capitalises on group discussion and communication between research participants to generate rich data. In health research, focus groups are especially suited to research questions that seek to understand or uncover how and why health professionals make decisions (Depoy and Gitlin 1994). Furthermore, group discussion can allow for participants to generate questions, exchange anecdotes and comment on experiences and points of view (Kitzinger 1994).

In common with other methods of data collection, focus groups allow for interaction to occur between the researcher and the participants and enable the researcher to probe topics and subjects that arise. In addition, clarifying responses and asking follow-up questions may facilitate further group discussion and further probing. An advantage of conducting a focus group over one-to-one interview is that a number of participants can

be interviewed at the same time and the focus group allows for group discussion. Vaughn *et al*, (1996) describes how these interactions often give rise to:

- *Synergism* – when broader data is generated through group interaction.
- *Snowballing* – when the comments of one participant generate a chain of reaction and additional comments.
- *Stimulation* – when excitement about a topic is generated.
- *Security* – when the group provides a comfort and encourages candid responses.
- *Spontaneity* – participants are not required to answer to all questions or respond to all the comments made. Therefore the responses may be more spontaneous and genuine (Vaughn *et al*, 1996).

Although there are many advantages and a clear rationale for using focus group as a method of data collection, the researcher must be aware of other factors. Firstly, as with any inquirer-respondent interaction, the moderator may introduce some bias throughout the discussion by providing cues and prompts to direct the participants. Secondly, members of the group may change or alter their opinions as a result of the discussion itself or if there are more senior members involved (Kitzinger 2005).

The researcher has less control over the focus group than a one-to-one interview; therefore the topics may drift away from the intended research area or become fragmented as members of the group speak to each other resulting in smaller conversations within the whole group discussion. In addition, some members of the group may become overpowering and suppress other members either through their personal communication or through hierarchy within the group. For example, a senior member may feel they are ‘representing’ the group or a junior member may feel they do not have the experience or expertise to contribute. It is therefore essential that the researcher is aware of the hierarchy and structure of the team (Kitzinger 2006).

Focus groups do not maintain the confidentiality of other methods of enquiry, such as, one-to-one interviews; every member of the group is exposed to sharing their opinions with the group and their participation within the research is also known to others. It is therefore imperative that this is explained to each member beforehand and that the group discussion and the members of the group do not share this information beyond the focus group itself. In addition, the researcher may offer members of the group the

opportunity to speak after the discussion if they feel they would like to contribute more to the discussion on a one-to-one basis (Kitzinger 2005; 2006).

To overcome these issues, a moderator guide was used to establish 'ground rules' prior to the group discussion (see appendix 3 p. 308). These 'ground rules include; not interrupting when another member of the group is speaking; respecting other people's opinions; there are no right or wrong answers; and not to criticise another member of the group.

The method, analysis and findings of the focus groups carried out for this research are detailed in chapter four.

What remains important within the process of gathering data is the ability to reduce bias and ensure rigor and trustworthiness of the data as well as gaining the appropriate ethical and research governance approval (Meyrick 2006).

### **3.5.5 Measurement of Functional Independence**

Two of the CMOC's (eight and nine) hypothesise that intense, repetitive, specific and salient practice may lead to improved motor and functional performance and increased usage of the affected upper-limb. Therefore, in addition to the qualitative measures described above, a quantitative measure was used to capture any changes in function.

#### **3.5.5.1 Functional Outcome Measures Considered**

- The Barthel Index (BI) (Mahoney and Barthel 1965) – This was eliminated as it contains items that using the SMART system would not change i.e. continence.
- The Functional Independence Measure (FIM) (Keith *et al*, 1987) – This was eliminated as it contains items that are not specific to functional and extended functional activities i.e. self-care, sphincter control, mobility, locomotion, communication and social cognition.
- The Frenchay Activities Index (FAI) (Holbrook and Skilbeck 1983) – This was eliminated as it is time specific in that it measures the extended activities of daily living during three and six months post-stroke (Wade *et al*, 1985).
- The Rivermead Motor Assessment (RMA) (Lincoln and Leadbitter 1979) – This was eliminated as it is time consuming (up to 40 minutes to complete) (Collin and Wade 1990) and the RMA does not include extended activities of daily living.

### 3.5.5.2 Choice of Measurement Tool

The Nottingham Extended Activities of Daily Living (NEADL) (Nouri and Lincoln 1987) (see appendix 4 p. 309) is a widely used functional outcome measure aimed specifically at stroke patients on their return to community (Chong 1995).

The NEADL was chosen because it covers a wide variety of functional activities of daily living and extended activities of daily living. The participants in this study had received up to twelve weeks of community rehabilitation and through this were likely to have improved levels of functional ability. The NEADL has a low floor and high ceiling which would allow for participants with poor functional ability as well as those with high levels of functional ability to be measured. In addition, the measure includes functional tasks that are associated with re-integration into the community such as going out socially.

Although the measure does not specifically focus on improvements in upper-limb function, many of the tasks directly include the use of the upper-limb, such as, feeding, and writing. In addition, although a number of tasks in the measure do not directly use the upper-limb, improvements in the upper-limb can be associated with improvements in the task, such as, walking (balance).

The NEADL was also chosen because the researcher aimed to obtain the subjective opinion of the participant of their functional improvement(s). The NEADL is a self-reported measure and therefore any changes (before and after using the SMART system) would be the subjective opinion of the participant.

The NEADL scale was used to establish changes in the function and independence of the participants (Nouri and Lincoln 1987) before and after using the SMART Rehabilitation system.

The measure uses an ordinal scale which comprises of 22 items that are divided into four sections; mobility, kitchen, domestic, and leisure ranging from four to six tasks in each domain. However, the ability to carry out the activities is dependent on the stroke survivor's desire to. For example, a participant may not wish to write letters or read books. Therefore, some of the items may be less relevant to each participant.

The scale is collapsed into 0 – dependent and 1 – independent scores for each of the 22 tasks. However, Harwood and Ebrahim (2000; 2002) expanded the NEADL by using a

likert scoring method which included increasing the sensitivity of the scale from a 2 point (0 –with help, 1 – independently) to a 4 point (0-3) score, therefore increasing the overall score from 22 to 66. The measure therefore provides dependent/independent scoring for each tasks as well as functional ability scoring that range from 0 – 18 in each category.

The NEADL has been found to be a valid (Gompertz *et al*, 1994), reliable, and responsive to clinically important changes (Harwood and Ebrahim 2002).

### **3.6 Data Analysis**

The focus of the data analysis in chapters four, five and six was based on both the exploration of the pre-existing context and the development and refinement of the hypothesised CMOC's using thematic and framework analysis (Yin 2003; Pope and Mays 2006). This innovative approach to the analysis draws on Yin (2003), Miles and Huberman (1998) and Patton (2008) and is underpinned by the principles of Pawson and Tilley's RE (1997). This involved: familiarising with the data; identifying a framework; indexing and coding existing and new context, mechanisms/ingredients; charting the data; and finally, refining the charted data (Yin 2003; Miles and Huberman 1998; Patton 2008).

This approach allowed for themes to emerge from multiple sources of data and examines interconnections and relationships between the mechanism(s) and context(s) in relation to proposed outcomes (Rycroft-Malone *et al*, 2011; Pope *et al*, 2006). Specific analyses of data for each data collection method are detailed in sections 4.3.4, 5.8 and 6.8.

The following table (3-1) provides an example of the method of analysis and charted data.

**Table 3-1: The Method of Data Analysis**

Context		Existing Mechanisms / Ingredients			New Context / Mechanisms/Ingredients
<b>Pre-existing</b>	<b>Current</b>	<b>Behaviour change and self-management</b>	<b>Feedback in post-Stroke rehabilitation</b>	<b>The theoretical approach to post-stroke rehabilitation incorporated within the SMART system</b>	
Int 1: "There was a sheet of paper with graphics on and an explanation of the graphics telling us how to do it [the exercises]" PE: I2	Obs: During the exercises the carer guided the participant throughout by providing verbal instruction such as, 'lift your arm higher.' CC: O1	Int 2: "Once I'd got up in the green, I was determined to stay there! I knew I had to keep using it [the computer] to stay in there so I'd want to have a go more often" BC: I3	Int 2: "I didn't really grasp the two men on the screen." FB: I1	Dis: "It's not me on the screen, that's a man and I'm a woman!" TA: D5	Int 2: "I can say to mum you are not doing it right, and I can show her" N: I10
Int 1: "We chucked them away... Once I could remember what she has to do I chucked the papers! PE: I4	Int 2: "It takes quite a while to get the equipment out and ready, then you've got to get her [Mrs. Green] dressed with all the sensors on only for it to say the sensors aren't working." CC: D3	Int 2: "It enabled me to help mum." SM: I6	Int 2: "The colours, the red, amber green and the dots. I think it's, I think that is a good way." FB: I2	Int 2: "I knew if I got in the green I'd done well" TA: I1	Dis: "it's disappointing... it puts me off bothering! Then when the sensors don't look right... how am I supposed to do that?" N: D7

### **3.7 Ethical and Research Governance Approval**

Ethical approval was been granted for the study ‘The extent to which stroke survivors can utilise extrinsic feedback from computer-based technology to facilitate rehabilitation in the home’ by the National research Ethics Service (NRES) which was confirmed in writing on the 5<sup>th</sup> September 2008 (see appendix 5 p310). In addition, Research Governance approval was granted on the 2<sup>nd</sup> October 2008 and an honorary contract was put in place to undertake the study (see appendix 6 p314). A further amendment was granted on the 18<sup>th</sup> February 2009 by the National Research Ethics Service (see appendix 7 p316) and 10<sup>th</sup> March 2009 by the Sheffield Health and Social Research Consortium (see appendix 8 p318). This amendment included the addition of using recognised and validated screening (assessment for suitability) tools during the recruitment of the participants. These were:

- The Mini-Mental State Examination – A cognitive impairment test consisting of a series of questions given by the researcher to the participant lasting up to 10 minutes (Tombaugh and McIntyre 1992).
- The Frenchay Aphasia Screening Test – A screening device to identify those patients with communication difficulties. It consists of a series of questions given by the researcher to the participant lasting up to 10 minutes (Enderby *et al*, 1987).

This study involves the use of computer technology and it was therefore imperative that the participants did not have severe cognitive impairment that may have affected their ability to use the equipment. The addition of these screening tools allowed the researcher to assess whether the participants were suitable for the study in terms of their cognitive status and that they will be able to converse with the researcher during the interviews.

### **3.8 Establishing Trustworthiness**

The trustworthiness of qualitative data is often questioned due to the subjective nature of data collection and subsequent analysis (Holloway 2005; Meyrick 2006). However, in common with all research methods is the awareness and acknowledgement of error by the author (Oakley 2000). Whilst quantitative methods may focus on standard methods within the research process to eliminate error, qualitative methods rely on a reflective, transparent and systematic approach to data collection and analysis (Nelson 2008).

Within the quantitative paradigm, internal and external validity, reliability and objectivity are used to establish the scientific credibility of the research (Golafshani 2003). In qualitative enquiry, these terms have been translated into: credibility (internal validity); transferability (external validity); dependability (reliability); and confirmability (objectivity) (Mays and Pope 2006).

In order to establish trustworthiness in qualitative research, Meyrick (2006) describes a model that proposes a pluralistic approach to quality and rigour by building on the common principles of transparency and the application of a systematic approach to data collection and data analysis (fig 3-6 below).

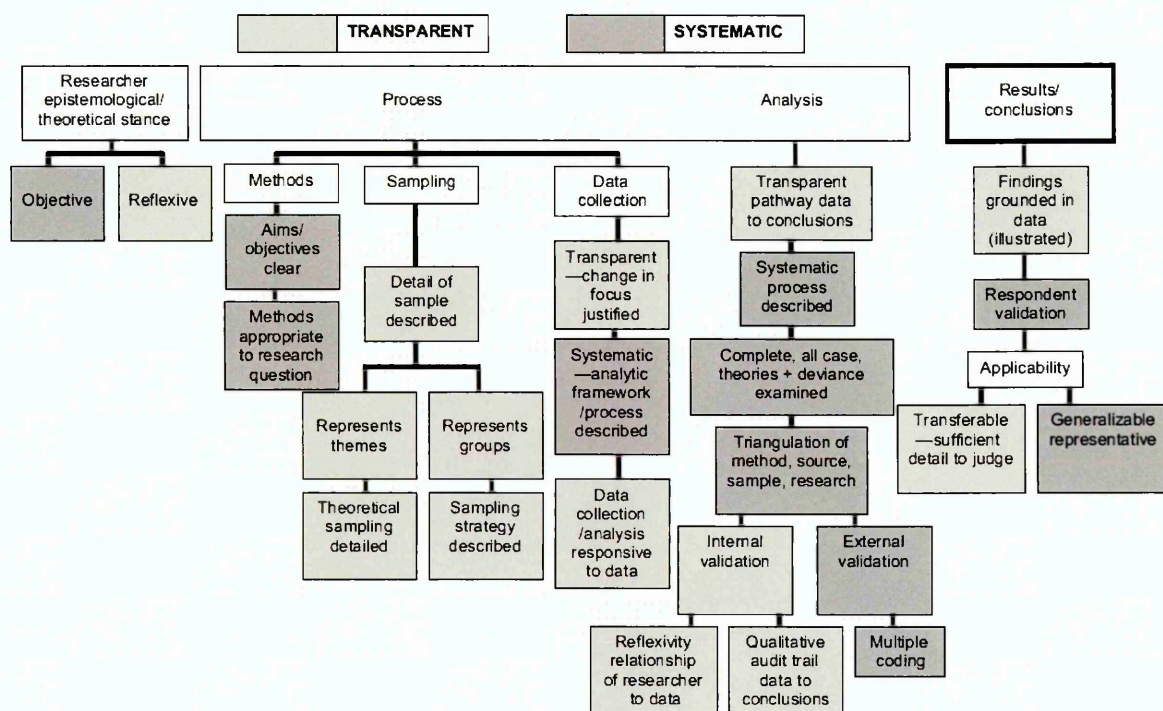


Fig 3-6: Quality framework for qualitative research; From: Meyrick (2006) p803.

### 3.9 Applying a Systematic and Transparent Approach

The model proposed by Meyrick (2006) shown above, provides a step-by-step process of collecting and analysing data through a systematic and transparent process.

- The epistemological stance – How researchers bring their own world views, paradigms or set of beliefs to their research project (Cresswell 2007).
- The methods used – How researchers set out their aims and objectives for the study and what methods are selected and why.



- Sampling – Has the researcher detailed the sample selected and the process involved?
- Data collection – Has the researcher detailed how the data was collected? Is there evidence of triangulation? What are the limitations of the method of data collection?
- Analysis – What steps were taken to ensure the analysis is complete, systematic, transparent, and valid?
- Results and conclusions – Are the findings grounded in the data? Is there evidence of respondent validation? Are the results generalisable? (Meyrick 2006).

### **3.10 Credibility**

Lincoln and Guba (1985) describe how credibility involves concerns over the accuracy of the description of the study parameters. This involves a thick description of the study setting, the sample(s), and the theoretical framework. Furthermore, in order to increase the probability of high credibility, the researcher is required to maintain prolonged engagement in the field to allow for sufficient time to gain the trust of those involved and increase the awareness of ‘their world’ (Lincoln and Guba 1985; pp301-307). Evaluating observations, interviews and focus group data will undoubtedly question the validity and trustworthiness of data. For example, how does one know that is what the participant actually said or even meant to say? What questions did the researcher ask to procure that answers? Are there any other factors to consider; such as, socio-economic background and family support?

What remains important is the ability of the reader to see through the process of how the conclusions were drawn. In addition, can the reader apply the findings to practice with a wider population?

Mays and Pope (2006) describe ways of assuring and assessing the validity of data.

- Respondent validation: Has the researcher checked the analysis of the data with the participant? Do they match? How is this reported?
- A clear exposition of methods, data collection and analysis.

- Reflexivity: Has the researcher accounted for how the process of data collection and how the researcher themselves may have influenced the data?

The researcher used respondent validation to ensure that the interpretation of the data matches that of the subject(s). This was done by explaining the transcription to the subject(s) by face-to-face conversation or telephone conversation. The researcher then made any necessary amendments to the transcripts. This applied to all interviews and focus groups. Lincoln and Guba (1985) regard this as the strongest available check on the credibility of a research project. This was done by clarifying their observed behaviours and probing what their meaning and rationale was for it.

Gaining trust with both the Community Stroke Teams (CST's) and the participants (stroke survivors) was achieved through prolonged involvement in the field and ensuring the provision of information sheets and accompanying letters of invitation were fully informative. In addition, the participants (both CST's and participants) were recruited through a prolonged, systematic process which allowed them to consider and discuss their involvement over a longer period with their CST therapist (for the case studies) and the researcher. This process is detailed in chapters four (therapists) and six (participants).

Throughout this study, the researcher also maintained regular supervision with both his Director of Studies (Dr. Jackie Hammerton) and his supervisors (Prof. Gail Mountain and Prof. Sue Mawson). In addition, further discussions (that did not compromise ethics) have taken place with a number of peers, health professionals, and experienced health and social care researchers. This has allowed for greater consideration of the processes and procedures during the project and assisted with an evaluation of the decisions made. Furthermore, a number of internal and external presentations at national and international conferences have also provided peer review (see 'Broadcasting' p. 278).

### **3.11 Transferability**

The question of external validity is often problematic with qualitative data as each set of data is individual to the participant providing it and may therefore not be applicable to the wider population (Holloway 2005). However, whilst problematic, an explanation of where the research fits into the overall inquiry of a particular area, experience and

condition may allow the reader to evaluate its applicability and validity to other settings (Mantzoukas 2004).

*“The more illustrative, explanatory and sophisticated the portrayal is, the more extended or applicable the acquired knowledge becomes” (Mantzoukas 2004, p994).*

Although one of the limitations of this research is the small number of cases, there are a number of similarities in each case that may be in common with the wider stroke population. For example, their age, social circumstances, history, physical limitations, and functional ability may be similar to other stroke survivors. In addition, the prolonged length of engagement with the case studies added to the depth and ‘thick description’ required in case study research (Yin 2003). However, the burden of proof lies with the person seeking to make an application elsewhere rather than the original investigator (Lincoln and Guba 1985).

### **3.12 Dependability and Confirmability**

Ensuring the research is both dependable and confirmable requires a process of overlapping methods and auditing their research (Holloway 2005). The audit should ensure that a complete paper trail is available for examination and that all the stages of the project are carried out correctly i.e. meeting the requirements of ethical and governance procedures. In addition, the researcher should maintain a research diary to detail the analytical processes undertaken.

The researcher’s prior assumptions and experiences may influence the enquiry and how they interpret their findings. Therefore Pope and Mays (2006) suggest that keeping a reflexive journal is also essential. This allows the researcher to reflect upon how they may have shaped the data collected (Pope and Mays 2006).

For this study, an investigator site file has been maintained throughout which holds key information of the processes and stages of the project, such as, details of scientific review, ethical and governance clearance was awarded, participants, indemnity, and storage of data. This study undertook an audit by Prof. Ann Macaskill and Brian Littlejohn on behalf of the Sheffield health and Social Care Research Consortium on the 20<sup>th</sup> August 2009. The audit team were satisfied with the contents of the file and that the study was being carried out within the standards set out by the DoH’s Research

Governance Framework for Health and Social Care. In addition, the site file was given a commendation (see appendix 9 p319).

### **3.13 Summary**

Due to the current limited knowledge base for using technology for upper-limb post-stroke rehabilitation in the context of the home, this complex intervention necessitates multiple research methods and the utilisation of a realistic evaluation methodological framework. This chapter has therefore outlined the underpinning philosophy and chosen methodology for this research; the chosen research design and methods employed, and how trustworthiness was built into the research intervention.

The next stage of the evaluation cycle begins the observations where multiple research methods are used to collect data that will enable the researcher to interrogate the hypotheses (Pawson and Tilley 1997; 2004). Therefore, the following chapter will explore the current delivery of feedback in clinical practice from the professional perspectives of the members of two community stroke teams who provide home-based post-stroke rehabilitation.

## **4. Chapter 4: Professional Perspectives of the Delivery of Feedback in Clinical Practice: Validating and Exploring Existing and New CMOC's**

### **4.1 Introduction**

The next process within the third stage of the RE cycle involves testing and validating the embryonic hypotheses by gaining the perspectives of practitioners that are deemed important stakeholders in the delivery of the intervention. This enables the researcher to gain an empirical insight and explore existing and new propositions. In other words, 'this is my theory, what is yours?' (Pawson and Tilley 2004).

This research involves exploring the shift from receiving feedback that is delivered by the empirical knowledge and clinical reasoning of a therapist (over 12 weeks during community rehabilitation) prior to receiving feedback from the SMART Rehabilitation Technology System. Therefore, the therapists involved in this study played a vital role in establishing the pre-existing context of the participants.

This chapter will describe how focus groups explored the existing propositions and elicited new, emerging theory from the perspectives of two groups of therapists working within different Community Stroke Teams employed in community rehabilitation by one Primary Care Trust (PCT). Initially, the aims of the focus groups are presented followed by the methods, study design, study sample, access to the sample, data collection, data analysis. The results are then presented with a discussion and concluding remarks.

### **4.2 Aim**

The focus groups aimed to:

- Explore the pre-existing context and mechanisms underpinning the delivery of feedback during community post-stroke rehabilitation to validate the embryonic hypotheses (described in chapter two).
- Establish the empirical theory underpinning what current practice and provision of information and extrinsic feedback therapists employ to assist patients to continue with their rehabilitation post hospital discharge.

### **4.3 Focus Group Method**

Focus groups are a qualitative method that relies on the systematic questioning of a group of individuals in a formal or informal setting (Fontana and Frey 2000). This form of group interview capitalises on group discussion and communication between research participants to generate rich data. Furthermore, group discussion can allow for participants to generate questions, exchange anecdotes and comment on experiences and points of view (Kitzinger 1994).

This method was therefore chosen for gathering data as it allowed health professionals to discuss the variation of opinions and experiences with each other as well as generating some consensus. For the purpose of the evaluation, these focus groups were employed to specifically explore and validate the existing propositions and elicit new, emerging empirical theory.

#### **4.3.1 Sampling and Recruitment**

Purposive sampling was used to recruit individual Occupational therapists (OT's) and Physiotherapists (PT's) that prescribe physical rehabilitation to stroke survivors in the stroke survivors' homes. This served two purposes; firstly, the OT's and PT's in the focus groups were the same therapists that were involved in the participants' <sup>5</sup> rehabilitation and had therefore contributed to the pre-existing context of the participant; and secondly, they were deemed as those who would enable the researcher to explore the existing theory as well as provide new emerging theory.

The researcher visited both teams to introduce the study and the computer equipment involved. This was followed by the distribution of letters of invitation (see appendix 10 p. 320) and information sheets (see appendix 11 p. 321) to qualified Occupational (OT's) and Physiotherapists (PT's) within each team. The letters of invite briefly introduced me as the researcher and outlined the purpose of the study. In addition, the letters invited the therapists to contact the researcher if they required any further information or wished to discuss their potential involvement or discuss any aspects of the study; this was reiterated during the visit. The information sheets described in detail what their participation in the study would involve. The therapists were then invited to contact the researcher personally by telephone or email to confirm their wish to take

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<sup>5</sup> The participants (stroke survivors) who used the SMART system in this research (described in chapter 6).

part in the study. Figure 4-1 illustrates the sampling and recruitment process for the focus groups with CST – North and South.

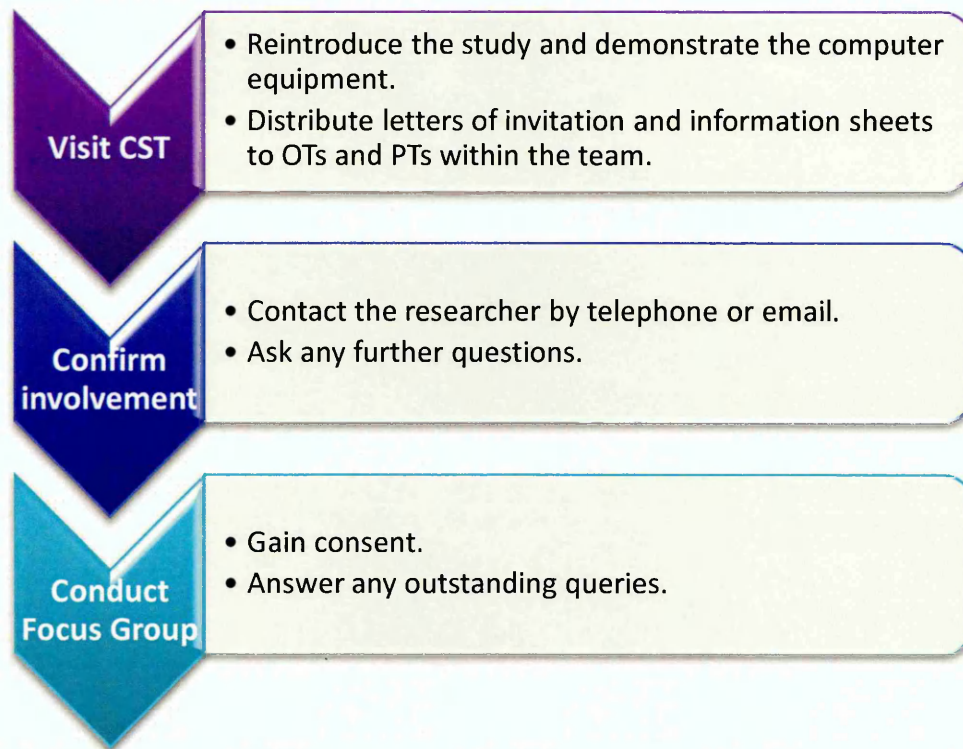


Fig 4-1: The sampling and recruitment process for the focus groups with CST – North and South.

### 4.3.2 Focus Group Preparation

Prior to the focus group respondents were invited to ask any outstanding questions or queries either as a group or separately before the commencement of the focus group. In addition, they were given a further explanation of the study, their involvement and how the focus group data will inform the study. This was in the form of a 15 minute PowerPoint presentation. The presentation described the aim of the research; the various forms of extrinsic feedback that have been identified, the feedback provided by the SMART rehabilitation system to date and a description of the research carried out with the SMART rehabilitation system. This enabled the group to focus on the topics of the group discussion as well as reflect on what they provide in clinical practice. In addition, the group were given a second demonstration and explanation of the SMART Rehabilitation Technology System.

Following this, the individuals were asked permission for the discussion to be audio-recorded. They were then given consent forms separately. They were also reminded that they were free to leave if they no longer wished to take part. Those who still wished to

take part were given a 'therapist details' form to fill in which documented their professional details such as their qualification, the length of time qualified, grade and length of time working within stroke rehabilitation (see appendix 12 p. 325).

A moderator's guide was developed to establish the course of the focus group and was informed by literature relating to conducting focus groups (Green 2007; Kitzinger 2006). The guide also acted as a reference for the researcher by listing the structure and order of the proceedings (see appendix 3 p. 308). These included; a welcoming brief to the procedure, confidentiality issues, ground rules and what would happen to the data.

The tape-recording equipment was checked to ensure it was in good working order prior to the group discussions.

### **4.3.3 Focus Group Procedure**

The therapists were thanked for volunteering to take part in the study. This was followed by a brief detailing the conduct of the focus group and what was required using the moderator's guide as reference. This involved a description of the ground rules and that there were no right or wrong answers. It was also explained to them that they did not have to agree with others but that they should respect the opinion of other group members. They were then asked if they had any final questions.

The researcher drew a seating plan listing the members of the group as A – I (CST south) and 1 -5 (CST north). As the group knew each other there was no requirement for group introductions. However, they were asked to introduce themselves to the researcher by saying their name, profession and seat letter. This enabled the researcher to recall who was speaking during the transcription.

The researcher followed a topic guide to structure the discussion and the questions were based on the underpinning propositions described in 2.12 (p. 81). These included what information/instructions they give to patients and carers as well as questions regarding how they feedback to patients in practice (see appendix 13 for discussion topics p. 326). During the discussion the researcher wrote the letter of the person speaking and the first words of what they said, for example, A – 'I think that feedback provision is...' The therapists were only interrupted when they either digressed to the extent that the discussion was not relevant to the study or they had no further comments on that particular aspect of the discussion. In these cases, they were given further questions to explore further or they were asked a different question to take the discussion forward.



Following the group discussion, the therapists were thanked for their involvement in the focus group and that the data would be transcribed exactly as they had said (verbatim). They were informed that the transcription would be sent to them for them to read and check for accuracy (respondent validation) (Lincoln and Guba 1985).

#### **4.3.4 Data Analysis**

The focus group data was analysed to specifically explore the pre-existing context and mechanisms underpinning the delivery of feedback during community post-stroke rehabilitation and validate the embryonic hypotheses (described in chapter two). This involved two processes. Firstly, the researcher observed for the theoretical ingredients described in 2.11 (p. 78) to establish whether the therapists utilise these ingredients and how they enable these ingredients to work; and secondly, what other ingredients and mechanisms are used within the context of home-based post-stroke rehabilitation (described in chapter three). In RE terms this involves exploring the regularities that occur within the pre-existing context.

##### **4.3.4.1 Data Analysis Procedure**

The focus group discussions were transcribed verbatim from the tape-recording. These were then checked for accuracy by listening to the recording and matching the audio to the transcription allowing for further accuracy as well as adding moments of expression by the therapists. Following this process, the transcriptions were delivered back to the therapists for respondent validation. Lincoln and Guba (1985) describe this as the strongest available check on the credibility of a research project. None of the therapists in either group contacted me to make alterations to the transcripts.

Transcriptions were analysed through an iterative process which involved; reading through each response by the therapists, identification of information units<sup>6</sup>, the formation of themes, sub-themes and sub-divisions of themes. Throughout this procedure, the transcripts were revisited for further refinement. The initial process involved, individual focus group analysis i.e. Stroke team south only followed by stroke team north. This allowed for an exploration of different information units to emerge from each team. Following this, connecting information units were then merged to establish a broader 'theme' and sub-themes. Finally, themes were then supported by corresponding statements.

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<sup>6</sup> 'The smallest amount of information that is informative in itself' (Vaughn *et al*, 1996).

Responses to personal details were analysed using the Microsoft EXCEL software package. Descriptive statistics were established for the nominal and ordinal level data (Moore *et al*, 2005).

### 4.3.5 Community Stroke Team Composition

Short informal interviews revealed that the Community Stroke Team (south) act as one of two early supported discharge teams within the Sheffield Primary Care Trust. Working alongside other teams such as; Day rehabilitation units: ARC (Assessment and Rehabilitation Centre) covering the south of the city and DRU (Day Rehabilitation Unit) covering the north; the multidisciplinary team was made up of Physiotherapists, Occupational Therapists, Speech and Language Therapists, Therapy Assistants, Nurses, Pharmacists, a Clinical Psychologist and Secretarial Staff who, following the patient's discharge from hospital, provide up to three months of rehabilitation. Table 4-1 (below) lists the health professions in the Community Stroke Teams of a PCT in the north of England.

Table 4-1: Composition of the Community Stroke Teams (North and South).

Health Profession	CST South (number of professionals)	CST North
<b>Physiotherapist</b>	7 (5 full-time, 2 three days per week)	6 (2 full-time, 3 four days per week, 1 three days per week)
<b>Occupational Therapist</b>	6 (5 full-time, 1 three days per week)	5 (4 full-time, 1 four days per week,)
<b>Speech and Language Therapists</b>	3 (2 full-time, 1 three days per week)	3 (1 full-time, 1 four days per week, 1 three days per week)
<b>Therapy Assistant</b>	4 (2 full-time, 2 three days per week)	3 (2 full time, 1 four days per week)
<b>Clinical Psychologist</b>	1 (full-time)	1 (unfilled)
<b>CST Nurse</b>	2 (unfilled vacancies)	2 1 (1 full time, 1 unfilled)

Physical therapy of the upper-limb is provided by the Physiotherapists and Occupational Therapists who are assisted by the therapy assistants.

#### **4.3.5.1 Workload**

The Community Stroke Team (south) aim to provide up to one hour of input for five days per week (Mon - Fri). Initial observations indicated that they provided on average fifty minutes face-to-face contact with the patient in the patient's home/care home. This package of rehabilitation is provided for up to twelve weeks and depending on the patient's on-going needs, referrals can be made to either ARC for patients living south of the city and DRU for those who live north of the city.

However, the stroke team leader explained how this is often limited and variable due to team members being absent, the changing numbers of patients and the variation in patient needs. For example, one patient may have higher needs and therefore require longer term care compared to a less severe stroke resulting in less requirement for therapy input.

#### **4.3.6 Focus Group Response Rate**

Letters and information sheets were given to 23 qualified OT's and PT's inviting them to take part in this part of the study. Of these 19 expressed an interest in taking part. However, although they were asked to respond by telephone or email, both teams chose to respond by collecting names together which were then sent to me by post. Of these 19, fourteen actually took part in the focus groups; 9 from the Community Stroke Team south and 5 from the Community Stroke Team north, giving a response rate of 60.8%. It must be noted that the main reason for the lower response rate from the CST north was that the focus group was held on a Monday during the school Easter holidays which resulted in some members of the group being absent.

##### **4.3.6.1 Participant Characteristics**

The demographic characteristics are presented in table 4-2 and 4-3 (overleaf).

<b>Therapist</b>	<b>OT/PT</b>	<b>Band</b>	<b>Months qualified</b>	<b>Qualification</b>	<b>Additional qualification</b>	<b>LOT with Stroke speciality (months)</b>
<b>HPA</b>	OT	7	240	Dip Cot	0	120
<b>HPB</b>	PT	7	120	Dip Grad Phys	0	84
<b>HPC</b>	PT	6	72	BSc (Hons)	0	24
<b>HPD</b>	PT	6	72	BSc (Hons)	0	2
<b>HPE</b>	PT	5	60	BSc (Hons)	0	4
<b>HPF</b>	OT	7	132	BSc (Hons)	MSc OT	90
<b>HPG</b>	PT	6	96	BSc (Hons)	MSc Mod Basic Bobath	72
<b>HPH</b>	OT	6	72	BSc (Hons)	Previous BSc (Hons)	16
<b>HPI</b>	OT	5	12	BSc (Hons)	0	5

<b>Therapist</b>	<b>OT/PT</b>	<b>Band</b>	<b>Months qualified</b>	<b>Qualification</b>	<b>Additional qualification</b>	<b>LOT with Stroke speciality (months)</b>
<b>HP1</b>	PT	6	72	BSc (Hons)	Basic Bobath	18
<b>HP2</b>	OT	7	240	Dip Cot	MSc Mods Basic Bobath	180
<b>HP3</b>	OT	5	24	BSc (Hons)	0	1
<b>HP4</b>	PT	6	156	BSc (Hons)	Basic Bobath Adv Bobath MSC Mods	36
<b>HP5</b>	OT	7	216	Dip Cot	0	168

## **4.4 Exploring Propositions, Theory Refinement and Generating New Theory**

### **4.4.1 Themes**

Following prolonged contact with the data, 42 information units were highlighted from the CST south transcript and 53 from the CST north transcript. These information units enabled the researcher to explore the pre-existing context; the mechanisms underpinning current service delivery; and emerging new theory.

#### **4.4.1.1 Context: The Environment**

The groups discussed how the physical environment focused the patient on what they would like to achieve. One member of the north team described how the environment changes the focus of the patient; how they reset their goals once they are back in their familiar surroundings,

*“I think it is different in their home as well. Their goals will be different when we see them once they have been at home for a bit than when they are in hospital where they just want to get out of hospital” HP4.*

By using familiar surroundings, an OT described how she believed it helped the patients evaluate any improvements which in itself provides an indirect form of feedback,

*“I think with it being in their own home as well, a lot of what we are doing is very... it’s all around their own environment, their own objects; the way they normally do things. It’s all very familiar to them and that can help them to understand what they to be able to do. It’s more automatic for them to be able to do things that they understand” HPF.*

One therapist described how she uses the environment to provide implicit challenges for the patient. By changing the environment she was able to utilise indirect feedback which could either reinforce a movement pattern that she wanted the patient to do or as a challenging functional activity demonstrate changes in their ability,

*“...you would rearrange the environment around them, so you would move their tea caddy along a bit so they have to stretch further for it.”*

*“...they can’t help but have to move in that particular pattern because you have changed their environment to make them do it.” HPA*

#### **4.4.1.2 Context: Carers**

A member of the north team discussed how therapists involve carers/family members in the rehabilitation process. A number of factors were highlighted that they take into consideration, such as, establishing whether carers actually wanted to be involved in the rehabilitation process,

*“I guess we try to get a sense of how much the carer wants to be involved and is able to be involved because I think that is quite a big thing. They have often got a lot on” HP4.*

One of the members of the south team thought that one the main reasons for not wanting to get involved was due to their personal circumstances such as, wanting to get

on with their own life. A member of the north team also suggested that they may need to carry out everyday tasks that they are not able to do or that they may have their own health limitations,

*“...some carers are very keen to be part of the rehab program. Other carers when we arrive want to get out the house as quick as possible to get on with their own life” HPF.*

*“...sometimes they are just swamped ...some of them just need to get out to the post office while we are there because it is the only time they can go” HP4.*

Two therapists thought that this more apparent if the patient was more dependent particularly with personal activities of daily living because of the amount of time and effort they need from the carer,

*“I think the carer involvement in therapy often depends on the dependency sometimes of the patient really because if they are quite heavily dependent and needing a lot assistance for sort of everyday activities such as toileting etc. Then the carers often feel that they haven’t got even though they maybe don’t appreciate that that activity is therapy really. They then don’t think they have time to do specific therapy as well. You know I’ve got to do x y and z, I haven’t got time for therapy as well” HPB.*

*“Sometimes as well the carers have got their own health issues. [group all agree]. Some of them are quite elderly and frail so I think when the carers are younger they are usually able to cope more than older carers” HPF.*

Three therapists also described how the relationship between the patient and carer can also impact on whether they are involved in the rehabilitation process. In particular, how getting the carer involved can be detrimental to their relationship and in some instances the patient can actually resent it,

*“It depends on their relationship as well. What their relationship is like can they actually do it without arguing” HPF.*

*“...you get carers who are over prescriptive at supervising exercises and tasks that you have asked them to do, you don’t want the carer to be sitting over them like some kind of school teacher saying whether it is right or it is wrong” HP5.*

*“You can sometimes get carers who are so involved in the rehab, that the patient almost sometimes starts to resent it. Because it’s almost as if alters the carer*

*relationship doesn't it. They become part of the therapy; they are almost not bullying them as such but the patient can start to feel as if there is someone watching them all the time, they are nagging and it changes everything in that it can sometimes be a negative aspect" HPE.*

However, if the carer did wish to be involved in the process, it was suggested that this was positive; especially in helping the patient remember what to do and maintaining motivation,

*"...for those that do want to be involved, they are just so valuable because if they can be observing you do a program with the patient then obviously then that's two brains working so they can remember the program" HPF.*

*"...there is no doubt you see much bigger improvements..."HPF.*

Although members of the groups described clear advantages of the carer being involved in the process; they also described disadvantages. Both of the focus groups spoke negatively about the carers' involvement in the provision of assistance with the exercise program and questioned their ability to provide assistance in the way therapists wanted,

*"...some carers are not quite clear on what they should be doing with them. So we'll be practicing something that either you haven't asked them to do or they are doing it in the wrong way. They are really keen and want to help but aren't actually helping" HPE.*

#### **4.4.1.3 Mechanisms: The Delivery of Feedback**

Both of the CST's discussed in detail what they take into consideration when delivering various forms of instruction and feedback. Having knowledge of the patients' impairments was important to making judgements as to how to deliver information, instruction and feedback. One therapist described how she thought this even dictated what she gave them,

*"Some people have impairments that dictate what you give them and what you don't give them. You know if they have cognitive memory troubles, attention deficit, memory deficit, you have to tailor things according to that. You are sometimes steered down particular routes" HPA.*

They discussed how the patients' and carers' ability to remember what home exercises to do and more importantly how to do them was problematic; it appeared to be one of their main considerations.

*“I mean if we feel that cognitively they can remember then it maybe that we can give them some written and diagrammatic prompts to do things. Because some of them we know there is absolutely no chance they can remember a set of exercises” HP4.*

A senior OT described how she would like something or someone to remind the patients to carry out the exercises,

*“I’ve said to them, do you know you could do with a little me on your shoulder when I’m not here saying remember to do this remember to do that remember to do the other” HPA.*

One therapist described how she considered this when determining what forms of instruction may enable her patient to remember which exercises to do after she had left,

*“I think that for some patients you know that they are going to remember things and so you can tell them verbally and you know they will remember; others you’ll give written instructions, sometimes you might get the carers involved and explain to the carer, husband or wife whoever, what you want them to do and what you are looking out for so that they can prompt” HPF.*

A PT added,

*“Not just written, pictorial as well” HPG.*

A theme that ran throughout both of the focus group discussions was how health professionals used their experience and their empirical understanding of patients to make judgements and assumptions as to which form of instruction they felt was most appropriate. A senior OT how she tailored her instruction and feedback specifically for the patient,

*“...that is based on the type of person that you have been able to establish they are and what they respond more positively to. What they are actually able to do” HPA.*

It was also suggested that if the patient had more previous experience of rehabilitating, they were more likely to understand the process and be more accepting of exercise programs,

*“Patients can relate to it because in the past they will have done exercise at some point and so they will accept it a little bit easier” HPE.*



*“...it depends on their background really. If they have come from a stroke unit they have obviously been around lots of people that use really professional speech and jargon about goals and they are more engaged with it but obviously if they have remained at home or if they have not been very well in the stroke unit then it is quite a novel concept to a lot of people” HP5.*

It was also suggested that the need to overcome language barriers may influence what forms of instruction they give,

*“I have used photographs with certain clients where there is a language barrier so we have had to do it more pictorially” HP4.*

Following the provision of instruction during face-to-face contact, therapists described how it was important to give feedback according to the individual, what they respond to and what feedback will avoid incorrect movement patterns that may be reinforced,

*“Sometimes you might use a mirror or something as well, so when you practice it with them to start with you are showing them the correct movement pattern and then with that they’ve got to try and remember but that is feedback for them as they are doing it” HPG.*

*“If someone doesn’t know where their arm is in space there is no point saying to them put your arm in this position. They need that hands-on feedback and verbal or indeed a mirror like we discussed earlier” HPG.*

*“...as part of your assessment you find out what they respond to so as [HPG] was saying the tactile response might be more useful than any verbal feedback that you can give them” HPC.*

*“We have also used videoing quite a bit... which is helpful, for some people it is really helpful, for others they can’t... they don’t get as much out of it as you might anticipate and I think it is because it is themselves on a screen and it is not the view that they get of them doing the activity and it is difficult to some people to then transpose that video in to useful information.” HPA*

Two members of the CST north team also described using videoing,

*“We’ve used videos in the past, a long time ago; we have not used them for a while now” HP5.*

*“Yeah with neglect patients you know showing them the video back they could see their contra-lateral side from their good side. But I wouldn’t like to say what the effect of that was really. We didn’t use it consistently enough. I think it was just difficult to set up. It is a practicality issue” HP2.*

Interestingly, an OT felt that more frequent and even instantaneous feedback was better because it may reduce the possibility of the patient performing the exercises incorrectly,

*“I think that the feedback is more effective when it is instantaneous as well, like when you giving them feedback as they go along in the session they are more likely to be successful than when you’re not there and when they are doing when you are not there they are not getting instantaneous feedback” HPF.*

When asked if and why they vary the feedback they give to patients she replied,

*“There’s different reasons aren’t there personality, a parent, environment, carers, you know what their household is like. There all sorts of different reasons why you choose different kinds of feedback so you tailor it according to that person and what their needs are. If someone has got no... you know if someone is very aphasic who’s got no comprehension of what you are saying to them you are not going to use verbal feedback [laughs]” HPF.*

*HPG [interrupts] >>More gesturing and hand movement things and nodding you head, that type of thing.”*

It was suggested that giving positive feedback is beneficial for the patient as it may give them a boost and for the therapist as it allows them to demonstrate changes over time,

*“...you can give them quite a lot of positive feedback verbally for just being motivated and finding time to do it” HP1.*

*“...so having a bit a feedback of it visually would perhaps help with that and also it would act as a way of showing how things are changing over time” HP4.*

The therapists also discussed how they feedback to patients the next day after they have given them exercises to do,

*“I’d probably ask them to show me it, so I can see whether they have actually got some grasp of what you are doing. Check whether they had actually... whether it had been realistic because it is not always realistic between one day and the next that they might have done it so you have that conversation about whether they can give it a go, have a look at what they were doing, possibly*

*need to modify the instruction, whether you need to give more prompts, whether you actually need to get someone involved and practicing it with them and then go from there” HP5.*

*“...you go back to see them the next time you go, right show me what you’ve been doing. So then you can see if they have been performing the exercise incorrectly and then again give verbal feedback that way” HPF.*

*“Because you are literally going back the next day to re-check what they have done so they getting that regular feedback rather than a week in between or two weeks in between” HPC.*

In addition, when asked what they felt was ‘meaningful’ feedback; it was noted that the groups found this question difficult to answer. In this instance the researcher had to prompt the groups by asking what forms of feedback actually meant something to them. An OT then described how patients valued achievement and whether they could manage a task independently,

*“I was going to say telling them they are doing well; I think they value the achievement having succeeded in it” HP2.*

However, two members of the other focus group (CST south) had described how this can be quite a negative influence when it is not given by a therapist,

*“They often go into hospital and things and people say how much they have improved and give them that feedback as well” HPC. “Which can sometimes be quite negative can’t it because some people can be very generous with their comments and not actually that realistic” HPA.*

Therapists also discussed how they felt limited by what tools they had to provide instruction and how their current provision may not provide what input they wanted. A PT described how she found that the software she uses is often limited and may differ from what she would do in a face-to-face treatment session,

*“...on Physio tools itself, there is not always the exercises that you want to give so you are a little bit limited. Maybe what you would do hands-on would be different than if you were to give them a sheet to do on their own” HPC.*

Interestingly, one of the members of the CST south discussed alternatives to current provision. They had recently (as a team) invested in three Nintendo Wii consoles to use with patients, they were asked how they thought patients might get on with using them,

*“I think it is going to be something that is going to have to be tailored to the individual massively. I think that some people are going to respond really really well to it but then there’s going to be so many factors to consider in it. In terms of whether patients are going to be able to carry out some of them because there are so many different games... so many different ways you can use it. I think there is going to be a lot of time that is going to go in to working out what is going to be best and then training everyone to be able to give it to the patients as well [ALL - Mmmm] and then also how they are going to respond to the feedback because not all of it is very functional and they may not be able to relate to it from that point of view. It is going to be something that we are going to have to look into” HPE.*

#### **4.4.1.4 Mechanisms: Goal-Setting**

Two senior members of the CST (north) described how goal-setting was key to focusing the patient, family members and the stroke team on what they are aiming towards. They described how they use the ‘what’s your goal’ booklet to focus the patient and the team,

*“...the first thing we give them is the ‘what’s your goal’ booklet really; which is a client-centered goal setting tool really, to help the clients identify their own goals and indeed their own problems before they set their own goals as well. ...it sets the scene for the team and the team approach really which is kind of focused around their goals and what they want to be able to achieve” HP2.*

*“I think sometimes it can be quite helpful because it focuses you and it focuses them on what you are working on” HP4.*

*HP2 [interrupts] >>it focuses the team all the team members...*

*“Yeah that’s what I mean, it is focusing the patient and we can kind of channel things a little bit” HP4.*

However, one member of the team later went on to describe how they did not use it for all patients and a number of factors depended on its use, such as: whether the patient can use it because of their impairments; their stage of rehabilitation and therapists being over familiar with it. When asked why they do not use the ‘what’s your goal’ booklet with all patients, they described how a number of reasons influence their decision to use it,

*“I think there are a lot of reasons, erm... sometimes the patient might not be able to make use of it for cognitive reasons or they maybe are at a different stage in their rehab. We take people from Osbourne who may have already had six to*

*nine months and they often come out with quite clear goals about what they want to achieve really so the process has already taken place somewhere else really” HP2.*

*“I think we have got lots of new staff that are maybe not so familiar with it. I think some people, we have had some people originally come into the team that were quite early on in their rehab and that’s when the system was developed to help them. But then for a few years in between we’ve been getting people at a high level in they have been walking wounded almost and the need for the goal booklet hasn’t been so needy. But now we are getting people that are coming back early again all of a sudden or potentially could be and I think maybe it will find its own again and we will start using it again. I think also it has been around a long time so familiarity breeds content to some extent” HP2.*

Although it was described as a ‘*client-centred goal-setting tool*’ (see HP2 above); two of the therapists thought it was hard for patients to use because of the language used within it. One of the therapists suggested it was more of a tool for them as opposed to the patient,

*“...for some of our clients, it is just really hard for them to generate their own goals so then you are having to guide them through it a lot more through the process” HP4.*

*“I think the other thing is for some patient is the language around goals and goal setting is you know it depends on their background really. If they have come from a stroke unit they have obviously been around lots of people that use really professional speech and jargon about goals and they are more engaged with it but obviously if they have remained at home or if they have not been very well in the stroke unit then it is quite a novel concept to a lot of people isn’t it you know. This goal-setting it is hard for them to relate to so I would say it is more of a professional’s tool to you know it is 75% us maybe 25 % of them using the booklet” HP5.*

However, a senior OT from the CST (south) team and a senior PT from the CST (north) team felt that goal setting was important. They described how this can help in establishing a partnership with the patient which in turn may gain compliance,

*“... it sets the scene for the team and the team approach really which is kind of focused around their goals and what they want to be able to achieve so we are trying to get them on board from a motivational point of view really” HP2.*

*“...we are relying on their wish to improve and work towards goals. We do goal setting and we try to work with them really to work towards those goals. So you are relying a lot on their compliance really” HPB.*

In addition, a basic grade (band five) PT (CST south) suggested the need to adapt to the patients' needs and expectations were an important process in maintaining motivation,

*“So we can maybe look at altering kind of goals half way through and the midway goal. So we will kind of change things even though we've got the short and long term thing, I know we are not going back to that but the fact that you can say that considering everything you are still doing well, well if they've only got certain things to look at they may think well actually I've gone backwards massively and I've actually failed here. So by going in and kind of giving our feedback we can maybe keep that going and progressing forwards from it” HPE.*

#### **4.4.1.5 Emerging Theory: Adapting Instruction and Feedback to the Individual**

A PT and an OT from each of the teams believed that tailoring and adapting the instruction and feedback to the individual was paramount and how they did that depended on the patients: impairments; ability to remember important aspects of instruction; what they respond to,

*“I mean if we feel that cognitively they can remember then it maybe that we can give them some written and diagrammatic prompts to do things. It is really individual which strategy we will use depending on the persons impairments really. Because some of them we know there is absolutely no chance they can remember a set of exercises” HP4.*

*“...for some patients you know that they are going to remember things and so you can tell them verbally and you know they will remember; others you'll give written instructions” HPF.*

When asked whether they vary the form of instruction they give to patients members of the CST (south) team replied unanimously,

*“YES” [loud voice] All (CST south).*

*“You even vary what you give to the same patient throughout the treatment almost every session” HPB.*

*“So you may use more than one method. You may start with one method and it not work so you find that you need to use another one as you go along” HPF.*

When asked why,

*“Some of that is based on the type of person that you have been able to establish they are and what they respond more positively to. What they are actually able to do, I mean some people don’t have a high literacy level you know so pictures would be better. Some people have impairments that dictate what you give them and what you don’t give them. You know if they have cognitive memory troubles, attention deficit, memory deficit, you have to tailor things according to that. You are sometimes steered down particular routes” HPA.*

Two therapists described how they adapt their therapeutic input depending on the patient’s circumstances in terms of their environment, their stage of rehabilitation and their personal needs,

*“I think with it being in their own home as well, a lot of what we are doing is very... it’s all around their own environment, their own objects, the way they normally do things. It’s all very familiar to them and that can help them to understand what they to be able to do” HPF.*

*“I think sometimes peoples’ insight moves as well. But it is always to get on the toilet, that’s always people’s initial goal, to be able to do that on their own. Once they have achieved that then they can start looking at other things. But I think it is different in their home as well. Their goals will be different when we see them once they have been at home for a bit than when they are in hospital where they just want to get out of hospital” HP4.*

*“I think as well in an activity over a longer period, I wouldn’t say the next day but maybe a week or even maybe more than a week, you would be looking to withdraw your hands on and become more distal in your handling to the extent that you may not be handling them at all so if they were like trying to dress like put their shirt on, when they can see that they can put their shirt on themselves without you doing it, that might be the sign to them that they can put their shirt on. But as soon as you put your hands on proximally or distally it might be to*

*them that they are needing help to do that so they haven't achieved it. So as soon as you think that they can do that for themselves then you withdraw that, I wouldn't say support, but you withdraw the handling so you are more distant to them it is maybe the way they are intrinsically getting feedback that they can put their own shirt on as we all do every day" HP2.*

#### **4.4.1.6 Enabling Self-Management: The Influence of the Therapist**

Throughout the focus group discussions, both teams expressed the need to feel in control of what the patient did and what influences their rehabilitation. In particular, members of the teams described how it is important to avoid the patient making errors and then reinforcing those errors. When asked about how much they worry about error they replied,

*"I think that depends on the grade of staff" HP3.*

*"Quite a lot I would say... [All- yeah]" HP5.*

*"I'd say we very regularly don't want patients to do things unless one of us is there to begin with because we have people from quite early on so you know would you not agree? I think we [HP2 - I do agree] don't give a lot of prescriptive exercises for that very reason as a team. I think because and also we have got the staff to go in, not always you know, but it is only you know an hour out 24 isn't it?" HP5.*

*"Obviously when you are not there with them, if they are not doing it correctly they are not getting instant feedback. You have to wait until you either see it or the carer sees them doing it to explain that they are not doing it quite as well as you wanted" HPF.*

When asked how what strategies they use to reduce errors a PT explained,

*"I'll write things down like say if their toe is turning out during the exercises, I'll say that you don't do this so if they've got the picture or the instruction of how to do the exercise and they've also got a little prompt to remind them what they were doing wrong while I was there to make sure it doesn't happen again" HPE.*

However, whilst discussing whether patients and carers were able to follow instructions, one therapist exclaimed,

*"...they don't always do it in the way you have asked them to do it! [Group laughs]" HPF.*



The therapists also discussed how patients are unaware of making mistakes (errors) because of their lack of ability to understand movement patterns and also because of their impairment(s). In conversation they discussed,

*“I personally think that unless they had something actually pointing it out I don’t think that they would be necessarily that great. I think a lot of people can’t... a lot of people aren’t aware they are doing the movement patterns wrongly because of their stroke” HPE.*

*All CST south) – “Even people who haven’t had a stroke can’t!”*

*“We have people with however many hours training, I mean the first year of physio is about movement recognition and you are then expecting a patient to do that themselves so I think what a lot of them maybe doing is if something is also painful or feels unnatural to them because their proprioceptive sensation of where they actually are and what is normal to them is so skewed that they can’t work out what is normal because for them it may feel perfectly normal to them but to us we know it is completely out” HPE.*

*“I think that’s is why I find that in the time span that we have you need that constant feedback from the physical person like a physiotherapist or an OT to until they get it in their head, until they get that feeling that that is ok that that movement is ok but that takes a long time” HPC.*

*“Also just thinking more about what we do as therapists, we actually provide the patient with afferent input by putting our hands on the patient as well, which you can’t get from a computer or anything else.” HPG [HPC agrees >>yeah... that extra tactile information.”*

However, in contrast to this, one therapist from the CST south pointed out that she liked the notion of the using technology to negate the need for someone to point out their movements,

*“... it is about the actual patient empowerment side again isn’t it? We said we don’t want necessarily the carers to be sitting there nagging you are doing that wrong you are doing this wrong but it is getting them to feedback to themselves. I think that’s the thing and that’s why the Wii FIT will actually be potentially quite good from that point of view that they can have feedback that they can literally see then and there and they are having to do it themselves as such.*

*They're getting it directly to them rather than someone else having to point it out" HPE.*

## **4.5 Validation and Exploration of Existing and New CMOC's**

The aim of the focus groups was firstly; to establish how the pre-existing context impacts on the mechanisms (identified in chapter two) during the delivery of feedback community post-stroke rehabilitation and secondly; to validate existing theory and explore new theories by gaining the opinion of practitioners as to what influences their decision-making when prescribing various forms of instruction / feedback to their stroke patients.

### **4.5.1 The Theoretical Approach Underpinning the Provision of Feedback**

The therapists in these focus groups suggested that in most instances patients and their carers do not have the ability to carry out exercises correctly or be analytical of the movements without professional input. They suggested a number of reasons for this such as, patient impairments, lack of understanding of the required movements and for carers; to what extent they wanted to be involved in the rehabilitation process. They therefore described the necessity for therapists to facilitate movement patterns through tactile (hands-on) feedback and guidance.

This concurs with the neurodevelopment (neurophysiological) training (NDT) approach which focuses on the manual facilitation of normal movement and control. In clinical practice, therapists utilising a neurodevelopmental (Bobath) approach are concerned with patients practicing outside of face-to-face therapy and carrying out exercise without the therapist's handling because this may hinder correct movement patterns and may even encourage abnormal patterns which may in turn create maladaptive plasticity (Lennon 2004). Significantly, the therapist has overall control of the patient's rehabilitation (Plant 1998).

Four of the therapists in the focus groups, who were also the more senior and experienced therapists, were trained in the neurodevelopment (neurophysiological) training (NDT) approach. This is consistent with most therapists in the UK (Lennon and Ashburn 2000; Lennon *et al*, 2001; Lennon 2003); Sweden (Nilsson and Nordholm 1992); Australia (Carr *et al*, 1994) and the Netherlands (Hafsteinsdottir *et al*, 2005). However, this approach is in contrast to the theoretical approach incorporated with the

SMART system used in this research which includes the principles of a motor re-learning, task-oriented paradigm (described in 2.8 p. 55).

This has implications for this study: firstly, the participants in this study may have experienced a model of rehabilitation provided by the community stroke team therapists that involves a contrasting approach to the SMART system where they have received tactile (hands-on facilitation) feedback and the therapist has maintained the locus of control; and secondly, there are unanswered questions as to whether a stroke survivor would be able to identify and subsequently alter incorrect movement patterns in the absence of a therapist. Also, there are unanswered questions as to whether a stroke survivor (and their carer) would embrace a self-managed model of rehabilitation that is less reliant on the therapist.

#### **4.5.2 Feedback Provision**

The focus groups discussed what forms of instruction and feedback therapists provide and also what their reasons were. The overriding factor with both groups centred on what they thought would be effective in enabling the patient and carer to perform an exercise correctly and how the instruction would be effective given the individualism of the patient and their context. In other words, how they could provide a form of instruction that the patient would understand, be able to remember, ensure the exercise is carried out correctly and produce better performance. To provide instruction(s) they used a number of methods such as, written, diagrammatic and pictorial information in the form of an exercise sheet, a diagram or photographs. For feedback they described how they used verbal and visual feedback. Interestingly, they suggested that instant feedback was better (feedback theory). However, the literature suggests that although instant feedback produces better immediate results, there is little retention of the improved performance. In addition, the performer then relies on the feedback to maintain their improved performance (Van Vliet and Wulf 2006). Therefore, questions remain as to whom may benefit from receiving instant feedback based on their personal context. For example, those who have memory deficits may require instant feedback whereas those who are able to hold information for longer may not.

Other considerations for providing instruction and feedback involved the patients' impairments and what they felt the patient would respond to. For example, one of the therapists suggested that some patients may have cognitive impairments that may affect their ability to assimilate information. Practical and motivational factors were also

discussed such as language barriers and trying to encourage patients to adhere to exercise programmes also influenced what therapists gave (motivation theory). In particular, the therapists suggested that the provision of positive feedback and task success were important for maintaining motivation. They also suggested that goal-setting and the involvement of a carer were also determinants for motivation.

In accordance with these findings, Maclean *et al*, (2000) suggests that rehabilitation professionals commonly believe that motivation affects the outcome of therapy and that highly motivated patients are more likely to view rehabilitation as essential to recovery. This may explain why the therapists in these focus groups discussed how they felt the need to provide positive encouragement during treatment and as a form of feedback. In other words, if the therapists can 'get the patient on board', treatment is more likely to be successful. However, Wulf (2007) suggests that allowing the learner to control the timing, frequency and presentation of feedback can enhance learning. She also speculates that self-controlled feedback may influence motivation and independence (Wulf 2007a) which may question the balance of control in the treatment sessions (Talvitie and Reunanen 2002).

### **4.5.3 Collaboration**

Both of the focus groups discussed how collaboration with the patient and carers / family members and other members of the team throughout the rehabilitation process was imperative. The teams discussed how 'working with the patient' using goal-setting was key to establishing a partnership as well as focusing and motivating those involved in the rehabilitation process (goal-setting theory). Interestingly, they described how this was particularly pertinent during the early stages of recovery where patients may need more guidance as to what they would like to achieve.

However, they also suggested that in some instances using their '*What's Your Goal*' booklet was less appropriate. Their reasons for this were that: patients may pathologically be unable to understand the process; they may be unrealistic in their aspirations; and they may already be further along in their rehabilitation and already have clear goals set. They also thought that because of staff turnover, newer members of the team may be less familiar with using that particular goal-setting tool. In addition, a member of the CST north team suggested that the goal setting tool they used was more of a professional's aid.

This may suggest that therapists are aware of contractual, legislative and professional requirements such as, the health service, quality auditors and their professional bodies (Levack *et al*, 2006). In other words, the goal setting tool is used by them as a method of outcome measurement and evaluating service provision and that contextual factors may impact on how and when therapists use goals. In addition, therapists are also aware of the limitations of patients for using and setting goals which suggests that the therapist can lead the goal-setting process. This concurs with Playford *et al*, (2000; 2009) who describe how goal-setting is often difficult to implement as a result of differences between patient and therapists expectations.

Although goal-setting has been described as '*central to effective and efficient rehabilitation*' (Intercollegiate Stroke Working Party 2008 p. 37) and '*one of the skills that most specifically characterises professionals involved in rehabilitation*' (Wade 1998 p. 273), the data from these focus groups suggest that although the application of goal-setting in community-based stroke rehabilitation may be important for the patient and team; there are particular issues that may impact on its use.

#### **4.5.4 The Impact of Context on Mechanisms**

In harmony with the International classification of functioning, disability and health (ICF) framework (WHO 2001), the focus groups highlighted a number of factors that therapists take into consideration when delivering instruction and when providing feedback to the patient during the rehabilitation process. They described how the pathology, impairments, functional status, participatory needs and environmental factors are considered when giving instructions and feedback to patients.

##### **4.5.4.1 The use of Feedback is Dependent on Contextual Factors**

Therapists described how personal and environmental circumstances can influence what forms of instruction and feedback therapists give.

Environmentally, therapists described how the patients' environment can play a role in how they structure their intervention and how it can provide indirect feedback. For example, one of therapists described how she uses known kitchen equipment to implicitly reinforce movement patterns (implicit motor-learning theory) and how a less familiar environment can enable the patient to evaluate their ability by having to overcome everyday environmental obstacles. This suggests that specificity may be an essential consideration.

In addition to their personal environment; their social environment was also considered. In particular, how carers / close family members may be involved in the rehabilitation process. Noticeably, they paid particular attention to the relationship of the patient and carer as well as describing a degree of empathy to the carers' lifestyle and requirements. For example: whether the carer actually wanted to be involved; whether involving the carer may disrupt the relationship with the patient and importantly, whether the carer needed respite particularly if the patient was heavily dependent on the carer. To add to this, it was also apparent that the therapists were not confident that carers had the ability to ensure the patient carried out exercises correctly in the absence of the therapist. Nevertheless, the groups suggested that carers who are keen to be involved enhance the outcome of therapy and that carers can play an important role in encouraging their patients to carry out their rehabilitation in the absence of a therapist and may therefore motivate and reinforce behavioural patterns.

However, in addition to confirming existing propositions, new theory emerged from the discussions.

They described how they felt they needed to establish 'what type of person' their patient was in order to provide the most effective form of instruction and feedback. This highlights how therapists feel that the stroke survivor's personal factors are considered and in fact play a part in how they individualise and adapt their intervention. They described how they intuitively adapt the form of feedback and the method of delivery to what they feel the patient will respond to.

It is clear from the focus group data that therapists take a number of factors into consideration before applying their empirical knowledge and understanding to guide their decision-making process. These decisions subsequently form the basis as to which type of instruction and subsequent feedback they think maybe effective and appropriate for the patient. However, it is unclear as to how much are patients involved in the goal-setting process and how much the therapists' patients are involved in self-managing their condition.

Although the therapists liked the idea of testing the Nintendo Wii FIT because it will give concurrent, instant feedback for the patient without the therapist or carer having to provide any input; it was apparent that therapists paid careful attention to ensuring patients carried out errorless movement patterns and were concerned by other influences

that may hinder this. Furthermore, the therapists expressed their concerns for using technology for rehabilitation as they believed it would not be; functional, patients' cognitive and physical limitations would hinder use, and patients' would not receive any afferent (tactile) input. Interestingly, they also suggested that their own limitations in that they were unsure how to implement the technology into mainstream rehabilitation would create practical barriers for use. Therefore, there are also unanswered questions surrounding the clinical acceptability for using technology in post-stroke rehabilitation.

#### 4.6 CMOC Refinement

Pawson and Tilley (2004) suggest that the involvement of practitioners at this stage of the evaluation is vital as they *“will have suggested a particular resource is vital”* (p11) and that they will enable the researcher to validate and refine the embryonic hypotheses (table 4-4). The mechanisms identified in chapter two include the process in which key ingredients may be enabled or constrained within the individual context of the user. The key point that has emerged from these focus groups is that the provision of feedback must be adaptable and personalised towards the specific context of the recipient. In order for the mechanisms to work, the context must therefore include a system that is adaptable and can be personalised for the user. To provide an example of this refinement, the following table is an excerpt from the CMOC variable book in chapter two with the added refinement. However, this refinement of the CMOC hypotheses applies to all.

<b>CMOC's</b>	<b>Plausible mechanisms: 'what'</b>	<b>Contexts: 'for whom' and 'in what circumstances'</b>	<b>Possible outcomes</b>	<b>Measures</b>
CMOC 1	M1: Receiving feedback from the system might improve the user's confidence by confirming performance.	C1: A system that <b>can be adapted and personalised to the individual personal, environmental and social context of the stroke survivor and is accessible</b> (in the home setting) and used by the stroke survivor, independently of the therapist.	O1: Adoption and development of a self-management approach to rehabilitation (behaviour change). <ul style="list-style-type: none"> <li>- Independent rehabilitation, self-evaluation and self-monitoring of recovery.</li> </ul>	Observation of use and avatar replays. User diary. Usage of the system. Interview data.

CMOC 2	M2: By receiving feedback, users might feel confident to be able to interpret their performance and changing their movements to improve subsequent performance(s).	C2: A system that <b>can be adapted and personalised to the individual personal, environmental and social context of the stroke survivor and</b> can be used independently by the stroke survivor in the home.	O2: Development of self-management skills. - Problem-solving.	Observation of use and avatar replays.  Interview data.
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## 4.7 Conclusion

These focus groups have highlighted how therapists take a number of factors into consideration when providing instruction and feedback in practice. In accordance with the ICF model (WHO 2001); these focus groups and other exploratory studies suggest that therapists providing instruction and feedback for stroke rehabilitation in the community take into consideration the medical, social and contextual components of health. However, the focus groups also highlighted how therapists control the rehabilitation process; what they include and who they include. For example, the therapists appear to make clinical decisions based on their empirical knowledge and understanding, their evaluation of contextual factors and what they believe will be effective for that individual patient. Therefore, if feedback is to be delivered through a different medium (technology), which changes the physical context of delivery, and is unable to think and intuitively adapt to varying contextual conditions; how this impacts on the use of the feedback and the mechanisms underpinning feedback remains unanswered. This has implications for the adoption of a self-managed rehabilitation paradigm in this study whereby stroke survivors may have to; problem solve, make decisions, utilise resources, take action and collaborate with others whilst using the SMART system.

These focus groups also described how a number of theories identified as those underpinning the use of computer-based feedback are used in current practice. These include; motor-learning, feedback, motivation, and goal-setting theories. However, the focus groups also highlighted how they are able to adapt and personalise the way in which theories are used and the environmental context in which feedback is delivered.



## 4.8 Summary

This chapter has highlighted how currently, the rehabilitation experience is led by the therapist. The therapist establishes a model of delivery that is individual to the stroke survivor within their personal and social environment. Therefore, how the stroke survivor ‘learns’ to rehabilitate is constructed by the empirical knowledge and understanding of the therapist. This learning experience may indeed impact on further rehabilitation experience(s) or models of care delivery; such as, autonomous rehabilitation using computer-based technology. Therefore, if patients have only experienced therapist led instruction and feedback; what is the patient’s experience of utilising feedback when it is delivered from a computer in the absence of the therapist? Furthermore, how does the contextual factors that therapists are able to consider impact on the theories underpinning the utilisation of computer-based feedback?

These findings have therefore contributed to the validation and refinement of the CMOC hypotheses described in chapter two.

The following chapter will describe the initial testing of the use of one form of computer to facilitate upper-limb post-stroke rehabilitation unsupervised in their home.

## **5. Chapter 5: Validating Existing CMOC's and Exploring New CMOC's Through the SMART Rehabilitation Technology System**

### **5.1 Introduction**

Chapter two set out the embryonic CMOC's and chapter four explored these existing propositions and elicited new, emerging theory. Therefore, prior to subjecting the CMOC's to a systematic test, it was imperative that initial testing was carried out to validate existing CMOC's and explore new CMOC's through the specific intervention as well as test the instruments and practical implications for further testing.

Baker (1994) describes how such testing can pre-test or 'try out' particular research instruments (Baker 1994 p182-3). Furthermore, one of the advantages of conducting a pilot study is that it might give advance warning about where problems may arise and where instruments may fail to answer the research question(s). In the words of De Vaus (1993 p54), "*Do not take the risk pilot test first.*" Also, Carpenter and Suto (2008) describe how the pilot study can provide invaluable experience of collecting data, practicing interview techniques and analysing data.

Therefore, this chapter describes the initial deployment of the SMART Rehabilitation Technology System for home-based upper-limb post-stroke rehabilitation.

### **5.2 Previous Research with the SMART Rehabilitation Technology System**

Previous research carried out by Mountain *et al*, (2006; 2010) (see 2.3 p. 43) highlighted some of the external issues that may impact upon further exploration of the concept of using computer technology in the home of the stroke survivor. For example, the practicality of storing equipment and wearing garments proved to be troublesome for some users. However, although these issues can be problematic for further exploration, this PhD programme aims to explore how the context of utilising extrinsic feedback from computer-based technology for upper-limb post-stroke rehabilitation in the home, impacts on the underpinning theory-driven mechanisms.

Before further exploration of the feedback could be investigated, a number of issues needed to be considered prior to subjecting the CMOC's to a systematic test. In

addition, the instruments for the systematic testing had to be tested to evaluate how they might draw appropriate data to answer the research question(s).

Following institutional ethical approval from Sheffield Hallam University (see appendix 14 p. 327), a pilot study was carried out using two participants (not National Health Service patients) and two carers who had previous experience of using computer technology in the home following their involvement in previous research with Mountain *et al*, (2010).

### **5.3 Aim**

To validate existing CMOC's and explore new CMOC's through the specific intervention and test the instruments that are to be used with future participants.

### **5.4 Methodology**

The methodology used throughout this thesis is based on the principles of RE (described on p.16). This multi-method collective case-study approach determines how the same mechanisms play out in different contexts, producing different outcomes (described in chapter 3) through multiple qualitative and quantitative observations (Stake 1995; Yin 2003; Pawson and Tilley 1997).

#### **5.4.1 Sampling**

In order to seek out the individuals, groups and settings that the processes being studied are most likely to occur and demonstrate salient features, categories and behaviour that are relevant to the research question (Denzin and Lincoln 1998; Pope and Mays 2006); the initial testing involved purposive sampling to identify participants who would enable the researcher to explore and validate the embryonic CMOC's.

#### **5.4.2 Recruitment**

Two participants and carers were contacted by an experienced Physiotherapist from a private practice who was also involved in the previous research carried out for SMART 1 (Mountain *et al*, 2010). The same participants and carers were used for both the first and the second round of interviews. The researcher believed the same subjects who gave their opinion on current provision should be used to provide their perspectives on the new concept/provision.

### 5.4.3 Inclusion Exclusion Criteria

- *Inclusion:*
  - A definitive diagnosis of stroke.
  - Participants who had previous experience of using the SMART rehabilitation system in their home.
  - Able to give informed consent to the participation in the study and for the researcher to receive clearance from their G.P.
  
- *Exclusion:*
  - Unable to speak or comprehend written English.
  - Severe communication, perceptual or cognitive disorders.
  - Visual impairment.
  - Apraxic.
  - Shoulder subluxation or arm pain.
  - Medically unstable and other neurological, neuromuscular, or orthopaedic disorders that would interfere with task performance.
  - Have not been referred for further rehabilitation and/or receiving further rehabilitation.
  - Do not have a co-resident carer.
  - Unable to give informed consent to the participation in the study and for the researcher to receive clearance from their G.P.
  
- **Carer** - The person who is likely to be with the participant the most during their use of the equipment and/or has been with the participant during their previous experience of using computer-based technology for rehabilitation in the home.

The participants' private physiotherapist evaluated their suitability to use the equipment according to the inclusion / exclusion criteria. She introduced the study and gained consent for their details to be passed to the researcher. Verbal consent was gained by the participants' physiotherapist to pass on their contact details to the researcher. The researcher firstly contacted the potential participants by telephone. During this conversation, the study was introduced to the person and their carer and they were invited to raise any concerns or questions. Following this, they were provided with letters of invitation by post. This enabled the participants and carers to consider their

involvement prior to a further telephone call a week after the information sheets and letters of invite was posted to ask if they had considered their involvement, answer any questions they had and arrange to visit them. During this visit the researcher explained the purpose of their involvement and what they would be required to do face-to-face. Informed consent form was signed by both the participant and their carer separately before testing commenced.

The following figure (5-1) illustrates the recruitment of the participants and carers for initial testing.

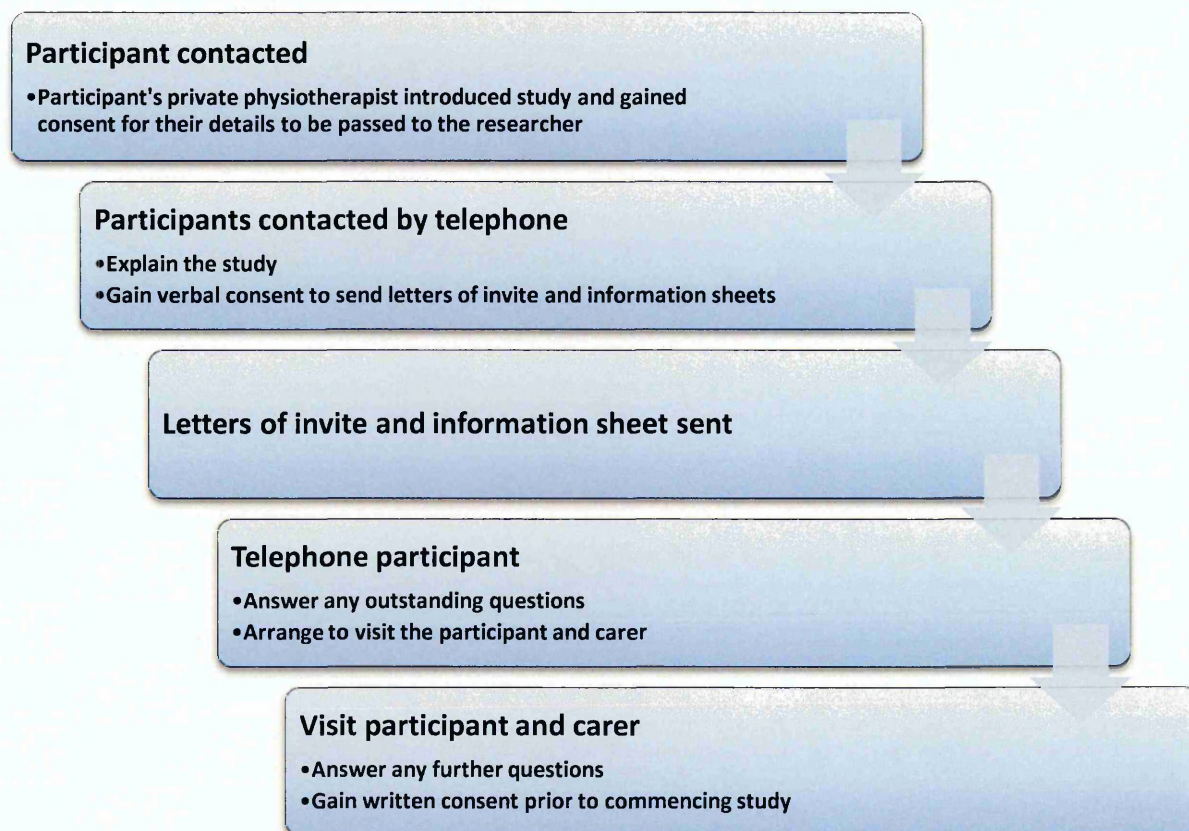


Fig 5-1: The recruitment of participants and their carers for initial testing.

Due to the qualitative nature of the research and requiring the individual participant to consent to interviews and constraints with regards to budget and subsequent payments to interpreters and translations services, persons who would not fully understand verbal or written English were not considered for this research. However, this did not exclude participants of ethnic origin or diverse culture.

## **5.5 Context**

### **5.5.1 Participants**

Participant 1: Mr Black was a 70 year old male chronic stroke survivor (24 months). He was a retired insurance broker who was familiar with using computers. Mr Black suffered a right cerebrovascular accident (CVA) resulting in left hemiparesis. However, at the time of study he had recovered sufficiently to be independently mobile with the use of a walking stick. His left upper limb had approximately 80° of shoulder flexion; 45° of abduction and full active elbow flex. His carer and wife (Mrs Black) was a 69 year old female who was a retired company director.

Participant 2: Mr White was a 75 year old male chronic stroke survivor (60 months). He was a retired economist who was also familiar with using computers. Mr White suffered a right CVA resulting in left hemiparesis. He had also recovered to be independently mobile with the use of a walking stick and had approximately 120° of shoulder flexion; 90° of abduction and full active elbow flexion of the left upper limb. His carer and wife (Mrs White) was a 75 year old female who was a retired teacher.

NB: The names of the participants have been changed for anonymity.

### **5.5.2 Research Setting**

Following consent, all contact with participants and their carers was in the participants' home. This allowed for the participants to be interviewed and use the computer system in their specific environmental context as well as meet the aims of the study; home-based rehabilitation using technology.

## **5.6 Methods**

In order to explore the interaction between the context and the mechanisms, the researcher gained the opinions and perspectives of the participants and their carers through semi-structured interviews in separate rooms in their home. The initial interview aimed to investigate the pre-existing context by exploring the current provision of feedback that had previously been provided with during community-based rehabilitation. In particular, what information they had been left with to facilitate rehabilitation in their home outside scheduled therapy sessions. The researcher then provided a SMART Rehabilitation Technology System (described in 2.4 p. 48) for each participant to use for up to one week in their own homes. Each person was given two

prescribed exercises to perform: Reaching forward and reaching sideways. During and following prescribed activity; feedback is provided via real-time 3-D images (fig 2-8 – 2-10); a qualitative chart (fig 2-11) and a graph (fig 2-12) were displayed on a lap-top computer screen (pp. 49-51).

At the end of the testing period (3 days Mr Black and 5 days Mr White) the researcher conducted semi-structured interviews with the participants and carers to allow them to express their views of the system and specifically of the decision support interface and feedback it provided.

## **5.7 Recording**

Semi-structured interviews were audio-taped to ensure the transcriptions were presented verbatim. In addition, observations and field notes were taken to account for informal discussion and physical behaviour.

## **5.8 Data Analysis**

The interviews and observations were used as the sources of data as neither of the participants chose to use the on-screen diary or take notes. Both of the participants explained that this was because they only had the equipment for three days (Mr Black) and five days (Mr White) and thought it was unnecessary. In addition, neither of the participants had any documentation such as exercise sheets or information booklets to examine. The method and process of data analysis is described in chapter three (pp. 99-100).

## **5.9 Exploring the Embryonic CMOC's**

### **5.9.1 Themes**

The aim of the first interview was to investigate the pre-existing context by exploring the current provision of feedback and how this was utilised.

#### **5.9.1.1 Pre-Existing Context: Provision of Information**

Both of the participants and carers explained that they did not have any documentation or information sheets as it had been so long since they had National Health Service professional involvement,

*“We did at first; they gave us some exercise sheets for him to use but that was a long time ago” Mrs. White.*

When asked what she thought of the exercise sheets they were initially given, Mrs White explained that her and her husband's personal context impacted on their ability to utilise the exercise sheets they had been given to carry out rehabilitation in the absence of the therapist,

*"They put about ten exercises on it but it was hard to remember how they wanted them doing. We just did what we could remember I suppose" Mrs. White.*

The participants and carers described how they relied heavily on observing the therapists to understand what exercises to do, how to do them and whether they are doing them correctly. When asked how they remembered how to do the exercises Mrs White went on to describe how they observed what the therapists did whilst they were carrying out their treatment,

*"...they let me sit in and watch what they were doing so that after they had gone I knew some of the things that I could help him" Mrs. White.*

However, when asked what would help her remember what exercises to do and how to do them; one carer suggested,

*"I suppose if one had had a video of the exercises that he had done with the physio then you could watch them and really watch how they worked that would have helped. Also written instruction sheets I mean I remembered the hand movements having an instruction sheet for that I mean there must have been a dozen exercises you know you could easily have missed one or two out" Mrs. White.*

This suggests that both the personal limitations of the stroke survivors and their carers as well as the limitations of current service provision may hinder their ability to carry out rehabilitation in the absence of external professional help. This may therefore be a barrier to self-managed rehabilitation.

#### **5.9.1.2 Reliance on External Help**

In contrast to elements of self-managed rehabilitation, all of the participants and their carers expressed the need to rely on external professional help for confirmation of progress (stroke survivors) and help (carers). Participants described how they found it difficult to notice recovery as progress was slow. When asked how they knew if they were improving or not, Mr White replied,

*"That is difficult because improvement after a stroke is not by leaps and bounds and it's not full of course so when you are doing something daily it's very*



*difficult to know that you are improving. I say you suddenly think arh... I couldn't do that two or three months ago" Mrs. White.*

Carers also expressed the need for external professional help to continue for longer as well as providing help themselves for assistance with exercises and safety,

*"Well I think the team that came around were very effective and if that could have gone on longer it would have been good. They seemed to just stop suddenly from virtually five days a week to one day a week" Mrs. White.*

### **5.9.1.3 Recovery**

Recovery was described by the participants and carers in two distinct ways:

#### **Motivation for Recovery**

Their motivation to continue the recovery process was expressed differently between the two participants; Mr Black described how his need to get better was affected by his social context,

*"I'm here a lot on my own because I have carers that come in at lunch time but they look after me alright. If I hadn't I'd have to use that trolley in the kitchen to get about but I could do but I suppose I'm waited on hand and foot really. But I quite like the company you see" Mr. Black.*

*"On a Tuesday it's my day off to play golf so the carer comes for his lunch but there's no reason he can't do it himself" Mrs. Black.*

Whereas Mr White described his motivation in terms of his personal expectations and potential for further recovery,

*"So I see J [his physiotherapist] now essentially to keep me flexible and to try to ensure that I don't deteriorate any further. But I don't have expectations above that... now it's a desire to not just sit and let things happen but resist any deterioration as much as I can" Mr. White.*

This suggests that the motivation for recovery may be affected by both the social context of the stroke survivor and the chronicity of the stroke.

#### **Measuring Recovery**

Participants and their carers measured recovery differently. Participants described how they were able to see recovery through what functional and social activities they could carry out,

*“I suddenly realised that when I was getting up I could stand up unaided... that was a distinct improvement, putting one leg under the other and being able to stand up” Mr. White.*

One carer described how she measured recovery by how much activity the person they care for could do over a day/week. When asked how she knew whether Mr White was improving she replied,

*“...when he started to move more easily and maybe when he could do those step ups, he didn't get tired quite as quickly they were the main things. He was able to get his own drinks and if I was out he could get his lunch and things” Mrs. White.*

#### **5.9.1.4 Confidence to Carry out Independent Rehabilitation**

Both participants were quick to describe without any prompting how their previous experience during recovery impacted on their confidence to carry out independent activities. Mr Black explained that falling out of his scooter had reduced his confidence;

*“A month ago I went over on my scooter ...I just laid there with people walking past me ...it knocked my confidence.” (Mr. Black)*

Mr White described how his accident affected his recovery,

*“A significant event took place a year last march in the kitchen when I had a very nasty fall. I fell on my spine, fell backwards and as a result of that they diagnosed that I'd got 3 vertebrae broken... that put me back a long way and I've not really recovered to the state of recovery that I had before that” Mr. White.*

This may suggest that previous life experiences may also impact on a stroke survivor's confidence to carry out rehabilitation in the absence of others (i.e. therapist / carer).

#### **5.9.1.5 The Impact on Relationships**

Throughout the first interviews carers described the conflict between being a wife for their husband as well as being a carer for a stroke survivor. This was apparent in their reluctance to critique the exercises being carried out and motivate. One carer also described her impatience and how she would relish something or someone to motivate her husband every day,

*“The exercise obviously does him some good but is he really as good as he should be? But there again if it was done every day, you would see a lot of difference wouldn't you? Its continuity really isn't it?”Mrs. Black.*

In anticipation of using the computer to exercise Mrs Black suggests,

*“But I do think that having set exercises might help. But that machine would probably make him go and do it and if it was recorded you’d be able to say well you’ve been useless that week.” Mrs. Black.*

The aim of the second interview was to explore the interaction between the context and the mechanisms by gathering the opinion of using the feedback from the computer technology within their environmental personal and social context.

The CMOC’s set out in chapter two proposed that ‘feedback’ provided by the SMART system may lead to the adoption and development of self-management and behavior change as well as increased motivation and improvements in motor and functional behaviour. However, this PhD programme aims to refine the CMOC’s and explore what form(s) and method(s) of feedback delivered by the SMART system works for whom in what circumstances and respects.

#### **5.9.1.6 Preferred Feedback from the SMART System**

Mr. Black explained how he preferred the chart display as opposed to the replay of the manikin. His reason for this appeared to be two-fold; firstly, by seeing the graphs he could see whether he had achieved the goal the therapist had set him and he could track his changes over a number of attempts. Secondly; when asked if he could recognize the differences between himself and the reference figure he did not like to be reminded of his body image,

*“Oh yes! [laughs loudly] A picture of a shabby figure... I knew which was the bad one” Mr. Black.*

He also suggested that because the graphs illustrated when he had done well, he found the reward motivating,

*“...when you get a green it gives you an uplift doesn’t it [laughs]” Mr. Black.*

However, Mr White explained that he didn’t like the graphs as they did not mean anything to him. This was mainly because they did not have any values for the x and y axis which therefore made it hard for him to quantify his changes.

Mr Black also described his preference for knowledge of results, summary feedback, concurrent feedback and feedback on errors as well as correct performance. However, when asked if he would prefer the computer to tell him how to improve his movements (prescriptive feedback) he abruptly suggested he would rather work it out himself.

### **5.9.1.7 Motor Learning**

Both participants were able to detect their own movements and change their movements as a result of the feedback they received. After watching the replay of the avatar Mr Black was able to analyse his posture and arm movement,

*“Well it’s me posture isn’t it a lot of it wasn’t it... It showed that I wasn’t getting the proper stretch that I ought to be getting” Mr. Black.*

Mr White also commented on his movement,

*“I appear to be leaning that way and my arm isn’t as high as that one” Mr. White.*

Mr White was able to use the avatar to increase his shoulder flexion and keep his trunk stable which he then confirmed by the results graphs whereas Mr Black only used the graphical feedback to analyse his movements and then made the movement changes on his second attempt. Both participants were keen to have a second attempt to improve on their first attempt.

Both carers also expressed an interest in the feedback. Speaking to her husband Mrs White commented,

*“Oh you can see the difference can’t you... that’s better you’re getting higher now” Mrs. White.*

## **5.10 Results of Testing**

### **5.10.1 Practical Considerations**

A number of practical issues were apparent during the initial deployment, some of which have also been documented previously (see 2.3 p. 43).

#### **5.10.1.1 Using the Equipment**

Mr. Black and his carer were unable to start up the computer program in the absence of the researcher or when given instruction over the telephone. In addition, they were unable to refer to the ‘user manual’ as a guide. However, the researcher was able to start up the program and the equipment did not appear to be faulty. Nevertheless, both of the participants felt that the on-screen instructions were easy to follow and with adequate practice, support and instruction they felt they would be able to start up the program independently.

**Garments:** Neither of the participants could don the garments independently and therefore relied on the researcher and/or carer to assist.

- Wrist sensor: The participants were unable to place it over their affected hand and wrist without fully undoing the strap.
- Upper arm sensor: They were unable to pull the sleeve high enough up the arm whilst ensuring the sensor remained in the correct position. Mr Black suggested that the sleeve was too tight for his arm.
- Chest sensor: They were unable to place the garment over their head and then tighten up the side Velcro adequately. This can then result in inaccurate on-screen representation due to the excessive movement of the chest sensor.

This suggests that if adequate training is not provided prior to the use of the SMART system, this in itself may impact on the potential for the underpinning mechanisms to work. For example, if they are unable to access the computer programme they will not both carry out the exercises and receive subsequent feedback which may impact on their motivation to continue rehabilitating. In addition, if the garments cannot be fitted independently and therefore requires another person to be present, this will impact on the level of independence for carrying out rehabilitation.

**Handling the equipment:** Both of the participants were able to stow the garments and correctly charge the sensors after use. However, both wanted to keep the equipment set up for use as they were only using it for three days (Mr Black) and five days (Mr White). However, careful consideration of health and safety issues by the researcher and awareness from the participants and carers was required due to computer leads and the sensor charger becoming a trip hazard.

#### **5.10.1.2 Procedures**

The researcher confirmed that the information sheets had been read and offered for any questions or concerns before the consent forms were initialed and signed. None of the participants and carers had any questions or concerns and they were able to read the information sheets, initial and sign the consent forms.

For participant 1 (Mr Black) the equipment was set up for use prior to the interview; this may have distracted the participant and carer as they made a number of references to its use during the interview itself. Therefore, for participant 2 (Mr White) the

equipment was set up after the interviews and this provided more focused data on their 'current' status.

### **5.11 Validation and Exploration of Existing and New CMOC's**

The results of this initial testing have confirmed how the utilisation of feedback, and indeed the mechanisms underpinning, may be affected by the personal, environmental and social context of the users such as: personal and pre-existing service delivery limitations; motivation for recovery; confidence to carry out independent rehabilitation; and the type of feedback they prefer as well as external factors such as, the practical issues inherent in using technological equipment in the home, the usability of the equipment and their social circumstances. However, both the stroke survivors and their carers were able to detect their own movements and change their movements as a result of the feedback they received by the SMART system.

This initial testing confirmed the need to explore the interaction between others involved in the rehabilitation process. The impact of stroke on the caregiver is profound (described in 1.4 p. 24) and in particular, their relationship with the stroke survivor can become strained (Bäckström *et al*, 2010). Indeed, studies suggest that the quality of the marital relationship decreases (Visser-Meily *et al*, 2005; 2006; Blonder *et al*, 2007) and there is often conflict between the spouse's role as a caregiver, a client, and a family member (Visser-Meily *et al*, 2006). The carers in this initial testing described the conflict between roles and the difficulties of assisting the stroke survivor during rehabilitation, such as, their own personal limitations (i.e. remembering what to do and how to do it), and providing critical feedback.

However, the provision of feedback through the medium of a computer enabled the carer to evaluate the rehabilitation tasks completed and how well the person they care for has performed. Therefore, the utilisation of computer feedback may provide a solution and indeed bridge the gap between their role as a spouse/carer and their role in the rehabilitation of the stroke survivor. For example, they may not feel critical towards the stroke survivor as the feedback is not coming from them directly. In other words, 'it's not me saying you have/have not done very well, the computer is.'

Furthermore, other factors also need to be considered, such as, the carer may not like having technological equipment in their living space and they may not be receptive to

the concept of using technology in what has traditionally been a therapist led 'hands-on' experience.

Initial findings have confirmed the value of individually adapted feedback as expressed by the focus groups in chapter four. Both of the participants in this study were similar in that they: both suffered a right sided CVA; were a similar age (70/75); had a moderate level of range of movement in the left arm; were independently mobile with the use of a walking stick; had a professional background and had previous experience using a computer. In addition, their carers were also a similar age (69/75) from a professional background and also had experience using a computer. However, despite these similarities, they expressed differing preferences for the type of on screen feedback and motivation for recovery.

Mr Black explained how his desire to carry out certain functional activities is reduced by the social support he receives. Therefore, if a stroke survivor believes that they may have reduced social interaction as a result of carrying out rehabilitation independently; does this become a barrier to the acceptance of a self-managed rehabilitation paradigm?

Mr White suggested that because a number of years had passed since he suffered his stroke, his personal expectations (goals) may have shifted from expecting improvements to maintaining his current performance. This concurs with studies which suggest that as the recovery progresses into the chronic stage, stroke survivors are more likely to have accepted their state of functional recovery and become focused on getting on with life (Ch'ng *et al*, 2008; Eilertsen *et al*, 2010). Therefore, the timing of rehabilitation may be crucial in that stroke survivors who have suffered their stroke more recently may still have the desire and motivation to carry out rehabilitation in order to continue recovering.

Therefore, further exploration of how these contextual factors may impact on how the context impacts on the theories underpinning the delivery of feedback via a computer, is required. This involves refining existing CMOC's (see 5.12.1 p. 150) and subjecting these refined CMOC's to a systematic test (chapter 6).

Significantly, these two users also revealed how both participants demonstrated the potential for physical behavior change even after minimal use and after a significant length of time post stroke. Further exploration may elicit how these preferences and motor learning opportunities are utilised by the stroke survivor to promote recovery and

potential behavior change both physically and socially. However, with the growing interest in gaming technology such as the Nintendo® Wii™; future users may be more receptive to computer interaction; although, they may also have higher expectations in terms of the interface and motivational components of rehabilitative devices.

## 5.12 Implications for Further Testing

Initial testing allowed the researcher to; evaluate the methods to be used; the processes involved; the practicalities of carrying out this research with a number of longer term participants; refine existing CMOC's and generate a new CMOC.

### 5.12.1 CMOC Refinement and Generation

This initial testing has allowed for the refinement of CMOC's 1 and 5 (table 5-1). These refinements now specify that firstly, a stroke survivor may adopt a self-managed approach to rehabilitation if they do not believe that they may become more socially isolated as a result of carrying out rehabilitation independently (CMOC 1); and secondly, their motivation to set goals towards recovery is subject to the stroke survivor having a continued desire to recover (CMOC 5).

**Table 5-1: Further CMOC Refinement**

CMOC 1	<p><b>M1: Receiving feedback from the system might improve the user's confidence by confirming performance.</b></p>	<p><b>C1: A system that can be adapted and personalised to the individual personal, environmental and social context of the stroke survivor and is accessible (in the home setting) and used by the stroke survivor <b>who does not believe they will become more socially isolated as a result of carrying out rehabilitation and subsequent ADL's, independently of the therapist.</b></b></p>	<p><b>O1: Adoption and development of a self-management approach to rehabilitation (behaviour change).</b></p> <ul style="list-style-type: none"> <li>- Independent rehabilitation, self-evaluation and self-monitoring of recovery.</li> </ul>	<p><b>Observation of use and avatar replays.</b></p> <p><b>Usage of the system.</b></p> <p><b>Interview data.</b></p> <p><b>User diary.</b></p>
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CMOC 5	M5: By receiving feedback, users might be motivated to set specific, measurable, realistic, and time specified goals (targets) to achieve that are confirmed by the computer feedback.	C5: A system that can be adapted and personalised to the individual personal, environmental and social context of the stroke survivor and allows stroke survivors who continue to have a desire to continue the recovery process to set goals in relation to the feedback provided.	O5: Increased motivation and self-management. - Goal-setting.	Observation of use and avatar replays.  Usage and number of repetitions.  Interview data.  User diary.
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The interview data also suggested that the carer was able to engage in the rehabilitation process because they did not feel that they were being critical of the person they care for. This has therefore, allowed for a new hypothesis to be tested (set out below). CMOC four hypothesises that using the system might enable the stroke survivor to collaborate with significant others (such as carers and close family members). However, this may indeed work as a ‘push and pull’ where the provision of feedback through computer technology may enable significant others to choose to be involved in the rehabilitation process. This may therefore, reinforce the attempts of the stroke survivor to involve and collaborate with others.

- Providing feedback through technology will enable significant others to take a more active role in the rehabilitation process and reinforce behaviour.

This has added a further CMOC that can be tested (table 5-2 below).

<b>Table 5-2: A New CMOC</b>				
CMOC 12	<b>M12: Providing feedback through technology may enable significant others to take a more active role in the rehabilitation process and reinforce behaviour.</b>	<b>C12: A system that can be adapted and personalised to the individual personal, environmental and social context of the stroke survivor and allows stroke survivors to utilise the feedback in the presence of significant others.</b>	<b>O12: Significant others are involved in their rehabilitation through choice.</b>	<b>Observation of use  Interview data</b>

## **5.13 Summary**

This chapter has confirmed how the utilisation of feedback may be affected by internal influences (personal context) as well as external factors (environmental context). In addition, this initial testing also confirmed the need to explore how the interaction between others involved in the rehabilitation process; namely, the carer/close family member and the therapist may also influence the utilisation of feedback. This has led to the refinement of existing CMOC's and the generation of a new CMOC.

The evidence clearly points to the need for further exploration to interrogate the CMOC's hypothesised in chapter two as well as the refined and newly generated CMOC's. In addition, further exploration of how contextual factors may impact on the utilisation of feedback and in particular, the theories underpinning the delivery of feedback via a computer. This will allow for the refinement of what contexts are / are not conducive for activating the ingredients highlighted in chapter two.

The following chapter of this thesis will subject the CMOC's to systematic testing by exploring the use of one form of computer to facilitate upper-limb post-stroke rehabilitation over an extended period of time unsupervised in their home with a number of users and their carers.

## **6. Chapter 6: Systematic Testing of the CMOC's**

### **6.1 Introduction**

Chapters four and five have highlighted how therapists seek to implement a model of delivery that is individual to the stroke survivor within their personal and social environment and how the utilisation of feedback provided through computer technology in the home may be affected by contextual factors (chapter five).

Exploring the perspectives of key stakeholders has enabled the validation and refinement of existing CMOC's and the generation of a new CMOC. Pawson and Tilley (2004) suggest that the next stage of the evaluation is to, '*subject the whole package of CMOC hypotheses to systematic test*' (Pawson and Tilley 2004 p.11).

Therefore, further exploration is required to subject the new and refined CMOC's to a systematic test by exploring the shift from receiving face-to-face feedback to receiving feedback provided by computer technology over a longer period of time in the absence of a therapist.

This chapter therefore describes the systematic testing of the CMOC's with five participants and their carers using the SMART Rehabilitation Technology System for up to five weeks in their own homes. This chapter presents the methods and findings case by case. A synthesis of these findings will be presented in chapter seven.

### **6.2 Aim**

To subject the new and refined CMOC's to a systematic test over an extended period of time.

### **6.3 Methodology**

As previously described in chapter five, the methodology used within the systematic testing of the CMOC's is based on the principles of RE. This multi-method collective case-study approach determines how the same mechanisms play out in different contexts, producing different outcomes (described in chapter 3) through multiple qualitative and quantitative observations (Stake 1995; Yin 2003; Pawson and Tilley 1997).

### **6.3.1 Sampling**

As with the initial testing (chapter five), purposive sampling was used to identify participants who had recently been discharged from a period of multidisciplinary community stroke rehabilitation and also met the inclusion / exclusion criteria. This would enable the researcher to explore the shift from receiving face-to-face feedback to receiving feedback provided by computer technology as well as systematically testing the CMOC's over a longer period of time.

The researcher was assisted in the identification of potential participants by the members of the Community Stroke Teams (described in chapter four).

### **6.3.2 Recruitment and Consent**

Participants and carers were sourced from local Community Stroke Teams (CSTs) following the cessation of the participant's rehabilitation period (up to 12 weeks). At the point of patients being discharged from the CST, the individual therapists from the CSTs provided the people they had been treating and their carers with letters of invitation to the study and information sheets (see appendices 15-18 pp. 329-335). The therapist (CST member) introduced the study to a patient who they had identified as being a suitable potential study participant (using the suitability criteria provided by the researcher, see appendix 19 p. 339); explained the screening process and what it involved; asked for verbal consent for the participant and carer's details to be sent to the researcher, and for the researcher to arrange a visit and screen for suitability.

The details accessed by the therapist and subsequently sent to the researcher included: the participant and carer's name and address; an inclusion / exclusion criteria checklist; age and gender; the site of the lesion; and the active range of movement and functional status at the point of discharge (see appendix 19 p. 339). The therapist then telephoned the researcher to inform him of the participants and their carers who were interested in taking part in the study.

Following this, the researcher telephoned the participant and carer to gain an agreed time and date for the researcher to visit them in their home. This telephone call also enabled the researcher to explain the purpose of the visit and answer any questions or concerns they may have had at this stage. The researcher again explained what was involved in the screening process both during the telephone conversation and face-to-

face on the home visit. This involved using recognised and validated screening tools (described in detail on pages 161 and 162).

If verbal consent to participation was provided, the participant and their carer were both asked to sign a written consent form. Following permission being obtained from the participant, the participant's G.P. was informed by letter to ensure the participants medically suitability and safety. Within the letter a request was made to let the researcher know if there were any problems with the volunteer's involvement. The letter also stipulated that if the researcher had not heard from the participant's G.P. within two weeks, the participant's G.P. could foresee no problems with their patient's involvement in the study (appendix 20 p. 341). Figure 6-1 (p. 157) illustrates the recruitment process.

For ethical and practical reasons as well as gaining access to the participants and their carers, the researcher required the CSTs to be involved in the recruitment process. This resulted in the CST therapists becoming the gatekeepers and 'choosing' which of their patients may be suitable to participate in the study. In order to try and manage this, the researcher provided a participant suitability profile (see appendix 19 p. 339) which included the inclusion/exclusion criterion that the therapists were asked to use to establish who may be suitable. This involved a series of yes/no questions that would enable the therapist to understand who may be suitable to refer to the researcher for subsequent screening and further assessment for suitability.

However, despite this guidance, over the study period the recruitment of participants became increasingly problematic. During telephone conversations with the CST therapists, they would suggest a number of reasons for slow recruitment. These included:

- Poor cognitive status – *'All of our patients are really cognitively poor at the moment' HPC.*
- Socioeconomic background – *'I can't give you him! His lives [in a less affluent area] it (SMART system) will get stolen!' HP4.*
- Poor physical and functional ability – *'They're all really limited at the moment. We seem to have a lot of bad ones right now' HPF.*

Also, two therapists (one from each team) suggested that they did not have any suitable participants because they did not believe that their patients would like to use the system (without asking the potential participant or carer). This demonstrates how their

preconceptions of using the SMART system may have affected the opportunity for their patients they were treating to participate in the study. The implications of this imply that in the future, if stroke survivors are to use technology within mainstream rehabilitation; therapists need to be provided with education to enable their full involvement.

However, this may not differ from current practice whereby therapists choose which tools to use to facilitate rehabilitation (Marshall 2004). If a technology system is to be viewed as a 'tool' similar to an exercise ball or putty, therapists already base their judgement(s) of what is suitable for an individual on their empirical knowledge and understanding. For example, a therapist may choose to use putty to enable their patient to perform hand exercises because through clinical reasoning, they believe the tool and the prescribed method of using the tool will benefit their patient. Therefore, if therapists are to use technology for rehabilitation, they will need to have a thorough understanding of technology, what it can do, how it may benefit the patient, and a good understanding of who may be suitable to use it.

Sixsmith *et al*, (2003) suggest that having gatekeepers in community-based research can add credibility and validity to the research project. In this study, the therapists were provided with the details to enable them to explain the purpose of the study, the benefits and drawbacks, and why they believe their patient may be suitable to participate. This may have been reassuring for their patient(s) because the patient may view the therapist as an expert and the most appropriate person to decide on their therapy. However, research also suggests that using the treating therapist as an active gatekeeper can be problematic and may even be a limiting factor as in this case (Gurwitz *et al*, 2001).

Interestingly, one of the stroke teams in this study had purchased three Nintendo® Wii™ consoles to use with their patients. However, these consoles remained in their boxes untouched for six months. When asked why they had not used them, a senior Physiotherapist replied,

*“We haven't got time to figure the best way of using them at the moment we're just too busy. We are hoping to come up with some guidelines as to how to use them effectively” HPE.*

This may suggest that although their intention was to use the consoles, they did not have the knowledge of how to utilise them.

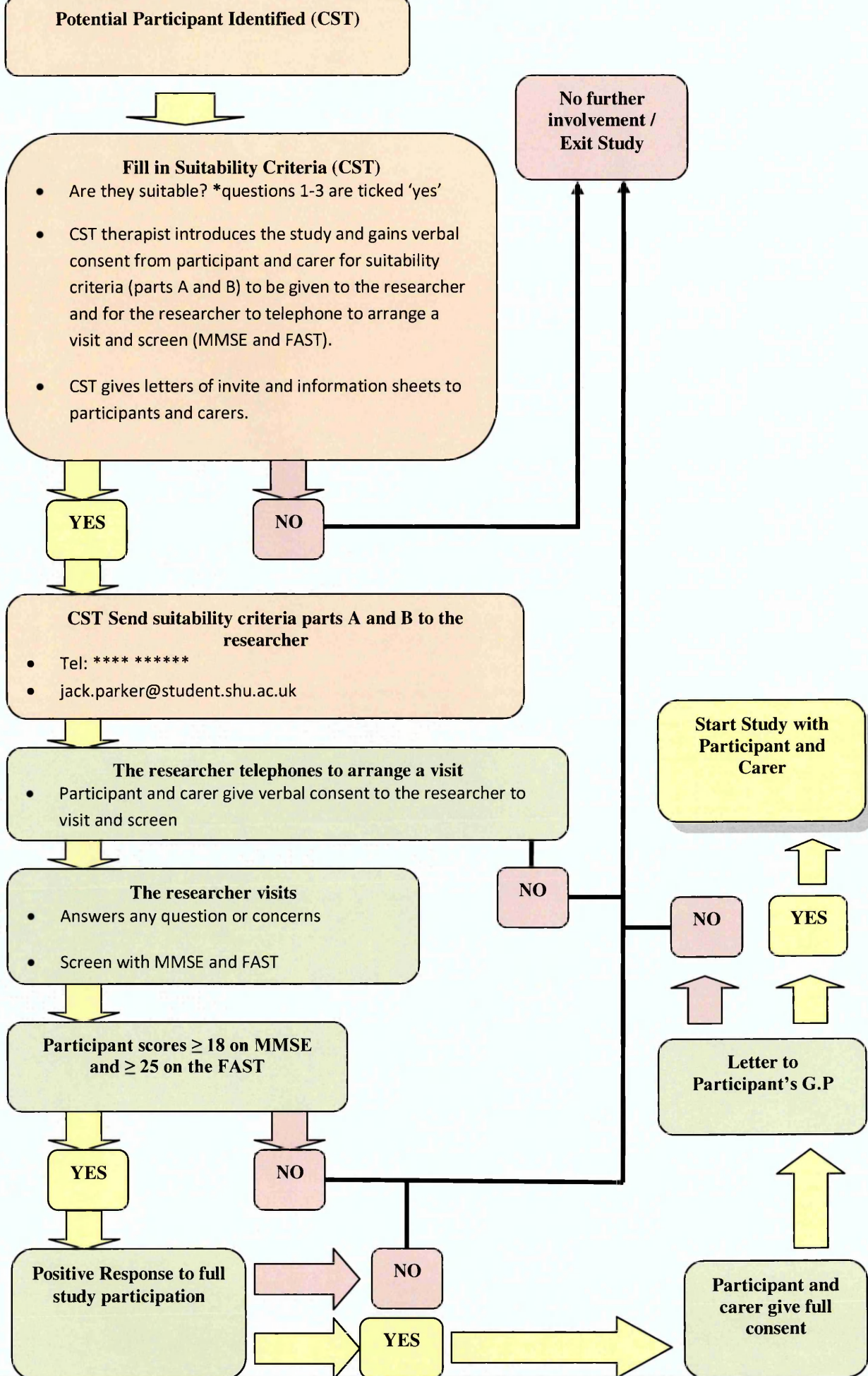


Fig 6-1: Recruitment procedure provided by the researcher to the CST therapists

### 6.3.3 Inclusion Exclusion Criteria

- *Inclusion:*
  - A definitive diagnosis of stroke (reported by the CST) and recently been discharged following a period of community rehabilitation provided by a CST.
  - Able to give informed consent to participation in the study and for the researcher to receive clearance from their G.P. (no response to the letter within two weeks).
- *Exclusion:*
  - Unable to speak or comprehend written English.
  - Severe communication, perceptual or cognitive disorders.
  - Visual impairment.
  - Apraxic.
  - Shoulder subluxation or arm pain.
  - Medically unstable and other neurological, neuromuscular, or orthopaedic disorders that would interfere with task performance.
  - Are not receiving further rehabilitation in the home.
  - Do not have a carer (see below).
  - Unable to give informed consent to the participation in the study and refused permission for the researcher to notify their G.P.
  - Presence of severe cognitive impairment (MMSE score  $\leq 17$ ).
  - Presence of aphasia (FAST score of  $\leq 24$ ).
- **Carer** – For the purpose of this study, the carer is the person who is likely to be with the participant the most during their use of the equipment and/or has been assisting/supporting the participant whilst they have been carrying out their rehabilitation with the CST.

The inclusion / exclusion criteria for involvement were based upon the participant's potential ability to interact with the SMART system. Judgements were also made by the CST therapists as to the severity of the sequelae of their stroke. For example, those with spatial and perceptual neglect were excluded because they may not be aware of their affected upper-limb during the use of the equipment.

Due to the qualitative nature of the research which also required the individual participant to consent to be interviewed and budgeting constraints, people who did not



understand verbal or written English were not considered for this research. This is due to the costs of interpretation and the use of English with the SMART system. However, this did not exclude participants of ethnic origin or diverse culture who were literate in English.

Although the inclusion / exclusion criteria may have restricted a number of stroke survivors from using the equipment, this adds to the findings of this research. A key aspect of this research includes the evaluation of ‘for whom in what circumstances.’ Therefore, by evaluating the personal, social and contextual factors of those who met the criteria for participation, this also highlights who may not be suitable and what circumstances are also not suitable for this intervention. This is discussed further in chapter seven.

## 6.4 Research Setting

Following consent being obtained, all contact with participants and their carers was in the participants’ home. This allowed the participants to be interviewed and undertake rehabilitation in a natural environment as well as meeting the aims of the study; that of home-based rehabilitation using technology (described in chapter 3).

## 6.5 Procedures

This research involved multiple observations captured through a collective case study approach (Stake 2000) whereby the researcher provided a SMART Rehabilitation Technology System for individual participants to use for up to five weeks (from initial face-to-face contact to removal of the system). The following figure illustrates a participant from previous initial user testing using the equipment (fig 6-2 below).



Fig 6-2: User participation with The SMART Rehabilitation Technology System in the home-setting ([www.thesmartconsortium.org](http://www.thesmartconsortium.org)).

Following the participant and carer signing the consent forms, participants and carers were instructed how to use the SMART Rehabilitation Technology System and were

provided with a hard copy user manual. The participants were then invited to conduct upper-limb rehabilitation using the SMART Rehabilitation Technology System and were visited at decreasing intervals during the intervention period. However, this was dependent on the amount of training the participant wanted/required to use the system as decided between the participant and their carer and the researcher. For example, during the first week, the researcher visited the participant between two and four times to demonstrate the operational procedures and provide troubleshooting advice. This was subsequently decreased to once per week by the end of the intervention (the researcher's involvement is described with each case-study).

Each participant was initially given reach forward and reach sideways exercises to perform. This was because they were simple exercises that enabled to see the avatar move in different planes. However, depending on their ability (and limitations) to perform the exercises and their desire to try more exercises, they were given others to attempt such as, hand-to-mouth; and a 'catch the ball' game. During and following prescribed activity; computer feedback was provided via real-time 3-D images (fig 2-8 – 2-10); a qualitative chart (fig 2-11) and a graph (fig 2-12) displayed on a lap-top computer, as previously described in chapter two (see pp. 49-51).

The participants were not advised as to the frequency of usage or the number of repetitions to perform but were encouraged to use the equipment as often as they wished. This allowed the researcher to evaluate the number of sessions the participant chose to do. This provided some insight of the participant's willingness to use the equipment. However, they may have felt obliged to use the equipment by agreeing to participate in the study.

## **6.6 Data collection**

Pawson and Tilley (2004) suggest that in order to allow for the interrogation of the CMOC hypotheses, the researcher 'scavenges' for the best available data through practitioner leads, where and with whom the mechanisms in context are most likely to happen. The subsequent case studies necessitated a number of methods of data collection to explore the pre-existing context of the participants; observe the mechanisms; and explore the outcomes of the intervention. This involved collecting data before, during and after using the SMART System (see figure 6-3 overleaf).

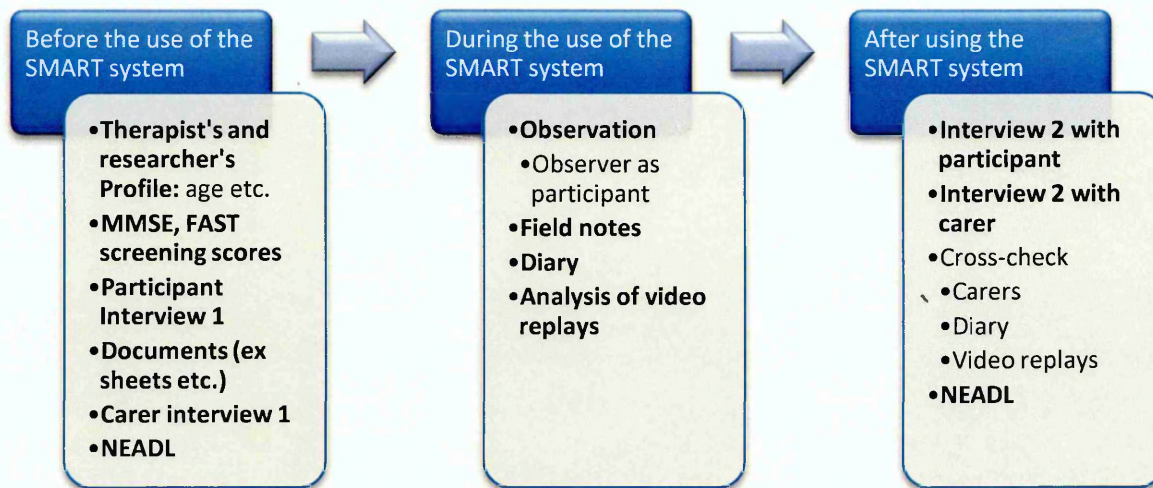


Fig 6-3: Data collection methods before, during and after using the SMART System.

### 6.6.1 Methods of Data Collection to Explore the Pre-existing Context

In order to explore the pre-existing context of the participants and their carers, a number of quantitative and qualitative observations were employed. These included the Mini Mental State Examination (MMSE), the Frenchay Aphasia Screening Test (FAST), profiles provided by the therapist(s) and the participant(s), and documentation provided by the CST therapist(s) to facilitate independent rehabilitation during the 12 week period of community rehabilitation.

#### 6.6.1.1 Assessment (screening) Tools

The use of the MMSE and the FAST served two purposes. Firstly, it was imperative to establish the participants' suitability for involvement; and secondly, the tasks would also provide an assessment of their pre-existing context.

**MMSE** - In order to establish the cognitive status of the potential participants, the MMSE was used to screen potential participants for cognitive impairment (Folstein *et al*, 1975). This enabled the researcher to exclude potential participants who may not have been cognitively capable of using the SMART system (a score of  $\leq 17$  indicates severe impairment).

The MMSE consists of eleven tasks that test various cognitive domains including; orientation to time and place, repetition, verbal recall, attention and calculation, language and visual construction (see appendix 21 p. 342). The MMSE is established as a valid, reliable and sensitive measure of cognitive impairment (Tombaugh and McIntyre 1992).

**Frenchay Aphasia Screening Test (FAST)** – The FAST was also used to screen potential participants who may have had communication difficulties (Enderby *et al*, 1987). Because the researcher required the participants to be interviewed and the SMART system cannot be used by those with communication difficulties, the researcher excluded potential participants who scored indicated a presence of aphasia (FAST score of  $\leq 24$ ).

The FAST consists of six tasks that include; following instructions, expression, reading, writing, and interpretation. These domains are scored 0 – 5 with five being the highest score. The overall score for the test is 0 – 30. This enabled the researcher to screen potential participants for communication difficulties that may have compromised their ability to interact with the SMART system and the researcher during the testing period. The FAST has been found to be a valid, reliable, and sensitive screening test for establishing the presence of aphasia in stroke (Enderby *et al*, 1987; Enderby and Crow 1996; O'Neill *et al*, 1990) (see appendix 22 p. 343).

#### **6.6.1.2 Profiles: ‘for whom’**

In order to establish the *‘for whom’* of the question, *‘what works for whom and in what circumstances and respects,’* a profile of the participant and carer was taken by the Community Stroke Team (CST) therapist (see appendix 19 p. 339). This enabled the researcher to gain information on the pre-existing context of the participant and their carer from the perspectives of their CST therapist at the point of discharge. Following screening and consent procedures, a further profile was taken by the researcher which enabled cross-checking of the status of the participant such as, site of the lesion, functional status, and co-morbidities. This also involved obtaining data on the social history, hobbies and interests and weekly activities of the participant from the participant’s perspective (see appendix 23 p. 344).

#### **6.6.1.3 Documents**

Documents of what the CST had provided the participant and carer to facilitate independent rehabilitation (i.e. exercise sheets) were examined and notes of their content were taken. This provided data of what the participant(s) were instructed to do and how to do it during their period of community rehabilitation with the CST therapists (their pre-existing context). This involved evaluating existing and current documentation used such as, exercise sheets and information booklets provided by the CST’s.

#### **6.6.1.4 Interview 1**

The researcher conducted separate semi-structured interviews in the participant's home with the stroke survivor and their carers to establish their perspectives regarding the provision of information and extrinsic feedback (see appendix 24 p. 345). The first interview aimed to ascertain what forms of information are given to participants and carers. A carer's perspective was also invited as the aim was to gain the views of those who are likely to be influenced by current service provision. In addition, the participant's carer may also influence how current home-based programmes are undertaken. For example, a carer may in some instances assist or instruct the participants in a variety of ways, in the absence of the therapist.

#### **6.6.2 Methods of Data Collection to Test the CMOC Hypotheses**

The following section sets out which methods of data collection that were employed to test the CMOC hypotheses.

##### **6.6.2.1 Measurement of Functional Independence: CMOC's 8 & 9**

Both of the participants in chapter five described how they measured recovery through their ability to carry out functional and social activities. This confirmed the requirement to include an outcome measure that would measure change in activities of daily living and extended activities of daily living through the subjective opinion of the users (see CMOC eight and nine). Therefore, prior to and on completion of the intervention period, the participant was asked to complete the NEADL (see appendix 4 p. 309) where outcome scores were taken. The rationale for using the NEADL is described in 3.5.5 (p. 97).

Although any changes in the NEADL score may not have been a result of using the equipment alone; this measure enabled the researcher to explore differences between the subjective accounts of the participants and the NEADL scores.

##### **6.6.2.2 Observations: CMOC's 1-3; 5-8 & 11**

The researcher's position during the observations of the participants moved to and from 'participant as observer' and 'observer as participant' throughout the period of data collection for each participant (up to five weeks). The researcher was required to initially set up the computer equipment and subsequently train both the participant and their carer to use it and change and adapt the exercises throughout the period. This directly involved the researcher (participant as observer). However, subsequent visits

allowed the researcher to step back from the participant and their carer during use and take the role of ‘observer as participant’ (described in chapter three).

#### **6.6.2.3 User Diary: CMOC’s 1; 3-5; 7 & 12**

Throughout the time they had the equipment, the participants and their carers were encouraged to keep either a written diary or input into the diary facility on the computer system. This allowed the participant and/or carer to describe the experience immediately during or after using the equipment. For example, they may have had a positive and/or negative experience of a session. Furthermore, the use of the diary enabled them to describe their perspectives without having to remember at a later date which may dilute their portrayal.

#### **6.6.2.4 Avatar Replays: CMOC’s 1-3; 5; 7-9; 11 & 12**

Each subsequent visit by the researcher began by asking the participant how they believed they had performed on the SMART system since the previous visit. This question was then followed with, “what makes you think this?” This was then followed by the researcher observing the video replays of sessions that had been carried out by the participant since the last visit.

This was followed by observing the avatar replays (in the participant’s house but not in view of the participant/carer); transcribing diary inputs and observing the participant use the equipment. This would involve the researcher instructing the participant and carer to ‘use the equipment as you normally would.’ This enabled the researcher to observe how the participant operated the equipment; how they utilised the feedback, and how independent they were (i.e. not requiring the assistance of the carer).

#### **6.6.2.5 Interview 2: CMOC’s 1-10 & 12**

Following the use of the equipment, separate semi-structured interviews were conducted separately with the participant and their carer (see appendix 25 p. 347). This interview aimed to access participants’ and carers’ opinions of their experience of utilising feedback from computer-based technology in the home. In a second separate interview was conducted with the participants’ carer as they may have influenced the participant’s experience of using the equipment.

### **6.7 Recording**

Semi-structured interviews were audio-taped to ensure the transcriptions were presented verbatim. In addition, observations and field notes were taken of informal discussion,

diary inputs and the observed physical behaviour of the participants and their carers. Diary inputs were taken through each visit and transcribed verbatim.

## **6.8 Data Analysis**

Data was analysed in relation to the hypothesised CMOC's case by case (in the order they are presented in this chapter). This is followed by a cross case analysis and a synthesis of the findings to answer the question, '*what works for whom and in what circumstances and respects?*' (Chapter 7). The method and process of data analysis is described in chapter three (pp. 99-100).

The first task involved organising the subsets of data into before, during and after the use of the equipment. This allowed for chronological analysis of the experience of using the equipment throughout the intervention. Data analysis involved close reading and rereading of the profiles; MMSE, FAST and NEADL scores; interview transcripts, field notes of the observations, avatar replays and informal discussions; and diary inputs.

### **Analysis of the participant profiles:**

In order to explore the pre-existing context of the participants, the details of the participant and their carer from the profile taken by the therapist were compared with the profile taken by the researcher. This allowed the researcher to examine similarities and differences between the two profiles exposing variations between the therapists' recorded opinion to the opinion of the participants.

### **The assessment (screening) tools:**

The MMSE and FAST were initially analysed applying the criteria of  $\geq 18$  (no severe cognitive impairment) (Tombaugh and McIntyre 1992) and  $\geq 25$  where the presence of aphasia is not indicated in those above 60 years of age (Enderby *et al*, 1987) to establish the participant's suitability for involvement. However, the data from the screening tools were also analysed by examining which aspects the participants were / were not able to complete or had difficulty with. For example, both of the screening tools include a number of different domains that examine different components. Therefore, the participant may have had difficulty in one domain but not in another which reveals specific abilities/disabilities within the tasks.

### **The measurement tool (NEADL):**

The NEADL is an ordinal scale and therefore only reflect ability in specific domains. For example, achieving a score of sixty would not mean that the participant is twice as

functional as a participant who scored thirty. The NEADL is divided into four areas: these are; mobility, in the kitchen, domestic tasks, and leisure activities with up to six questions in each category. Therefore a score is provided for each division and subdivision of the measure. For example, a participant may be highly mobile (a predominantly lower-limb function) but unable to carryout tasks in the kitchen (requiring upper-limb functional ability) (Stevens 1946).

Although an overall score is produced, the NEADL scores were examined to establish the individual components of the measure. This provided detail as to the categorical functional ability of the participant before and after using the SMART system (Stevens 1946).

**The interview data:** Interviews were analysed in relation to the hypothesised CMOC's using thematic analysis (Pope and Mays 2006) where they were transcribed verbatim from the tape-recording. The transcriptions were then checked for accuracy by listening to the recording and matching the audio to the transcription allowing for further accuracy as well as including moments of expression by the interviewees. Following this process, the transcriptions were delivered back to the interviewees for respondent validation.

- Transcriptions were thematically analysed through an iterative process which involved; reading through each response by the participants/carers, identification of information units; the formation of themes, sub-themes and sub-divisions of themes. Throughout this procedure, the transcripts were revisited for further refinement.

**The documentary evidence:** This was analysed for content and coupled with the interview data. This allowed for the aim of interview one to analyse what the participant and carer reported they received from the CST and what the CST actually gave them.

**Observations and avatar replays:** Detailed field notes were taken at the time of observing both the participant using the equipment and the avatar replays of previous sessions. These were subsequently searched for recurring themes and items. The themes and categories were then coded and labelled to provide thematic, conceptual headings (Pope *et al*, 2006).

**Diary inputs:** Diary inputs were analysed by transcribing the inputs verbatim. These were then coupled with the field notes of the informal discussions. These notes were



checked during these discussions with the participant and carer to clarify meaning from their perspective.

Throughout the data collection period, the researcher analysed and reflected on the data collection process and aimed to improve it. For example, after the first participant, subsequent participants were introduced to the equipment more gradually. For example, for the second participant, the equipment was set up on day one which included an initial attempt by the participant. The next attempt by the participant to use the equipment was supervised by the researcher three days later.

## 6.9 Socio-Demographic Profile of the Participants

The five participants referred by the CST therapists who chose to take part, included four male users and one female user all of which had female carers. Four of the participants were left sided lesion / right side affected (4/5) and were between five and eight months post-stroke (see table 7-1 below). However, there was variation in age (62 – 79), functional independence (NEADL score 4 – 11 and 10 – 48) and computer experience.

Table 6-1: Demographics of the Case Studies							
Case Study	Age	CVA / Side affected	Time since stroke	MMSE Score /30	FAST Score /30	Computer experience	Active range of movement (affected shoulder)
Mr. Brown	70	L / R Hemi	6 months	25	28	+(minimal)	90° Flexion 45° Abd
Mrs. Green	79	L / R Hemi	8 months	23	25	-(none)	70° Flexion 70° Abd
Mr. Gray	62	R / L Hemi	5 months	30	30	++(moderate)	30° Flexion 20° Abd
Mr. Blackwell	65	L / R Hemi	5 months	30	29	+++ (extensive)	20° Flexion 20° Abd
Mr. Redmond	79	L / R Hemi	5 months	27	25	+(minimal)	90° Flexion 90° Abd

## 6.10 Testing the CMOC's

The following section describes the case studies. All names have been changes to ensure confidentiality and anonymity of the participants and their carers. The case studies are presented in chronological order of recruitment and data collected. A brief discussion

follows each case study; however, the findings are synthesized in CMOC form in chapter seven.

## 6.11 User Testing with the Participants

During the use of the SMART Rehabilitation Technology system, the researcher conducted a number of visits to screen for suitability, gain written consent, observe and collect data. The following table lists the chronology of each case. Each case study describes the procedures that took place during each visit.

	Visit 1	Visit 2	Visit 3	Visit 4	Visit 5	Visit 6	Visit 7	Visit 8
<b>Mr. Brown</b>	Day 1	Day 3	Day 7	Day 11	Day 14			
<b>Mrs. Green</b>	Day 1	Day 3	Day 7	Day 10	Day 16	Day 23	Day 23	
<b>Mr. Gray</b>	Day 1	Day 4	Day 11	Day 15	Day 18	Day 23	Day 28	Day 23
<b>Mr. Blackwell</b>	Day 1	Day 4	Day 10	Day 12	Day 18	Day 26	Day 33	
<b>Mr. Redmond</b>	Day 1	Day 5	Day 8	Day 12	Day 19	Day 25	Day 29	Day 33

## 6.12 Case Study 1: Mr. Brown

### 6.12.1 Context

#### Therapist's Participant Profile

Mr. Brown was a seventy year old gentleman who sustained a left ischemic cardiovascular accident (CVA) (right sided hemiparesis) six months prior to participating in the study. The therapist reported that Mr. Brown required supervision and the use of a walking stick to mobilize around his house, although he was able to go up and down stairs independently. However, he used a wheelchair for further distances outside. He was able to carry out personal activities of daily living such as, washing and dressing independently and was also able to use his right (affected) upper-limb for writing, washing dishes, and small DIY jobs. His active range of movement for his affected upper-limb was reported to be; 90° shoulder flexion, 45° abduction; with full

elbow flexion and extension. He was also reported as having low-tone throughout the affected upper-limb and hand. His past medical history was reported as: asthma; a bilateral hernia repair; a left lung lobectomy (aged 16); and arthritis in both his hands and feet.

#### **6.12.1.1 First Visit**

During the first visit Mr Brown was screened using the MMSE and FAST. His scores revealed that he was eligible to participate in the study.

#### **6.12.1.2 Second Visit**

##### **Researcher's Participant Profile**

Mr. Brown lived in an end-terraced house which had stairs to the first floor and stair rails fitted on both sides. He had a bath board, a raised toilet seat and raised chair blocks to help with his mobility and independence around the house. His previous occupation before retirement involved working in an office carrying out administration tasks and the occasional use of a computer.

Since his stroke, Mr. Brown said that he enjoyed doing crosswords, and repairing wooden dolls houses (requiring an amount of fine dexterity), and some light gardening. He also enjoyed visiting his static caravan for holiday periods.

Mr. Brown's wife (Mrs. Brown) was also his full-time carer and lived in the same house. She was a 52 years old former cleaner but gave up her occupation to become Mr. Brown's full-time carer following Mr. Brown's stroke. She explained that she had no previous experience of using a computer.

At the time of his participation in the study, Mr. Brown was continuing his rehabilitation at the assessment and rehabilitation centre (ARC) in Sheffield every Friday where he spent a full day carrying out various activities and he reported receiving up to one hour of rehabilitation with Physiotherapists and Occupational therapists.

##### **Baseline NEADL score**

The NEADL overall score for independence was 15/22 and functional ability 48/66 using the Likert scoring method (Harwood and Ebrahim 2002).

The NEADL found that his (self-reported) subsection scores were:

- Mobility – 13/18

- He needed help getting in and out of a car and travelling on public transport.
- In the kitchen – 13/15
  - He needed help to use a knife in his right hand.
- Domestic tasks – 13/15
  - He suggested he was able to manage most tasks alone but with difficulty. However, he commented that he has never carried out domestic tasks. He believed that was his wife's responsibility. He was then asked if he could do the tasks if his wife was not present.
- Leisure activities – 9/18
  - He was able to use the telephone and read independently but needed help with writing letters, going out socially, and gardening. He was also unable to drive a car.

## **Results of the Analysis of the First Interviews**

### **Provision of information / feedback**

When asked what he was given by the CST therapists to help him get better, Mr Brown explained that he had been given a number of exercises to do that were recorded and provided on sheets for him to follow. However, in contrast to self-managed rehabilitation, he tended to rely on his carer to explain what to do. He therefore included his wife (carer) as a recipient of rehabilitation,

*“Yes we've got loads of ...what do you call them again... papers with different things on what you can do, she [Mrs. Brown] puts them on the bed when she's doing my exercises with me” Mr. Brown.*

Mrs Brown confirmed that they were given a number of forms of literature to help Mr Brown to carry out the home exercise programme. Interestingly, she suggested that the programme was for both of them,

*“They gave us lots of exercise, papers with exercises on ...err, forms with different contact numbers on” Mrs. Brown.*

She also suggested that the exercise sheets were easy to follow because she had been shown what the exercises were and how Mr Brown should perform them during the sessions. She appeared to be adopting the role of a therapist during the rehabilitation process,

*“They would let me sit and watch what they were doing and explain to me as she was doing it because I needed to help him with some of them like lifting his arm and that. Plus it was all wrote down on the sheets” Mrs. Brown.*

However, when asked if the therapists provided any feedback on their home exercises during subsequent visits, both Mr and Mrs Brown explained that the therapists did not,

*“No. They [therapists] used to come in and say we ’ll do something on your leg... we ’ll do something on your arm... we ’ll do this. That is what they used to do... Then [the] next day they would come and tell us what they wanted. What they wanted to do to us [me]” Mr. Brown.*

*“...she just asked if we had been doing them, that’s all!” Mrs. Brown.*

Although Mr and Mrs Brown explained how they had been given a number of forms of documentation providing instructions and information; when asked if they still had them, they explained that because they were no longer under the care of the CST, they had thrown most of them away. However, they had retained one of the exercise sheets to continue the exercises that had previously been prescribed.

### **Time limitations**

Mr Brown described throughout the first interview how he felt frustrated that in his opinion the CST therapists did not have enough time to give him the treatment he wanted,

*“They didn’t seem to have time, enough time to give you a good session. They haven’t got time. Some days they didn’t come some days they did. They just haven’t got time to push you on” Mr. Brown.*

*“As I say, I don’t think they had long enough to get around to everybody” Mr. Brown.*

Mr Brown explained that he felt the therapists would often come in and tell him what they were planning to do that day. He also described how the therapists would maintain the locus of control over him during the sessions,

*“They come and tell you what they are going to do to you. That day they came and said we are going to try something else on your arm; next day they would come and tell us what they wanted ... What they wanted to do to us [me]” Mr. Brown.*

### **Preferred treatment approach**

During the interview Mr Brown provided some insight into what his preferred treatment approach was and what he expected from the CST. He explained how he preferred a more direct approach by the therapist whereby they would maintain the locus of control enabling him to take a more passive role,

*“Like now that I’m at ARC, they just come and say ‘Mr. Brown... in!’ I’ve learnt a lot more at ARC. I know them lasses what were here, they were good, they helped you out but ARC they’re like proper nurses and physios for me” Mr. Brown.*

*“At ARC she gives you a real session. S [the CST Physiotherapist] used to do sometimes when she come she’d say do this do that but this one [at ARC] more or less pulls you around [laughs] which I’d sooner have that than anyone pussy foot around me” Mr. Brown.*

When asked if he had been given too many home exercises for him to remember, he explained how he was unable to remember all the exercises and that he preferred to be under the guidance of a therapist,

*“Well you couldn’t remember them all at once put it that way. That is why up there [ARC] there is more people so they can get hold of you get you down and say we are doing this we are doing that and it puts you to your limit that’s what I found better” Mr. Brown.*

### **Document Analysis**

The document that the Browns could retrieve contained four exercises; three for the lower limb and one for the upper-limb. The lower-limb exercises were: 1) shifting his weight from one side to the other; 2) sit to stand without the use of the walking aid; 3) step standing with the aid of the stair rail. The upper-limb exercise involved rolling plastic putty between the fingers.

The document used ‘Physio tools’ which comprises of basic line drawn pictures with a short caption underneath explaining to the patient how to perform the exercise, how many repetitions to perform and how often to perform the exercise per day ([www.physiotools.com](http://www.physiotools.com)).

## 6.12.2 Observing the CMOC's

### 6.12.2.1 Third Visit

#### Initial set-up of the system

Following a discussion as to where the equipment should be used and stored with the participant and carer, the SMART Rehabilitation Technology System was set up in the lounge on a 'cake stand' and stored next to the sofa with the wires tucked away. Mr Brown was given reach forward and reach sideways exercises to perform. The parameters were set at 80 – 110° for shoulder flexion and 30 – 50° for abduction.

Mr Brown was then instructed on how to use the equipment by taking him through a step-by-step demonstration with Mr Brown using the equipment sitting on his sofa with the equipment on the cake stand in front of him and his carer observing. This was followed by observing him and his carer (assisting where necessary) using the equipment independent of the researcher.

#### Observations

Watching Mr Brown using the SMART system during the third visit revealed how he was able to put the arm garment on independently but found the wrist and trunk garment difficult. As a result his carer, Mrs Brown was quick to assist him. Although he appeared to find the set up and instruction easy to undertake, he became easily frustrated with the results. For example, he commented that because the reference figure was not a mirror, he found it off putting that the reference figure lifted the arm much higher than he could,

*“If I'm only able to lift my arm to there [demonstrates 90 degrees of shoulder flexion with his unaffected arm], why does that [the reference figure] expect me to lift it all the way up there? It's impossible that!” Mr. Brown.*

During a second repetition of the exercise, he extended and side flexed his trunk to facilitate more flexion. However, the system provided verbal feedback, 'keep your trunk stable.' He then got annoyed and shouted, “How am I supposed to do it like that then?”

### 6.12.2.2 Fourth Visit

#### Discussion with the Participant

Mr Brown reported that he had used the equipment only once since the initial set up. He explained how he didn't think he had performed very well as the black dots in the qualitative chart were not up in the green zone. Mr Brown also explained how he found the exercises difficult because he could not relate to the screen avatar,

*“I don’t understand how it moves [the avatar image] and that... I move one way and it goes the other. How are you meant to get those dots up in the green?” Mr. Brown.*

When asked if he would like to go through the programme in the presence of the researcher, he said that he would prefer to carry out the exercise programme later in the day. The researcher then arranged to visit Mr Brown the following week (four days later); however, Mr Brown telephoned to cancel this visit as he was going to his caravan.

### **Analysis of Avatar Replays**

Analysis of the video replays since the previous visit (initial set up) was carried after the informal discussion with the participant (in the presence of the participant). The replays indicated that Mr Brown had performed two sets of four repetitions for the forward reach and reach sideways exercises on one occasion. The replays suggested that during the forward reach and reach sideways exercises he had side flexed his trunk beyond the parameters of the system.

#### **6.12.2.3 Fifth (final) Visit**

Mr Brown kept the equipment for a total of seven days. He then telephoned the researcher explaining that he found the equipment too hard to use and no longer wanted to keep it. However, Mr and Mrs Brown were willing to discuss in an interview their experience of using the equipment.

### **Results of the Analysis of the Second Interviews**

#### **Expectations of Service Delivery**

During the final interview Mr Brown explained that he did not expect or wish to carry out his rehabilitation independently,

*“It’s not up to me to sit here and do it all myself is it... You’re the experts you should be doing it!” Mr. Brown.*

He went on to explain how he felt the CST therapists did not have the time to treat him. He thought that this was a result of resource limitations,

*“They were decent lasses that came here and they got on with it; but there’s not enough of them, they haven’t got time to see everyone and even when they do come, they are only here for a bit because they’ve got someone else to see” Mr. Brown.*



However, he suggested that his expectations of what treatment he should have received maybe down to his personality and more specifically, his impatience to get better,

*“I just wanted to get better; I haven’t got time for faffing around with all that computer stuff. I just want to get sorted, and for me, that’s up to you lot isn’t it! I don’t know what I’m meant to be doing, so yeah... err... well... as I say, it’s up to the experts!” Mr. Brown.*

### **Experience of using the SMART System**

When asked what he liked and disliked about using the SMART system, Mr Brown explained how he liked the idea of the equipment, which was why he agreed to take part in the study. However, he also said that he thought that the technology needs to be easier to use,

*“I just didn’t get it... you move one way and it goes the other! I’ve used computers before so I thought it’d be easier. Every time I tried to get the dots up in the green it said I was doing it wrong! How are you meant to do it? I lifted my arm up like this [demonstrates his movement with his affected arm] but on that [points to the computer system] the other arm moves” Mr. Brown.*

When asked how he would improve the system,

*“It just needs to look like you... look like it’s you on there moving. It’s just hard to figure out how to get it... get it right y’know. I tried to get my arm as high as I could but then when the dots [chart feedback] come on it was at the bottom. Doesn’t matter what you do...” Mr. Brown.*

When asked if he thought that with practice, he would be able to use the technology independently, Mr Brown thought he would but would need help with the setup of the equipment. In addition, he suggested that if the therapist sat with him and they worked through the programme together, he would feel more confident,

*“I’d need T [Mrs. Brown] to help set it up, y’know put the gear on and that, but I’d be able to... with a bit of practice... yeah maybe. It’d be better if someone sat with you like a proper physio to help you understand it. You’d still need that time with them. You just can’t do it by yourself can you?” Mr. Brown.*

When asked why,

*“...well, you’re not sure are you? It’s just reassuring to have someone with you who knows what they’re doing” Mr. Brown.*

Mrs. Brown commented that she thought that his impatience and forthright personality was the reason for his unacceptance of using the equipment,

*“I think it’s just him, it’s just the way he is. He’s got no patience with it; he has to be able to do straight away! He won’t faff about; he’ll just say it as it is” Mrs. Brown.*

### **NEADL Score**

Mr Brown’s NEADL score did not change from the baseline score taken before using the equipment.

### **6.12.3 Case Discussion**

Mr Brown had limited impairments and was able to carry out most activities independently. However, he viewed the rehabilitation period passively in that he placed the locus of control on the CST therapists for his management of his rehabilitation as well as a great deal of reliance on his carer to assist with his home exercise programme. He also commented on how he felt that his impatient personality may impact on his expectations of recovery. During the use of the equipment, he was reluctant to persevere with ‘learning’ how to both use the equipment and carry out his rehabilitation independently. However, Mr Brown described how his involvement in the rehabilitation process with the CST therapists was limited, which may suggest that the rehabilitation he received was led by the therapist(s). This may have impacted on his ability to self-manage and his confidence to self-manage during the use of the SMART system. This was also highlighted by his belief that that once the CST was no longer involved he did not need to keep any of the exercise sheets or information they provided to continue his rehabilitation following discharge.

In addition, to his personal context and expectations of service delivery, a number of other factors impacted on his use of the SMART system feedback. He found the avatar difficult to relate to because it was not a mirror of him which made it difficult for him to analyse his movement(s). This led to poor feedback in that the qualitative chart showed his results (black dots) to stay within the red/amber zone. This affected his motivation to continue using the system as he was unable to problem-solve and change his movement patterns to receive improved results. Therefore, because the SMART system could not be adapted and personalised for Mr Brown (CMOC’s 1 & 2), this impacted on his motivation to use the SMART system and his confidence to carry out independent rehabilitation.

Mr Brown suggested that if he was to use the equipment one-to-one with a therapist, he would have more confidence to use the system and interpret the feedback it provided. However, it was the researcher's original intention to remain objective and impartial throughout the participant's use of the system (to reduce the therapist's influence on the data). Nevertheless, this suggests that with adequate resources and support, he may have been able to problem-solve which may have increased his confidence to use the system (CMOC 6).

This case study demonstrates the impact that 'expected' service delivery has on the introduction of new models of rehabilitation and what influence this may have on newer models of service delivery. Mr Brown also highlighted the influence of having adaptable and personalised feedback on motivation and confidence.

## **6.13 Case Study 2: Mrs. Green**

### **6.13.1 Context**

#### **Therapist's Participant Profile**

The therapist stated that Mrs. Green was a 79 year old lady who sustained a left ischemic cardiovascular accident (CVA) (right sided hemiparesis) eight months prior to participating in the study. Mrs. Green was a wheel chair user for both indoor and outdoor mobility and required a hoist for transfers in the home.

She required some help to carry out personal activities of daily living such as, washing and dressing independently but was also able to use her right (affected) upper-limb for writing and feeding herself. Her active range of movement for her affected upper-limb was reported to be; 70° shoulder flexion, 70° abduction; with full elbow flexion and extension. The therapist's patient profile also reported Mrs Green as having low-tone throughout the affected upper-limb and hand. Her past medical history was reported as having an above knee amputation following a blood clot in her femoral artery three months after having her stroke (affected side), high blood pressure and Angina.

#### **6.13.1.1 First Visit**

During the first visit Mrs Green was screened using the MMSE and FAST. Her scores revealed that she was eligible to participate in the study.

### **6.13.1.2 Second Visit**

#### **Researcher's Participant Profile**

Mrs. Green lived by herself in a semi-detached house with stair access to the first floor. Mrs. Green had a stair lift fitted and a bath hoist had been installed in the bathroom. However, because she was unable to manoeuvre her wheelchair into the hallway to access the stair lift, she slept downstairs. She also used a downstairs commode for toileting. Before retirement she was a newsagent; however, since retirement she liked to occupy herself by watching television and reading. She had difficulties with memory and relied heavily on her carer for activities of daily living and administrative tasks such as, paying bills and contacting outside agencies.

Mrs. Green's carer (Mrs. Whiting) was her daughter who lived across the road on the same street. She was a 53 years old former pub manager but had given up her occupation to become Mrs. Green's full-time carer. She explained that she had experience of using a computer and was confident in using one.

At the time of his participation in the study, Mrs. Green was continuing her rehabilitation at the assessment and rehabilitation centre (ARC) in Sheffield every Friday where she spent a full day carrying out various activities under the supervision and guidance of Physiotherapists and Occupational therapists.

#### **Baseline NEADL Score**

The NEADL overall score for independence was 5/22 and functional ability 20/66 using the Likert scoring method (Harwood and Ebrahim 2002).

The NEADL found that her subsection scores were:

- Mobility – 0/18
  - She was unable to carry out tasks such as, walking, stairs, getting in and out of a car, crossing roads or travel on public transport. She believed that this was because she was a wheelchair user and an amputee (which hindered transfers).
- In the kitchen – 9/15
  - She was able to feed herself but found washing up difficult. She needed help with making a hot drink and snack and could not take hot drinks from one room to another
- Domestic tasks – 5/15

- She was able to manage handling money but needed help with laundry and was unable to do her own shopping.
- Leisure activities – 6/18
  - She was able to use the telephone and read independently but needed help with writing letters, and could not go out socially or carry out gardening tasks. She was also unable to drive a car.

## **Results of the Analysis of the First interviews**

### **Provision of information / feedback**

Mrs Green described how her personal limitations resulted in her having difficulty remembering what the CST therapist had given her during her rehabilitation period with them,

*“They gave me some sheets of paper with things to do on. Oh this brain of mine, it just shuts off! I think... like I did some hand exercises... Oh I can’t really remember S [Mrs. Whiting] will know” Mrs. Green.*

Her daughter (carer) explained that they had been given a sheet of paper with some pictures and writing on to help them remember what exercises to do between face-to-face therapy sessions with the CST,

*“There was a sheet of paper with graphics on and an explanation of the graphics telling us how to do it [the exercises] and then a writing exercise” Mrs. Whiting.*

When asked if the CST therapist checked whether Mrs Green had been doing her exercises in between therapy sessions, Mrs Whiting explained that they did not and that this was due to the CST therapist not having enough time,

*“No they didn’t! Well they haven’t got time for that have they? They need to be getting on with other things and they’ve got other people to see after us so they are always in a rush” Mrs. Whiting.*

After the interviews they were asked if they had any documentation for examination. Mrs Green could not remember where she had put them. However, her daughter confirmed that they had thrown them away,

*“We chucked them away... Once I could remember what she has to do I chucked the papers! We were only given one exercise to do with her hand. That was the putty one wasn’t it mum...” Mrs. Green replied, “I don’t know love.”*

Mrs Whiting assisted with Mrs Green in demonstrating the putty exercises that they had been asked to carry out by the CST therapist in between therapy sessions.

- These consisted of:
  - Sausage rolling forward and back with the hand flat.
  - Placing it in the palm for opposition.
  - Placing it in the palm and squashing the thumb into it.
  - Adduction and abduction of the fingers.
    - They were told to do 3-5 repetitions of each.
    - They were not told what to look out for i.e. how they might know if they are doing it wrong or for the carer – how to correct.

### **Inclusion of the carer**

Mrs. Whiting was pleased with the way the CST therapists allowed her to be involved in the rehabilitation. She described how although they did not initially ask her if she would like to be involved, they did however explain what they were doing thoroughly and allowed her to watch the sessions,

*“No they didn’t ask me! But I wanted to get involved with it; you see I knew that mum wouldn’t remember any of it so I think it was important that I did. But they were really good; they explained everything [places emphasis on ‘everything’]. I used to think I was getting in the way sometimes but I wanted to help mum. Anyway they showed me what to do and how to do it right y’know” Mrs. Whiting.*

Mrs Whiting also said that because the CST were only able to visit once or twice per week, it was imperative that she helped to maintain progress,

*“They could only come perhaps once or twice a week. They have not got all the time in the world and therefore if I can help to do something with mum when they were not here, it is just helping mum progress instead of waiting from one session to another and everything going stagnant” Mrs. Whiting.*

When asked about whether she thought she was carrying out the exercises correctly with her mum and if her mum was improving, she said,

*“I don’t know really, you just try and copy them [the CST] as much as you can remember, but I suppose if she is able to do things like hold her knife and eat her tea then she must be getting better... I must be doing something right” Mrs. Whiting.*

## 6.13.2 Observing the CMOC's

### 6.13.2.1 Third Visit

#### Initial set up of the System

It was decided between the participant, her carer and the researcher to set up the SMART Rehabilitation Technology System in the lounge on a table where it was stored next to the sofa with the wires tucked away. The researcher gave Mrs Green the reach forward and reach sideways exercises to perform. The parameters were set at 60 – 80° for shoulder flexion and 60 – 80° for abduction. Mrs Green was given instructions on how to use the equipment by taking her and her carer through a step by step demonstration with Mrs Green using the equipment on a coffee stand in front of her wheelchair with Mrs Whiting observing. Mrs Green had difficulty donning all of the garments (trunk, upper arm, and wrist) which meant that her daughter had to help. Mrs Green carried out two sets of four repetitions for the forward reach and reach sideways exercises.

Given though they were anxious about using the technology, Mrs. Whiting appeared to relish the challenge of using the equipment,

*“It will take some getting used to, but it is good, you can see how you are doing; it gives you something to aim for!” Mrs. Whiting.*

*“We’ll beat this won’t we mum?” Mrs. Whiting.*

### 6.13.2.2 Fourth Visit

#### Analysis of Avatar Replays

Analysis of the video replays since the previous visit (initial set up 3 days previous) indicated that Mrs Green had performed one set of four repetitions for the forward reach and reach sideways exercises on two separate occasions.

The video replays suggested that she had achieved a greater amount of movement than during the observations with the researcher present. For example, she achieved 90 degrees of flexion but could only manage 60 degrees of observed movement during the visit. However, the carer suggested that she tended to encourage the participant more than when the researcher was present,

*“I tend to tell her what to do more when you’re not here, I perhaps shouldn’t but I’ve always helped her with her other [putty] exercise. I don’t think she’d be able to use it on her own, she wouldn’t remember what to do” Mrs. Whiting.*

She also suggested that her performance varies from one day to another,

*“She [the participant] has good and bad days; we tend to use it every other day because she gets tired” Mrs. Whiting.*

During the visit Mrs. Green did not wish to use the equipment because she was feeling too tired.

### **6.13.2.3 Fifth Visit**

#### **Analysis of Avatar Replays**

Analysis of the video replays since the previous visit (visit four 6 days previous) indicated that Mrs Green had performed one set of ten repetitions for the forward reach and reach sideways exercises on two separate occasions.

#### **Discussion during the Visit**

During this visit Mrs. Green and her daughter made a number of comments suggesting how Mrs. Green found it difficult to relate to the avatar. In particular, she found it difficult to understand that the avatar was her because she thought it didn't look like her,

*“It's not me on the screen, that's a man and I'm a woman!” Mrs. Green.*

Her carer described how this impacted on Mrs Green carrying out the exercises,

*“She'll just sit there, I have to say, 'that's not going to move until you move' once she sees it moving she gets the hang of it” Mrs. Whiting.*

Mrs. Green was unable to use the equipment during this visit because the sensors were not working accurately which presented as an inaccurate on-screen image.

### **6.13.2.4 Sixth Visit**

#### **Analysis of Avatar replays**

Analysis of the video replays since the previous visit (visit five 7 days previous) indicated that Mrs Green had performed one set of ten repetitions for the forward reach and reach sideways exercises on three separate occasions.

#### **Discussion during the Visit**

During this visit Mrs Whiting suggested that she thought Mrs Green was getting better at using the equipment because she was becoming more familiar with it. However, Mrs Whiting also explained how Mrs Green used it on alternative days because she found using the system tiring and hard to concentrate and that she did not want poor feedback as a result,

*“I think she's getting the hang of it now! The more we use it the happier she seems. We use it on alternate days; she gets tired you see, it's no good her not*



*doing very well and the dots being in the red just because she's tired" Mrs. Whiting.*

## Observations

Observations of using the equipment in the presence of the researcher revealed how the carer was required to work with the participant at all stages of using the equipment. This included:

- Charging the sensors and stowing the equipment.
- Donning and doffing the garments.
- Setting the equipment up (placing it on the table and turning the computer on).

During the exercises the carer guided the participant throughout by providing verbal instruction such as, 'lift your arm higher.'

### 6.13.2.5 Seventh (final) Visit

#### Analysis of Avatar Replays

Analysis of the avatar replays since the previous visit (visit six 7 days previous) indicated that Mrs Green had performed one set of ten repetitions for the forward reach and reach sideways exercises on one occasion. However, it was reported that on two occasions since the previous visit, the on-screen display did not visually display the participant's anatomical orientation (figure 6-4). This made it difficult for Mrs. Green to analyse her movements.

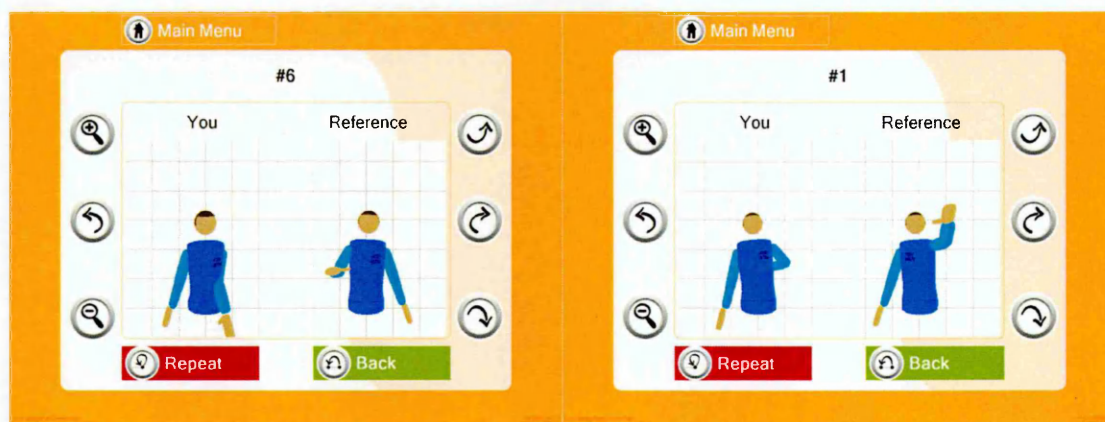


Fig 6-4: Two screen shots taken of the sensor distortion during video replays with Mrs. Green.

In addition, Mrs. Whiting reported that the sensors had failed to charge properly. This resulted in an on-screen and verbal message, 'some sensors are not properly connected,

place the sensors in the chargers and try again.’ They both said that this had put them off using the equipment,

*“It takes quite a while to get the equipment out and ready, then you’ve got to get her [Mrs. Green] dressed with all the sensors on only for it to say the sensors aren’t working. It makes you think why bother... we’ll have another go tomorrow” Mrs. Whiting.*

Mrs. Green also remarked,

*“It’s disappointing... it puts me off bothering! Then when the sensors don’t look right... how am I supposed to do that?” Mrs. Green.*

## **Results of the Analysis of the Second Interviews**

### **Feedback preferences**

Both Mrs. Green and her carer preferred the qualitative chart to the avatar, reference figure screen, and the line graph. In particular, the red, amber green sections enabled her to interpret how well she had performed,

*“I didn’t really grasp the two men on the screen. Those dots were much easier but it still took a few go’s to get used to it. I knew if I got in the green I’d done well” Mrs. Green.*

Mrs. Whiting said that she thought that the line graph was confusing. She also described how the qualitative chart was easier to understand and more personal. When asked which feedback she preferred and whether that helped her to interpret the performance, she replied,

*“The colours, the red, amber green and the dots. I think it’s, I think that is a good way. I don’t know perhaps easier for me to read dots than like when you’ve got that graph going up and down, I think it seems to all merge into one! Whereas dots are individual and I think it stands out more and you can see right if she hasn’t done such a good movement it does drop down a bit or it goes up” Mrs. Whiting.*

### **The benefits of rewards**

Mrs. Green suggested that when she was able to achieve good results; interpreted by getting the black dots on the qualitative chart up into the green zone, she was uplifted and more motivated to use the system. However, as described earlier, if the system failed to work correctly she was unable to use it,

*“Once I’d got up in the green, I was determined to stay there! I knew I had to keep using it [the computer] to stay in there so I’d want to have a go more often, but sometimes it wouldn’t work” Mrs. Green.*

Her daughter reiterated her motivation to use the system if Mrs. Green thought she had performed well and received positive feedback by getting her results up into the green zone,

*“ I mean when we got her right up to the top she were looking forward to going onto it for the first time because she were determined she were gonna keep it there! I think that is the only time she really showed any enthusiasm for it [laughs loudly]” Mrs. Whiting.*

Mrs. Whiting also remarked that it was only when she was achieving good results that Mrs. Green wanted to use the equipment more often,

*“It was only when she got all the dots in the green she really wanted to go on it again” Mrs. Whiting.*

#### **A tool for the carer**

The strongest theme that emerged from interview two with the carer was how the carer benefited from using the system. Mrs. Whiting was able to help Mrs. Green carry out her rehabilitation using the system. Mrs. Whiting described how she was able to use the system to interpret her mother’s performance and subsequently inform Mrs. Green that she was improving,

*“It enabled me to help mum. Because like those dots it showed you whether she had done a good movement or one not quite as good as the one before but I don’t think mum fully grasped what it was all about. But by showing her those dots and the different colours, I was able to explain to her that each colour was one step better than the one before and the dots, the higher she went the better that she was going and it gives her... able to urge her on to try that little bit harder, to just get her to lift that little bit higher” Mrs. Whiting.*

Mrs Whiting also alluded to the possibility of how using the system may have the potential to allow for more independence, thus placing less demands on her as the carer,

*“I said [to Mrs. Green] you might not appreciate it I said but I think it is a really good thing. I said I can see where it is coming from and like I said to mum, at the moment you can’t really do that [functional activity] because your arm’s*

*not strong enough so you have got to keep using it to make it stronger so that then I dare think well mum can do that on her own, I'm not frightened to leave her. Whereas at the moment I can't" Mrs. Whiting.*

Mrs Whiting also described how she liked to be involved in her mother's rehabilitation and that she could use the system as a tool to enable her to provide some input. Although she explained that she did not feel awkward to be involved, she liked the thought that the system (and to an extent) interprets performance, she would have some objective evidence to use. When asked how she found using the system with her mother Mrs Whiting replied,

*"I think with the stroke team they come in and do it all for you. You don't have to be involved at all if you don't want, whereas I do like being involved, I want to be there for mum and help as much as I can. So this helps me... It's like I've got something there to use with her and I can show her how she's doing, I can say look you've not done so well this time and I've got proof [laughs]. Don't get me wrong the stroke team were great but they can't be here all the time like I can. I'm sure it's not for everyone and there's probably people like me who haven't got time to help but I like it... it is quite satisfying in a way you know that I can be part of helping her get better" Mrs. Whiting.*

*"...you've got proof on there that you either are doing it right or you are not doing it good enough" Mrs. Whiting.*

*"I can say to mum you are not doing it right, and I can show her" Mrs. Whiting.*

### **NEADL Score**

The NEADL score increased by one point from 20/66 to 21/66 However, this was due to Mrs Green receiving new reading glasses.

Nevertheless, Mrs Whiting reported that for the first time, Mrs Green had started to use to a knife to eat with and was also using her affected arm/hand to drink from her beaker.

### **6.13.3 Case Discussion**

Mrs. Green was a very quiet lady who appeared subdued in nature throughout the testing period. Therefore, Mrs. Whiting was quick to speak up for her mother if she was having difficulties with answering questions or remembering the operating sequencing for using the equipment. Mrs. Green also had limited functional independence as a

result of her use of a wheel chair, her amputation and her stroke. Mrs. Green suffered a Medial Cerebral Artery / Posterior Cerebral Artery infarct. This affects the key memory centres – the medial temporal lobe, thalamus, Basal Ganglia and parahippocampal regions (Kenyon and Kenyon 2004). In addition, environmental restrictions also limited her independence as she was unable to manoeuvre her wheel chair around her house which restricted her access to the kitchen, bathroom and outdoor areas. She therefore relied on her carer for a number of tasks such as, making meals, laundry, and shopping and importantly, the amount of support she required to use the SMART system.

Both Mrs Green and Mrs Whiting reported difficulties relating to and understanding the avatar feedback preferring the qualitative chart. However, it was evident during the observations (in the presence of the researcher) that they found it difficult to analyse the avatar to the reference figure (providing visual concurrent, descriptive knowledge of performance feedback), whereas the preferred qualitative chart provides visual explicit knowledge of results feedback. In other words, they both wanted to know the results of Mrs Green's performance rather than how she had performed the exercise. This adds refinement to what form of feedback works for whom in what context. However, this refinement will be synthesised with other cases and is presented in chapter seven.

The rewarding knowledge of results feedback and the positive reinforcement from Mrs Whiting impacted on Mrs Green's motivation to use the SMART system in that it was only when she was achieving good results and positive encouragement did she wish to use the system and improve her level of performance (CMOC's 7, 8, 10, 11 & 12). This also impacted on their confidence to use the system and make decisions based on the feedback received (CMOC 3). Indeed, as they became more familiar with using the system, their confidence and willingness to engage with it increased which was reinforced through positive feedback (CMOC 3 & 7).

However, their motivation to use the SMART system may have also been affected by the reliability of the system. For example, when Mrs Green achieved good results she was keen to use the system more and when the sensors were not working (providing inaccurate feedback) she found this confusing and demotivating. This impacted on the amount of times she used the equipment and therefore how many repetitions of the exercises she performed (CMOC 3).

This highlighted the importance of setting the parameters at the right level in that the settings should not be too low and therefore discourage the use of the system but also not too high where the user would not be challenged to achieve better results.

Using the SMART system enabled Mrs Whiting to assist Mrs Green to carry out exercises and it provided feedback that Mrs Whiting could use to inform Mrs Green on her performance objectively (CMOC 4 & 12). This moved the feedback from a purely subjective interpretation of performance to an objective interpretation which they found easier to comprehend.

The participant and her carer in this case study have highlighted the importance of personalising the feedback for the user (as found during previous validation) and the subsequent impact this and positive feedback can have on the motivation to use the system (CMOC 7 & 10). In addition, they have also highlighted how using technology may provide a tool for other family members who choose to be involved in the rehabilitation process particularly when the participant requires greater support (CMOC 12).

This has implications on the ability of the stroke survivor to adopt self-management principles through the medium of technology. For example, the setting up of the equipment (setting exercises and targets) relied on the researcher's judgement and the ability of the user to utilise the feedback required the assistance of the carer (in the absence of the researcher). Therefore, although the (positive) feedback may provide a stimulus for motivation to rehabilitate, the process of achieving positive feedback is reliant on others.

## **6.14 Case Study 3: Mr. Gray**

### **6.14.1 Context**

#### **Therapist's Participant Profile**

The CST therapist stated that Mr. Gray was a 62 year old gentleman who sustained a right ischemic cardiovascular accident (CVA) (left sided hemiparesis) five months prior to participating in the study. Mr. Gray was a wheel chair user for both indoor and outdoor mobility but was able to transfer independently. Mr. Gray lived with his wife who was also his full-time carer.

He was reported as being able to carry out personal activities of daily living such as, washing and dressing independently. His active range of movement for his affected upper-limb was reported to be; 30° shoulder flexion, 20° abduction; with 5° elbow flexion and 80° extension. The therapist's patient profile also reported Mr Gray as having low-tone throughout the affected upper-limb and hand. His past medical history was reported as: arthritis in his left knee and high blood pressure.

#### **6.14.1.1 First Visit**

During the first visit Mr Gray was screened using the MMSE and FAST. His scores revealed that he was eligible to participate in the study.

#### **6.14.1.2 Second Visit**

##### **Researcher's Participant Profile**

His semi-detached house (with stairs) had no adaptations although Mr. Gray and his wife were waiting for a stair lift and hand rails to be fitted. His previous occupation before his stroke involved making small engineering components which included the occasional use of a computer. Mr. Gray was no longer in employment as a result of his stroke.

Mr. Gray's interests and hobbies included reading and watching television; he also had a particular interest in railways.

Mr. Gray's wife (Mrs. Gray) was also his full-time carer and lived in the same house. She was a 42 years old former nurse but had given up her occupation to become Mr. Gray's full-time carer. She explained that she was experienced and confident in using a computer.

At the time of his participation in the study, Mr. Gray was continuing his rehabilitation at the Assessment and Rehabilitation Centre (ARC) every Tuesday where he spent a full day carrying out various activities under the supervision and guidance of Physiotherapists and Occupational therapists.

##### **Baseline NEADL Score**

The NEADL overall score for independence was 5/22 and functional ability 18/66 for using the Likert scoring method (Harwood and Ebrahim 2002).

The NEADL found that his subsection scores were:

- Mobility – 1/18

- Mr Gray was a wheelchair user and had mobility limitations but reported that he was able to transfer in and out of a car with help.
- In the kitchen – 5/15
  - He was able to take hot drinks from one room to another and feed himself with difficulty but was unable to make hot snacks or drinks independently.
- Domestic tasks – 2/15
  - Mr Gray was unable to manage laundry but reported that he was able to manage money and do his shopping with help. However, he stated that he did not carry out domestic tasks even before his stroke. When asked if he thought he could carry out domestic tasks if Mrs Gray was not present, Mr Gray said that he would not know how to.
- Leisure activities – 10/18
  - He was able to use the telephone, read newspapers and books and write letters independently but needed help going out socially. He was unable to do any gardening and he was also unable to drive a car.

It must be noted that Mr Gray was restricted by his environment in that his house was cluttered with objects and he had difficulties negotiating his wheelchair around the downstairs floor. This also restricted his access to the kitchen and the outdoor areas. Mr and Mrs Gray also had a large pet dog.

## **Results of the Analysis of the First Interviews**

### **Provision of information / feedback**

Mr Gray explained how he could not remember what information he had been given during his time with the CST. However, he was able to remember some of his hand exercises. These consisted of sensory stimulation using various different textures. He was also working towards gaining more movement in his fingers.

He also said that the Physiotherapist had been using a specially constructed mirror (mirror therapy) to encourage more movement in his affected hand. He enjoyed using the mirror because he was able to see his movements but felt that he did not know how to continue using it following discharge from the CST. His reasons for this was that the CST therapist took the mirror away and that he did not know what to do and how to continue the exercises without the help of the therapist,



*“I can’t remember if they gave me anything to do in my own time. I just used to do the tooth brush and sponge things we’d been doing” Mr. Gray.*

*“They made a mirror for us [me] to use. It was good because I could see what was going on. I could see the image of the mirror and I tried to tap both sides [demonstrates bi-lateral tapping] well that would tap anyway but the left hand one as well; tap the right to stimulate the left you know” Mr. Gray.*

When asked if he thought he would be able to continue his rehabilitation independently,

*“Not really. I still feel I need them there to help or somebody there to help you know. I suppose I need someone to tell me exactly what to do at any one time you know” Mr. Gray.*

His carer detailed what they had received from the CST therapists prior to her husband’s discharge,

*“We were given a pack of things, different leaflets like who does what and about the stroke team, who to call you know which one was which. They talked about the Stroke Association what they were there for and how long they would come – obviously we have got them for longer than the CST” Mrs. Gray.*

### **Document analysis**

On inspection of the documents, they included a pack of information of the different stroke services that are available and where Mr and Mrs Gray could access further information such as, the Stroke Association.

### **Inclusion of the carer**

Mrs Gray was asked if she wanted to be involved with Mr Gray’s rehabilitation by the CST nurse,

*“At the start SB [the nurse] said did I want to be involved in his rehab or did I want to use that time to go and do things for myself so I said yes I would like to be involved” Mrs. Gray.*

However, she was pleased with the way in which the Physiotherapist had encouraged her involvement by showing her what they had been working on during the sessions.

*“Sometimes K [CST Physiotherapist] would come out and say I’ve just been working with Mr. Gray’s foot can you at some point just move his foot up and down you know and erm... like the sensory box. I put everything in a box and he*

*can find it. Like massaging his hand you know like stimulation stuff like that with the tooth brush and the sponges. So yes I was encouraged to do things with him” Mrs. Gray.*

However, she explained that although she was willing to provide feedback, this sometimes caused some anxiety if she felt she was unable to remember how to do the exercises with Mr Gray. She was also worried that she may cause ‘damage’ or ‘harm’ if she did not carry out the prescribed exercises correctly. She also commented on the CST therapist’s expertise and alluded to the need for professional training.

*“If I wasn’t sure I wouldn’t do it rather than cause him damage you know” Mrs. Gray.*

*“I might have said your foot needs to be in a straight line. I might say if he stands I’ll say your foot needs to be a little bit straighter than that. Or to sit with his fingers open. I listen to what the professionals say because otherwise you can be doing harm if you go against what they are saying because obviously they have had the training” Mrs. Gray.*

### **Motivation to exercise**

Mr Gray explained that his motivation to carry out rehabilitation during his period with the CST therapists was adversely affected by his inability to detect improvements and by ‘feeling let down’ by the CST therapist not turning up for planned sessions. He also described how he ‘needed’ the CST therapist to provide feedback on his improvements,

*“It’s hard to know whether you’re getting better; I’ve noticed more movement since I came out [of hospital] but it is small... it makes you think why bother! You need them [the CST therapists] to come and tell you. But then if they don’t come... well you feel let down. I know they’ve got loads of people to see, but you need them... you need them to come and let you know how you are doing” Mr. Gray.*

His carer reiterated this and also suggested that he responds well when he receives encouragement from other people,

*“He was always better if they had been because he needs that motivation and if it is somebody other than me he is likely to do it. It is that motivation I think it’s just him I think it is a lot of people if they have got it there... people encouraging*

*him other than family then they tend to respond better because they don't want to be rude by not doing it" Mrs. Gray.*

## **6.14.2 Observing the CMOC's**

### **6.14.2.1 Third Visit**

#### **Initial set up of the System**

It was decided between the participant, his carer and the researcher to set up the SMART Rehabilitation Technology System in the lounge on a table and store the system in the dining room with the wires tucked away. Mr Gray was given reach forward and reach sideways exercises to perform as these were judged to be achievable during the initial set up. Following the reported and observed active range of movement for Mr Gray's affected upper-limb, the researcher decided to set the parameters at 20 – 40° for shoulder flexion and 10 – 30° for abduction. Mr Gray was then instructed to how to use the equipment by taking him and his carer through a step by step demonstration with Mr Gray using the equipment on a coffee stand in front of his wheelchair. Mr Gray was unable to don all of the garments independently requiring his carer to assist. He carried out two sets of four repetitions for the forward reach and reach sideways exercises whilst the Mrs Gray observed.

### **6.14.2.2 Fourth visit**

#### **Analysis of Avatar Replays**

Analysis of the video replays since the previous visit (initial set up) indicated that Mr Gray had performed two sets of five repetitions for the forward reach and reach sideways exercises on two occasions.

#### **Observations**

During the fourth visit, there appeared to be some problems with the sensor orientation. This may have resulted from the sensor charger being next to their radiator causing ferromagnetic interference<sup>7</sup>. Therefore, the charging unit was moved to a wooden table in another room. There was also a problem with the charger plug staying in the sensor during charging; it appeared that the fit had loosened somewhat resulting in the sensors not having a full charge prior to use.

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<sup>7</sup> Ferromagnetic interference – magnetic objects near to the sensors can disturb the magnetometer signals embedded within the inertial sensor resulting in distortion of the orientation measurement(s) (Roetenberg *et al*, 2003).

Observations of the participant and carer using the system during visit four revealed that Mr Gray was able to use the on-screen tools to enable him to analyse his performance. Although he found the analysis of his movement by observing the avatar difficult, he explained that to make this easier he turned the avatar to the left (on the screen) and used the zoom to focus in on his affected arm. This was because his limited movement was harder to detect on the standard (default) display. He also said that he noticed he had not improved following his analysis of the qualitative chart and the graph as they were still in the yellow (bottom) zone indicating that he had performed below the expectations (parameters) set for him.

*“I have to zoom in because there’s not much movement is there... I think it’s easier to see from the side as well. It’s hard to see any improvement there... the dots make it easier, you know how you’ve done then” Mr. Gray.*

*“Nope... Still in the yellow! No better than before” Mr. Gray.*

#### **6.14.2.3 Fifth visit**

##### **Analysis of Avatar Replays**

Analysis of the video replays since the previous visit (fourth visit 3days previous) indicated that Mr Gray had performed two sets of five repetitions for the forward reach and reach sideways exercises on one occasion.

##### **Observations**

During the fifth visit Mr Gray said that he had still not improved; when asked how he knew, he explained that the black dots in the qualitative chart were still in the yellow zone. He was also frustrated by these results because he felt that he was physically moving his arm more. However, analysis of the video replay revealed that he appeared to be adducting his affected upper-limb during the forward reach exercise. Therefore, because the sensors were measuring (pure) flexion, they did not detect and subsequently display an increase. After the researcher explained to Mr Gray that the sensors only measure his arm movement in one direction (flexion), his following attempts displayed an improvement in his performance. This was evident by four of the five black dots in the qualitative chart being in the green zone. He also said that he did not like the line graph (summary feedback) as it was too confusing.

#### **6.14.2.4 Sixth visit**

##### **Analysis of the Avatar Replays**

Analysis of the video replays since the previous visit (fifth visit 5 days previous) indicated that Mr Gray had performed two sets of five repetitions for the forward reach and reach sideways exercises on one occasion.

##### **Observations**

During this visit, Mr Gray said that he thought that his poor performance was a result of the unreliability of the sensors. He remarked that he felt he had not performed as well over the week and he thought this because he could see that the black dots in the chart were not as high as previously. He said that he felt he had moved his arm more and suggested that the sensors 'playing up' or that they may not have been working very well,

*"I feel like I'm moving my arm more but they [the sensors] are not picking that up; they must be playing up again" Mr. Gray.*

His carer explained that he was despondent that his visual results were lower than previous attempts. She also remarked that he found his results frustrating as she believed he did not know what to do to improve them,

*"It's a real shame when he tries so hard and that [the SMART system] says he hasn't done so well. The thing is... I don't know if he knows what to do to get them [the results] up" Mrs. Gray.*

##### **Diary Input**

Mrs Gray had also entered a diary input suggesting that his poorer performance was a result of the sensors not working properly,

*"The shoulder movements show he's in the red today, I don't think the sensors are working properly" Mrs. Gray.*

#### **6.14.2.5 Seventh visit**

##### **Analysis of Avatar Replays**

Analysis of the video replays since the previous visit (sixth visit 5 days previous) indicated that Mr Gray had performed two sets of five repetitions for the forward reach and reach sideways exercises on three occasions.

## **Observations**

Observations during the visit revealed how Mr Gray had achieved a number of attempts that resulted in the black dots being in the green zone providing him with positive feedback. He suggested that this made him more motivated to use the equipment,

*“Well I’m mostly in the green! Once you know you are going in the right direction y’know doing it right, it makes you want to do it again to sort off... confirm it” Mr. Gray.*

He also suggested that he liked the computer to confirm how he thought he had performed,

*“You have an idea how you’ve done but the beauty of that [the SMART system] is that it confirms it” Mr. Gray.*

### **6.14.2.6 Eighth (final) Visit**

#### **Analysis of Avatar Replays**

Analysis of the video replays since the previous visit (seventh visit 4 days previous) indicated that Mr Gray had performed two sets of five repetitions for the forward reach and reach sideways exercises on three occasions. The video replays also suggested that Mr Gray was achieving more movement than previously (approx. 20° of flexion for the forward reach exercise).

#### **Results of the Analysis of the Second Interviews**

##### **Feedback preferences**

Mr Gray described how he was able to use the avatar to analyse his performance; however, he preferred to watch his own arm during performance but used the replay alongside the reference figure for his analysis. Despite this, he said that he preferred the qualitative chart to the avatar because he felt that the charts provided results of his performance. He also reported that he did not like the line graph,

*“I looked at the figure but I preferred the dots after that. They tell you how you have done and where you should be. It confirms how you have done. I watched my arm and then checked it with the dots” Mr. Gray.*

*“The weekly graph was too busy especially if you had had a few goes on it” Mr. Gray.*

Mrs Gray also reported that she preferred the qualitative chart to the avatar and the line graph due to the inaccuracy of the on-screen display,

*“I wasn’t so keen on the little fella [avatar] because like I say however he was sitting or moving it didn’t seem to represent the way he was actually doing it. The dots were good because it was clearer to see and like when he has done several movements in one session the line graph looked a bit busy. So I preferred the dots to the line graph and the man [avatar]” Mrs. Gray.*

### **Trust in technology**

Both the participant and his carer commented on the poor reliability of the sensors and how this affected their use of the system and subsequent interpretation of the feedback. Mr Gray suggested that although he preferred the black dots on the qualitative chart, he did not always trust the results obtained through the system, especially if he thought he had physically performed better,

*“The dots were a help although some seemed to be in the wrong place! Sometimes you felt like you had done really well and the dots would be low which was disappointing but I guess it was the sensors maybe. The line graph of the week was too busy to understand, I tended to have a few goes on that exercise [reach forward] and so the line thing would be all over the place” Mr. Gray.*

*“I watched my arm and then checked it with the dots. They didn’t always match up though but I suspect that is the sensors” Mr. Gray.*

*“I could see the figure move when I moved although I sometimes disappeared into myself [laughs]” Mr. Gray.*

The following figure (6-5) is an example of the inaccurate the on-screen display Mr Gray received.

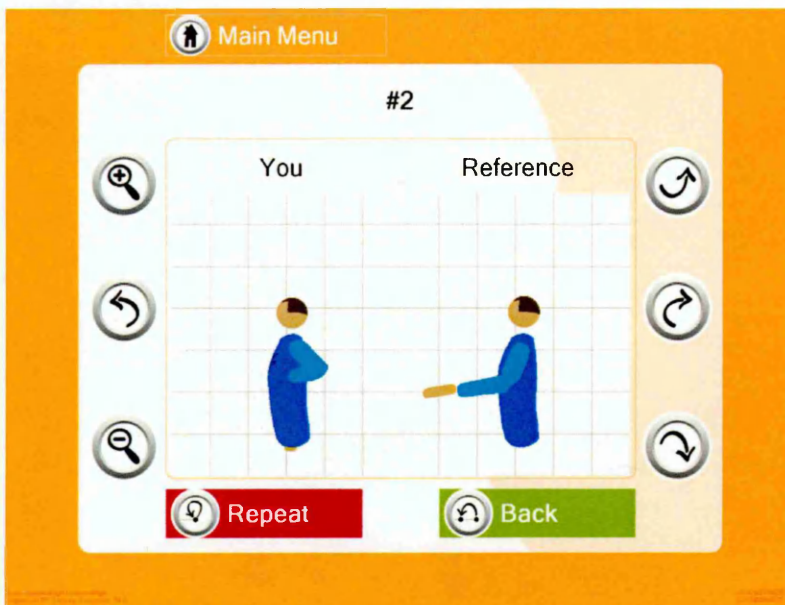


Fig 6-5: The inaccurate on-screen display with Mr Gray.

### Carer involvement

Mrs Gray was very positive about how the SMART system enabled her to be involved in her husband’s rehabilitation. She described how the system helped her to evaluate Mr Gray’s performance,

*“I could see whether he was slouching or you know how much movement was coming from his shoulder rather than his arm. Obviously the idea is to get his arm moving rather than this business [demonstrates a compensatory movement by flexing the trunk] all the time. So yeah, we were able to plot in on the dots and everything, they were brilliant to see how his posture was and everything to see if he was getting better” Mrs. Gray.*

She also described how this compared to her involvement during his rehabilitation sessions with the CST therapists. She considered that the SMART system could have the potential to provide her with a tool to use that would enable her to continue his rehabilitation in the absence of a therapist,

*“With this system I was able to be involved with everything he was doing because sometimes with the stroke team the doors were shut so I couldn’t see what they were doing so I was able to... because I like to make sure that I’m helping him and with this I was able to support him a lot”*

*“This meant I couldn’t help him through the week in-between visits whereas with the system obviously I’ve got to help him put the garments on anyway and then I can help him and encourage him while he is doing it you see” Mrs. Gray.*



## **Improvements**

When asked if he thought he had improved since using the SMART system, stayed the same or was worse, he believed he had improved,

*“Getting better! I can definitely move my arm more now than at the beginning”*

*Mr. Gray.*

When asked how he knew,

*“I can see my arm move more and the dots are mostly in the green now. Also people have told me like T [Mrs. Gray] and the people at ARC” Mr. Gray.*

When his carer was asked if she thought he had improved, stayed the same or was worse since he started using the system,

*“Oh yes, you could see once the dots were getting up into the yellow and the green that he was improving. Or when he was tired and it was in the red that he wasn’t doing so well that day. But when he perked back up the following day then they were back up again so yeah...” Mrs. Gray.*

Both Mr. and Mrs. Gray suggested that they wished they could have kept the system for longer,

*“I’d keep it yes... it gives me something to work on y’know. It tells you how you are doing” Mr. Gray.*

*“We would love to keep going with it, doing it [using the SMART system] is giving him instant feedback to what he is doing and its encouraging as well”*

*Mrs. Gray.*

## **NEADL Score**

The NEADL score did not change from the baseline measurement. However, Mrs Gray reported that Mr Gray had started to help her dress him,

*“I can see that he is attempting to move his arm when I am dressing him and when he eats, things like that really” Mrs. Gray.*

## **6.14.3 Case Discussion**

Mr. Gray had difficulty analyzing his movements displayed by the avatar compared to the reference figure. However, it should be noted that he had minimal active range of movement, which may have contributed to this. As a result of Mr. Gray being unable to detect small changes in performance and alter his movements to improve his results, he

became frustrated which negatively impacted on his motivation to use the system (CMOC's 1, 7, 8 & 10). However, when he was taught how to manipulate the avatar replays by the researcher and 'zoom in' on the avatar, he was able to see his movements although he was still unable to fathom how to alter his movements to improve his results (CMOC 2 & 3). Therefore the researcher was required to explain how the sensors measured his movements and offer advice as to how he needed to change his arm movements during subsequent performance(s).

His motivation was also detrimentally affected by the accuracy and reliability of the sensors. Following occasions where the sensors had been affected by the ferromagnetic interference and were not providing accurate feedback, Mr. Gray lost trust with the feedback and blamed any subsequent poor performance(s) on the sensors. This also reduced the amount he used the system and therefore his rehabilitation intensity (CMOC's 6, 8 & 10). However, when the sensors were working, Mr. Gray liked the confirmation of performance the system provided following use and was able to interpret the results to determine if had improved. In particular, he liked the objective knowledge of results feedback provided by the qualitative chart. Similar to previous users, Mr. Gray enjoyed the positive feedback (when the black dots on the qualitative chart were in the green zone) which increased his motivation to use the system (CMOC's 1, 7 & 10). This enabled him to 'confirm' his subjective interpretation, the consistency of his performance and collaborate with others such as his wife and his therapists at ARC by informing them of his improvements which enabled them to reinforce his behaviour (CMOC's 4 & 12).

The process of setting up the system and training Mr. Gray and his carer to use the system was key to his subsequent use. Firstly, the system had to be accessible for use without undue effort; secondly, the parameters had to be set so that Mr. Gray was at a level where he would not receive poor feedback but also where he would have a target to aim for; and thirdly, the researcher had to ensure that he was able to manipulate the feedback tools and assist with problem solving (i.e. how he needed to alter his movements) for subsequent performance(s) (CMOC 2). Therefore, although the goal (target) setting, and problem solving was carried out in collaboration with the researcher, his independence in the process was limited (CMOC 5).

His carer was very keen to be involved in his rehabilitation and liked the thought of using the system to help her work through his programme with him. During the

observation (in the presence of the researcher) she was very encouraging and gave a lot of praise if he had performed well. This would involve jumping up and down and clapping loudly which also reinforced his behaviour. Therefore, it was unsurprising that she appreciated the potential for the technology to provide rewards suggesting that this would help to motivate her husband (CMOC's 7, 10 & 12). It was also reported by Mrs. Gray that since using the equipment, Mr. Gray had increased his usage of his affected upper-limb (CMOC 9).

Mr. Gray's reaction to the technology highlighted how the reliability and trust in technology may impact on using technology for upper-limb post-stroke rehabilitation. Both the participant and his carer believed that on occasion, the sensors and on-screen display may have been inaccurate. In particular, Mr. Gray described how he was confused when he felt he had physically performed better than the computer results suggested which affected his motivation and trust in the technology (CMOC's 7 & 10).

## **6.15 Case Study 4: Mr. Blackwell**

### **6.15.1 Context**

#### **Therapist's Participant Profile**

The CST therapist stated that Mr. Blackwell was a 65 year old gentleman who had sustained a left ischemic cardiovascular accident (CVA) (right sided hemiparesis) five months prior to participating in the study. The therapist's patient profile documented that Mr. Blackwell required supervision and the use of a walking stick to mobilize around his house, although he was able to go up and down stairs independently.

The therapist's profile also reported that he required the assistance of his carer to carry out personal activities of daily living such as, washing, dressing and toileting. His active range of movement for his affected upper-limb was reported to be; 20° shoulder flexion, 20° abduction; with 5° elbow flexion and full extension. The therapist's patient profile also reported Mr Blackwell as having low-tone throughout the affected upper-limb and hand and that his past medical history involved two previous myocardial infarctions in 2004.

#### **6.15.1.1 First Visit**

During the first visit Mr Blackwell was screened using the MMSE and FAST. His scores revealed that he was eligible to participate in the study.

### **6.15.1.2 Second Visit**

#### **Researcher's Participant Profile**

His detached dorma-bungalow (with stairs) had two stair rails, a raised toilet seat, and a low floor walk in shower cubicle. Mr. Blackwell was due to retire as a computer consultant in the same week his stroke occurred. He therefore had extensive computer programming knowledge which contributed to his interests and hobbies. These included composing music on his computer and editing photographs. Mr. Blackwell was keen to establish a good rapport with the researcher which was demonstrated during the second visit when he requested that he could show the researcher a Power-Point presentation of his life and his awards and accreditations. He reported that up to the age of fifty, had been a national swimming and cycling champion, an international cyclo-cross athlete, and a national level basketball coach. Since then he has been a keen golfer, a guitarist, stamp collector and he also enjoyed designing jewellery.

Mr. Blackwell's wife (Mrs. Blackwell) was also his full-time carer and lived with him. She was a 60 year old housewife. She explained that she was not experienced or confident using a computer and joked that she had never needed to be because of her husband's expertise.

At the time of his participation in the study, Mr. Blackwell was continuing his rehabilitation at the assessment and rehabilitation centre (ARC) every Thursday where he spent a full day carrying out various activities under the supervision and guidance of Physiotherapists and Occupational therapists.

#### **Baseline NEADL Score**

The baseline NEADL overall score for independence was 11/22 and functional ability 35/66 for using the Likert scoring method (Harwood and Ebrahim 2002).

The baseline NEADL found that his subsection scores were:

- Mobility – 9/18
  - Mr Blackwell was able to walk around outside the house with difficulty and needed help with, climbing stairs, crossing roads, travelling on public transport and walking on uneven ground. However, he was able to get in and out of a car independently.
- In the kitchen – 10/15

- He was unable to take hot drinks from one room to another and feed himself independently (he needed his food cutting up) but he reported being able to make hot snacks and drinks and wash up with help.
- Domestic tasks – 7/15
  - Mr Blackwell was unable to manage laundry with help but reported that he was able to manage money and do his shopping with help.
- Leisure activities – 9/18
  - He was able to independently use the telephone, read, and go out socially. He was unable to do any gardening and he was also unable to drive a car or write letters.

It must be noted that although Mr Blackwell reported being able to carry out a number of domestic tasks, he explained that he never needed (or wanted) to because his wife was responsible for them. Mrs. Blackwell was very respectful of her husband and looked upon him in awe. She was very quick to praise him for his efforts since his stroke, his persona and his professional expertise. She portrayed herself as his ‘assistant’ in life in that it was her responsibility to carry out menial tasks for him. Mr. Blackwell was also portrayed by his carer to be ‘the expert’ in the relationship and that he was ‘the boss of the house’.

## **Results of the Analysis of the First Interviews**

### **Goal-setting**

On referral to the researcher, the CST therapist said that Mr. Blackwell was an ‘inspirational,’ motivated self-directed gentleman who was keen to be involved in the planning and recording of both his rehabilitation and his goal achievement. He described how he had set his own goals with his CST therapist and how they would act as a measure of recovery,

*“I did it all myself! I told them what I wanted to do... We sat down [Mr. and Mrs. Blackwell and his CST therapist] and I said this is what I am going to be able to do by the time we’ve finished! They [his CST therapist] helped but they were my ideas. That was important to me, you know, you have to know what you want... something to aim for” Mr. Blackwell.*

When asked how he knew he was getting better and what feedback he had received, Mr Blackwell said that he measured his recovery by achieving his goals and from the feedback from other people,

*“Well it was linked to goals and then how they measure goals. I would get that feedback from them; like I’d be able to say I could do this I could do that for myself” Mr. Blackwell.*

*“I’d get feedback from family like err... if people had not seen me they would comment. I think that helped me to know if I was getting better” Mr. Blackwell.*

### **Limitations and value of the CST to the carer**

Mrs. Blackwell described how she felt that it was important that Mr. Blackwell received more therapy than the CST were able to provide,

*“It was important to him [Mr. Blackwell] that they came out every day because he wanted to be doing things every day and if he wasn’t doing something one day he’d be a bit fed up you know. Alright he’s got his computer and he can always find things to do but he wanted to be walking and going up and down stairs and they sometimes say they were coming and they didn’t come or they’d ring and say there was not enough staff and they couldn’t come out. It was frustrating that for both of us because I knew he really wanted to do it you know; so it was important that we had that time with them” Mrs. Blackwell.*

When asked how they involved her (Mrs Blackwell) in the rehabilitation process, she said that they had involved her from the start and that this was important for long term care,

*“They asked me at the start... they said that it would help in the long run. Because they only have twelve weeks, they’d like to go on for longer but they can’t. So I helped all along really; they were really good, they let me sit in and watch what they were doing and that way I’d be more confident... especially with stairs [laughs nervously]!”*

### **Documents**

The examination of existing documentation found that Mr. Blackwell had a record of his goals that he had set in conjunction with his CST therapist. These were:

1. Walk around the house with the assistance another person.
2. Going to the toilet with the assistance of his carer.
3. Washing and dressing independently.
4. Climb the stairs with the assistance of two people.
5. Use the shower room in the upstairs bathroom with the help of one person.

6. Exiting the house via the main exits.
7. Transfer into the passenger seat of a car independently.
8. Verbally order a meal in a restaurant.
9. Be verbally understood by friends and family.
10. Use the telephone.

These goals suggest that Mr. Blackwell placed an emphasis on regaining his ability to carry out personal activities of daily living, increase his independence to mobilize in and out of his house, and improve his speech. Mr. Blackwell reported that he had achieved all of his goals prior to participation in this study and therefore no longer had any of his exercise sheets provided by his CST therapist.

Mrs Blackwell remembered that during the rehabilitation period with the CST, Mr Blackwell had been given him a number of sheets of exercises to do that were all based around his goals. The booklet also contained general information about stroke and other agencies that may be able to help.

Each of the exercise sheets had between seven and ten exercises to do. The instructions were given using wording and 'Physio tools' pictures.

## **6.15.2 Observing the CMOC's**

### **6.15.2.1 Third Visit**

#### **Initial set up of the System**

It was decided between the participant, her carer and the researcher to set up and stored the SMART Rehabilitation Technology System in the dining room on the sideboard with the wires tucked away. Mr Blackwell was given reach forward and reach sideways exercises to perform as these were judged to be achievable during the initial set up. The parameters were set at 10 – 30° for shoulder flexion and 10 – 30° for abduction. Mr Blackwell was then instructed to how to use the equipment by taking him and his carer through a step by step demonstration with Mr Blackwell using the equipment on a coffee stand in front of his wheelchair. Mr Blackwell was unable to don all of the garments independently, requiring his carer to assist. They carried out two sets of four repetitions for the forward reach and reach sideways exercises.

### 6.15.2.2 Fourth visit

#### Analysis of Avatar Replays

Analysis of the video replays since the previous visit (initial set up 2 days previous) indicated that Mr Blackwell had not used the SMART system since the initial set up.

Prior to the fourth visit Mrs Blackwell telephoned to say the equipment was not working. However, on arrival it was apparent that the sensors had not been charged correctly because Mr and Mrs Blackwell had unplugged the charging unit overnight.

#### Observations

The researcher recharged the sensors and observed Mr Blackwell using the system. Through this, he was able to identify his movement and, following the verbal instruction from the system 'keep your trunk stable', he suggested that he needed to keep his trunk movement to a minimum. He explained that he did not like the avatar as he said that it did not seem to show him 'how he had done',

*"I need to keep still, it's telling me off [laughs]! I'm not so keen on that figure [avatar] I like to know how I've done... those dots are better" Mr. Blackwell.*

He also suggested that he had not performed very well although the black dots in the qualitative chart were mostly in the green for both the shoulder and trunk measurements indicating that he had performed above the expected target. He explained that his disappointment was because he wanted to be perfect and have all of the green dots at the top of the green zone.

### 6.15.2.3 Fifth visit

#### Analysis of Avatar Replays

Analysis of the video replays since the previous visit (fourth visit 6 days previous) indicated that Mr Blackwell had performed four sets of four repetitions for the forward reach and reach sideways exercises on two occasions.

Observation of the video replays suggested that he had performed within the parameters set by the researcher (0-30° of flexion and abduction).

When asked how he felt he had performed, he believed that he done 'as well as before',

*"The dots are in the same place as before [during the previous visit], so I'm about the same as then" Mr. Blackwell.*



## **Observations**

During the visit he carried out one forward reach and had all of his shoulder dots at the very top of the green and all of his trunk dots in the green. Mr Blackwell was pleased with how he had done. As a result of his performance the researcher changed the settings from 0-30° to 0-40° for flexion. Mr Blackwell asked if there were other exercises he could try so the researcher added hand to mouth with the settings set at 0° - 20° elbow flexion.

Mrs Blackwell explained that her only involvement of using the equipment was to assist Mr Blackwell with donning and doffing the garments, getting the system ready for use (placing it on the table), and charging the sensors after use. She thought that Mr Blackwell was very comfortable with using the computer system as he was an expert,

*“I only need to get it [the SMART system] out and put it away. I help him with the garments and I put the charger plugs back in after he’s finished. He loves computers and is used to them... it was his job [laughs]!” Mrs. Blackwell.*

## **Testing New Garments**

During the fifth visit new prototype garments were tested (see appendix 26 p.349).

The new garments did not interfere with the sensors (in that they did not affect the components i.e. magnetometers, gyroscopes and accelerometers). The sensor placement on all of the garments worked well. This was a particular problem with the old vest garment because it did not secure the sensor (prevent unwanted movement) which subsequently led to inaccurate representation of the avatar.

Mr Blackwell was able to put the new wrist and trunk garments on independently which was very good considering he had minimal active movement in his affected arm and hand. He did however; have difficulty donning the upper arm garment. This was because of the Velcro strap was interfering with the arm casing. Nevertheless, Mr Blackwell was able to remove all of the garments independently and with ease.

In addition, both donning and doffing the garments did not fatigue him and he did not become flustered during this process. This was important as one of the questions asked by the SMART system includes; 'are you feeling exhausted?' if the user answer is 'yes' they are advised not to continue using the system without consulting the therapist / researcher.

#### 6.15.2.4 Sixth Visit

##### Analysis of Avatar Replays

Analysis of the video replays since the previous visit (fifth visit 8 days previous) indicated that Mr Gray had performed one set of four repetitions for the forward reach, reach sideways, and hand to mouth exercises on two occasions.

The replays suggested that he had performed within the parameters set by the researcher (0-40° of flexion and abduction).

##### Observations

He was able to don and doff the new garments independently before and after use. He was also able to work through the programme. However, he (as previously) skipped straight past the replay of the avatar and preferred to use the black dots on the qualitative chart and the line graph. Mr Blackwell suggested that he was pleased with his performance as he was in the green zone for the both the shoulder and trunk on three out of four of the forward flexion attempts.

He also explained that the feedback would be more meaningful if it was something he could relate to in everyday life like being able to play his guitar or using his hand to hold a plectrum,

*“The feedback would be better if I could relate it to playing my guitar or holding the plectrum because these are things I want to be able to do... goals” Mr. Blackwell.*

He also suggested that to see how the exercise related to targets or goals; a scoring system would improve the feedback provided by the system. For example, he suggested that by increasing 5° degrees of shoulder flexion the user has gained 5% towards their final target. Therefore progression and recovery would be easier to relate to a final goal.

Mr Blackwell also suggested that using a ghost figure would make it easier to visualise how he had performed compared to the reference figure and also to see small differences compared to the reference figure. He also suggested that more prescriptive feedback would be useful, but interestingly, he knew what he needed to do to improve his performance,

*“It tells you that your trunk needs to stay stable but it doesn’t tell you how to improve your arm score (shoulder). It could say pull your arm back further or try to lift your arm higher” Mr. Blackwell.*

### **6.15.2.5 Seventh (final) visit**

#### **Analysis of Avatar Replays**

Mr Blackwell had used the system twice over the previous seven days since the last visit carrying out one set of four repetitions of each exercise (forward flex, reach sideways and hand to mouth) on each of the occasions. The replays suggested that he had performed at the upper limit of parameters set by the researcher (0-40° of flexion and abduction and 0-20° of elbow flexion).

When asked how he thought he had performed he reported that he thought he was 'getting all the dots in the green' and therefore believed that he had performed well. He also suggested that he was 'better than when he started.'

*"I've done fairly well; kept them [black dots] up in the green so that's good isn't it? Much better than at the start!" Mr. Blackwell.*

#### **Results of the Analysis of the Second Interviews**

##### **Feedback preferences**

Mr. Blackwell described how he preferred the black dots on the qualitative chart to the avatar because it provided him with some knowledge of how he had performed. He was not confident with his ability to analyse the avatar and he needed the qualitative chart to confirm how he had performed. He also suggested that he would like the feedback to be more quantitative as it would be a form of feedback he was familiar with from his previous sports background,

*"You see with those dots you know how you've done. I think you need that because you can watch the man [avatar] but you're kind of guessing aren't you, whereas those dots confirm what you are thinking" Mr. Blackwell.*

*"What I look at is a score... I've got a certain amount of points for things. What do I compare it to? Because I do think you do need that. It's like when you go running, you have a watch or something to measure how you've done like lap times. I used to record all them" Mr. Blackwell.*

Nevertheless, Mr Blackwell was able to evaluate his performance over the four weeks of testing from the computer feedback,

*"I could see that at the beginning I'd sometimes be in the green but by the end I was nearly always in the green and that's after you had changed it as well" Mr. Blackwell.*

## Using the system to augment therapy

Mrs Blackwell described how the SMART system would be a useful way of continuing rehabilitation. She suggested that they were desperate to continue making progress and improvements,

*“We felt it helped K [Mr. Blackwell] with the movement in his arm and wrist and we found it a useful follow up after hospital and Physio and it was something different to try because to be honest we would have grabbed at anything y’know to err... move on” Mrs. Blackwell.*

When asked whether she would like to use the system over an even longer period, Mrs Blackwell suggested that the system would be a useful tool to continue rehabilitating without having to depend on a therapist; therefore enabling her husband to be more independent,

*“I think it was good, I think that it is something that you’d perhaps want to use long term y’know have in your home and use whenever. It seems like the last four weeks have whizzed past and we’ve hardly got stuck into it [laughs]. I think it is handy to have something like that where you’re not waiting for a Physio to come and knock on your door and do something with you, you can do it yourself and it makes K [Mr. Blackwell] at bit more independent” Mrs. Blackwell.*

Mrs Blackwell also suggested that the system could be used during their twelve week rehabilitation period with the CST because the CST therapists may use their time to focus on another activity. Mr Blackwell had stated that his initial goals were to improve his walking mobility and speech; therefore the therapist may have focussed the sessions on the lower limb. However, Mrs Blackwell suggested that the system may have enabled her husband to carry out upper-limb rehabilitation alongside the therapist working towards other goals,

*“I think it would have been beneficial to use at the same time as the CST because they would have worked on his arm earlier and as well you’ve got something to do if they can’t come that day. You’re not missing out on time. I mean K [Mr. Blackwell] had to instigate them to start working on his arm, he asked them to” Mrs. Blackwell.*

During informal discussions after the second interview, in conversation, Mr and Mrs Blackwell described how their CST therapist may influence their decisions to continue rehabilitation,

*“After the Physio stopped coming that was a bit of a blank wall for us.” Mrs. Blackwell.*

*“We didn’t know what was going to happen did we?” Mr. Blackwell.*

*“Yeah we knew that he was going to start going to the Northern [their local hospital] on a Thursday but we didn’t know whether he would want to do that” Mrs. Blackwell.*

*“Well my first reaction was that I didn’t want to do it! I thought it would be full of old fogies!” Mr. Blackwell.*

*“Well C [CST physiotherapist] had said ‘we want you to go because we want you to do the Physio but we don’t know whether you’ll fit in’. But he’s fairly flexible with people so I couldn’t see the problem but like I’ve said anything offered we would never have refused because when she mentioned it we thought yeah brilliant... something else to carry us on sort of thing” Mrs. Blackwell.*

### **NEADL Score**

The NEADL score did not change from the baseline measurement. However, Mr Blackwell reported that he was able to hold a cup with his affected hand which he believed he was unable to do prior to using the SMART system. In addition, during the testing period, the researcher was required to increase the parameters originally set.

### **6.15.3 Case Discussion**

This case study highlighted how the personal context of the user can impact on the utilisation of the computer feedback. Prior to his stroke, Mr Blackwell was a successful high achieving sportsman which may have led to him being motivated to carry out his rehabilitation and indeed take a ‘lead’ in the process. In addition, as a result of his previous occupation, Mr Blackwell was a confident user of a computer and was also motivated to use the SMART system to carry out rehabilitation.

However, during the use of the system Mr Blackwell was impatient with the feedback the system provided and was only interested in the results from the qualitative chart. However, his impatience may have been a result of his lack of confidence in the analysis of the avatar feedback and his prior experience of using more quantitative feedback (as a sportsman). Therefore, in order to maintain his engagement with the SMART system it was imperative for the researcher to set the parameters at the correct

level where he was able to see the improvement and positive results he achieved during his use of the equipment (CMOC's 1, 3, 7, 8, 10 & 11). It was also reported that since using the equipment, Mr. Blackwell had increased his usage of his affected upper-limb (CMOC 9).

This case also highlighted the importance of relating improvements to both functional tasks and the goals set by the user. Mr Blackwell had set his own goals for his rehabilitation and therefore measured his improvements by completing them. Indeed, during his use of the SMART system, he was keen to try new exercises and set his own targets for achievement (CMOC 3, 5). He suggested that feedback provided by the system would be more meaningful if the improvements made were both measurable (quantitatively) and related to his goals. This suggests that in order for the feedback to demonstrate improvement, the feedback from the computer must be both relevant and salient for the individual user (CMOC 10).

Mr Blackwell experienced initial problems with charging the sensors which impacted on his initial usage. However, following advice provided by the researcher, he was able to overcome them and did not experience further problems with the reliability or accuracy of the sensors which may have been a result of his environment (CMOC's 2, 4 & 6). He lived in a large dorma-bungalow that was kept in a very tidy condition with ample space to both use and store the equipment without interference from other objects, people or pets.

Both Mr and Mrs Blackwell valued the input from the CST but described how the limitations of service provision left them frustrated. They both felt that the use of a technology system would augment Mr Blackwell's rehabilitation by providing a means to continue rehabilitating in the absence of a therapist over a longer period of time. However, it must be noted that Mr Blackwell was familiar with using a computer which may have contributed to his admiration of using technology for post-stroke rehabilitation.

This case also highlights how the CST therapist may be influential in deciding what choices their patients make during and following their period of rehabilitation. For example, in this instance, the therapist made judgements as to whether her patient would 'fit in' with other attendees. In the context of this research and future use of technology

in mainstream rehabilitation, a therapist may not choose to use technology as a result of their own beliefs or impressions.

## **6.16 Case Study 5: Mr. Redmond**

### **6.16.1 Context**

#### **Therapist's Participant Profile**

The CST therapist stated that Mr. Redmond was a 79 year old gentleman who had sustained a left ischemic cardiovascular accident (CVA) (right sided hemiparesis) five months prior to participating in the study. Mr. Redmond was a wheel chair user for both indoor and outdoor mobility and required a hoist for transfers.

The therapist's profile also reported that he required the assistance of his carer to carry out personal activities of daily living such as, washing, dressing and toileting. However, he was able to use his affected upper-limb for feeding, taking tablets and using a drinking cup (beaker). His active range of movement for his affected upper-limb was reported to be; 90° shoulder flexion, 90° abduction; with full elbow flexion and full extension. He was also reported as having low-tone throughout the affected upper-limb and hand. The therapist's patient profile also reported that he had metastatic prostate cancer with a terminal diagnosis. He also had spinal cord compression resulting in paraplegia from the fourth lumbar vertebra.

#### **6.16.1.1 First Visit**

During the first visit Mr Redmond was screened using the MMSE and FAST. His scores revealed that he was eligible to participate in the study.

#### **6.16.1.2 Second Visit**

##### **Researcher's Participant Profile**

His detached house (with stairs) had a bed and commode downstairs. Mr. Redmond's previous occupation involved making car batteries. He reported having minimal computer experience and enjoyed watching television, playing Jenga (as part of his rehabilitation) and sitting in the garden.

Mr. Redmond's daughter-in-law (Mrs. Gold) was also his full-time carer and lived in the same house (with her husband, Mr. Redmond's son). She was a 45 years old former cleaner but gave up her occupation to become Mr. Redmond's full-time carer. She

explained that she was experienced and confident in using a computer. Mrs. Gold described how Mr. Redmond was prone to getting emotional which she found difficult to deal with. She preferred to allow his daughter, who visited occasionally, to provide compassionate support. She also described how Mr Redmond was an inquisitive gentleman who *'wanted to know everything that was going on and why therapists did what they did'* throughout his rehabilitation.

At the time of his participation in the study, Mr. Redmond was attending St. Luke's hospice every Friday where he was under the supervision and guidance of a Physiotherapist.

### **Baseline NEADL Score**

The baseline NEADL overall score for independence was 4/22 and functional ability 10/66 for using the Likert scoring method (Harwood and Ebrahim 2002).

The NEADL found that his subsection scores were:

- Mobility – 0/18
  - Mr Redmond had limited mobility as he was a wheelchair user and unable to manoeuvre his wheelchair independently.
- In the kitchen – 3/15
  - He was unable to carry out most kitchen tasks as a result of being unable to access the kitchen and manoeuvre his wheelchair independently. However, he was able to feed himself without help.
- Domestic tasks – 2/15
  - Mr Redmond was unable to manage laundry but reported that he was able to manage money and do his shopping with help. He also reported that he would not know how to carry out domestic tasks because he had never had to do them.
- Leisure activities – 5/18
  - He was able to use the telephone and read independently. He was able to go out socially but needed help. However, he was unable to do any and gardening and he was also unable to drive a car or write letters.

### **Results of the Analysis of the First Interviews**

#### **Provision of information and feedback**

When asked 'what did the CST give you to do when they had left', Mr. Redmond described how his CST therapist gave him activities that included playing Jenga,



Connect Four, and placing clothes pegs on the rim of a biscuit tin. He also described how they would check his ability to carry out those activities on subsequent visits. Interestingly, he mentioned how many pegs he was able to place on the tin at the beginning to how many he was able to do at the time of the interview. This may suggest that he evaluated his improvements quantitatively,

*“They gave me the blocks to do [Jenga], the discs in the holes [Connect Four] and the pegs. I put the pegs on the edge. It’s quite hard... I could only do three at first but I can do seven now” Mr. Redmond.*

Although Mr. Redmond knew he was able to place more pegs on the tin than at the beginning of his rehabilitation he valued the CST therapist’s feedback to inform him that he was improving,

*“They said I was improving, she said I’m getting stronger with my right hand” Mr. Redmond.*

When asked if she (Mrs. Gold) provided any instruction or feedback when Mr. Redmond carried out his exercises in the absence of the CST therapist, Mrs. Gold explained how she did not like to as she felt awkward and believed it was up to the CST therapist to provide it,

*“Err not I haven’t! [laughs] It’s a little awkward, I don’t want to be on his back the whole time and if he is doing anything wrong they will tell him. I mean I don’t particularly... Err... No! As long as he is doing his exercises I think anything has got to be good for him so...No!” Mrs. Gold.*

### **Limitations of the CST**

Mr Redmond was a gentleman who liked to have a routine for his everyday activities which included when he carried out his rehabilitation in the absence of the CST therapist.

His day would start from getting up in the morning and having the same breakfast at the same time followed by his games of Jenga, Connect Four, and putting pegs on a tin. He then watched the television for one hour, slept for one hour and then had lunch.

His carer described how his routine was important to him because he was then able to predict what he was going to do,

*“He needs his routine, It’s like a comfort blanket [laughs], I don’t think it is a bad thing though and in a way it makes things easier for us. He knows what is going to happen and we know what to do for him” Mrs. Gold.*

However, Mrs Gold also described how the inflexibility of the CST disrupted Mr Redmond’s daily routine which may have limited the CST’s ability to provide effective treatment,

*“If they could fit into his timetable it would have been better. There were times when they couldn’t visit on time and he had to have treatment in bed which they said was very difficult for them, it limited what they could do. But they were limited to what times they could come so it would be sort of ring up in the morning, ok I’ll be there at 2pm then the next time I’ll be there at 10am and you know so and it had to be on the day you know so they would ring up and say I’m coming today so there was no structured time so if there was a structured timetable, he would know when they were coming and I would know when they were coming and that would have been nicer” Mrs. Gold.*

## **6.16.2 Observing the CMOC’s**

### **6.16.2.1 Third Visit**

#### **Initial set up of the Equipment**

It was decided between the participant, his carer and the researcher to set up the SMART Rehabilitation Technology System in the lounge. The system was then stored in one of the bedrooms as Mrs Gold suggested that this would provide an ideal place where there was no interference from large metal objects and the family’s pet dog would not ‘chew it’. Mr Redmond was given reach forward and reach sideways exercises to perform. In addition, because (unlike previous cases) he was able to pronate and supinate his wrist adequately, he was also given the ‘catch the ball game’ to perform. The catch the ball game involves pronation and supination of the wrist to move a virtual cup angled to catch a virtual ball falling at different angles from the top of the screen. All of these exercises were judged to be achievable during the initial set up (by the researcher and participant). The parameters were set at 80 – 100° for shoulder flexion and 80 – 100° for abduction. The catch the ball game was set at a window of 90° from left of centre to right of centre.

Mr Redmond was then instructed to how to use the equipment by taking him and his carer through a step by step demonstration with Mr Redmond using the equipment on a

coffee stand in front of his wheelchair. They carried out two sets of four repetitions for the forward reach and reach sideways exercises as well as two attempts of the ‘catch the ball’ game where he scored 1800 and 2000.

Garments: The new garments used with case study four were going through another phase of development; therefore Mr Redmond used the older version. He was unable to don all of the garments independently, requiring his carer to assist.

#### **6.16.2.2 Fourth Visit**

##### **Analysis of the Avatar Replays**

Since the initial set up of the equipment (visit three 4 days previous), Mr Redmond had had three sessions on the system over two of the days. He had performed the ‘catch the ball’ game and one attempt of the forward reach and reach sideways on each occasion. His carer reported that he had scored 2100 on the catch the ball game and that Mr Redmond was better on the second day (third day after the initial set up) after he had got used to it the day before. Mr Redmond suggested that his performance had also improved because the line graph was higher than on the previous attempt.

##### **Discussion during the Visit**

Mr Redmond was asked what his initial impressions of using the system were; Mr Redmond explained how he still found it a bit confusing on the second day but he thought it was something he would get used to. He also suggested that the qualitative chart feedback and the score from the ‘catch the ball’ game were motivating,

*“It’s a good idea; you can see a target to aim for! I can see the dots getting higher and my score going up on that game” Mr. Redmond.*

Mr Redmond also remarked that it provided ‘definite’ (objective) feedback on performance which may differ from the subjective feedback provided by his therapist,

*“Seeing it on there [the computer], it can’t lie, a person can! The therapists often tell you how well you are doing but I didn’t always believe them. I’m sure they just say it to make you feel better, but with that [the computer] well it won’t lie to you, it’ll just tell you how you are really doing” Mr. Redmond.*

*“St. Luke’s tell me I’m getting better but I don’t know if I am or if they are just saying it” Mr. Redmond.*

Mr Redmond also suggested that it would need to be part of a routine in order to get used to using it every day. However, Mrs Gold remarked how she hoped he would ask to use the system without prompt,

*“He doesn’t think to ask to bring it down [it is kept in the bedroom upstairs] for himself” Mrs. Gold.*

## **Observations**

During the visit, the researcher was unable to observe the participant use the system because the computer was not detecting the sensors. This may have been a result of the sensors not being fully charged up prior to use. As a result, the researcher advised Mr Redmond and Mrs Gold to keep the sensors on charge and before using the system, Mrs Gold should unplug the sensors and then plug them back in to make sure they were on charge just before use.

### **6.16.2.3 Fifth visit**

#### **Analysis of the Avatar Replays**

Analysis of the video replays since the previous visit (fourth visit 7 days previous) indicated that Mr Redmond had performed one set of five repetitions for the forward reach and reach sideways exercises on three occasions. It was reported that he had two attempts at the ‘catch the ball game’ on each occasion (the system does not indicate any previous ‘catch the ball’ attempts).

Mrs Gold suggested that the sensors had worked well since the last visit. Mr Redmond and Mrs Gold reported that they felt he had improved since the start because they could see that all of the black dots in the qualitative chart were in the green and the line graph also indicated an improvement between uses (fig 6-6 overleaf). Mrs Gold took a screen shot of the line graph.

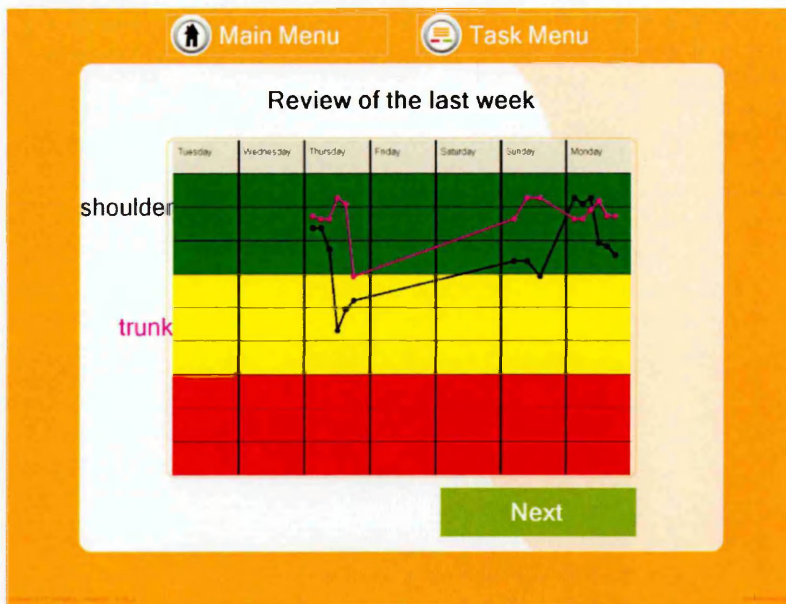


Fig 6-6: Screen shot of Mr Redmond line graph feedback.

Mr Redmond described how using the system had affected his movements,

*“it helps to speed you up’ when doing the catch the ball game. You have to go at the speed of the computer and not a person!” Mr. Redmond.*

### **Observations**

During the observations of Mr Redmond and Mrs Gold using the system, Mrs Gold explained that she performed passive movements with his arm before Mr Redmond carried out the exercises whilst they watched the demonstration video on the system. During this observation Mrs Gold gave verbal instruction at the same time as Mr Redmond moved his arm,

*“that’s it move your arm up, up, up... well done, now try and straighten your elbow... and bring it back down to the table” Mrs. Gold.*

Mrs Gold reported that Mr Redmond had scored 2700 for the catch the ball game prior to the visit. However, the score on observation was 2200 on the first attempt and 2400 on the second attempt.

During the observation of Mr Redmond carrying out the forward reach and whilst reviewing the replay from frontal and sagittal planes, he was unable to recognise differences between himself and the avatar. This was still the case when he was given prompts such as, ‘can you tell which arm is higher?’ and ‘Can you see any differences in the elbows?’ The researcher then told him what the differences were i.e. ‘can you see

your elbow is bent and that one is not – ‘yes...’ The researcher then asked if he could think of how to correct the differences; Mr Redmond was unable to do this.

#### 6.16.2.4 Sixth visit

##### Analysis of Avatar Replays

Analysis of the video replays since the previous visit (fifth visit 6 days previous) indicated that Mr Redmond had performed one set of four repetitions for the forward reach and reach sideways exercises on one occasion. It was reported that he also had one attempt at the ‘catch the ball game’.

##### Discussion during the Visit

During the sixth visit Mrs Gold reported that Mr Redmond had improved his catch the ball score to 2700 (from 2400).

Mrs Gold suggested that they had had problems with the sensors since the last visit in that they were not showing a true representation of his image on the screen i.e. his arm was above his head when he had it by his side. Mrs Gold took a screen shot of this (fig 6-7).

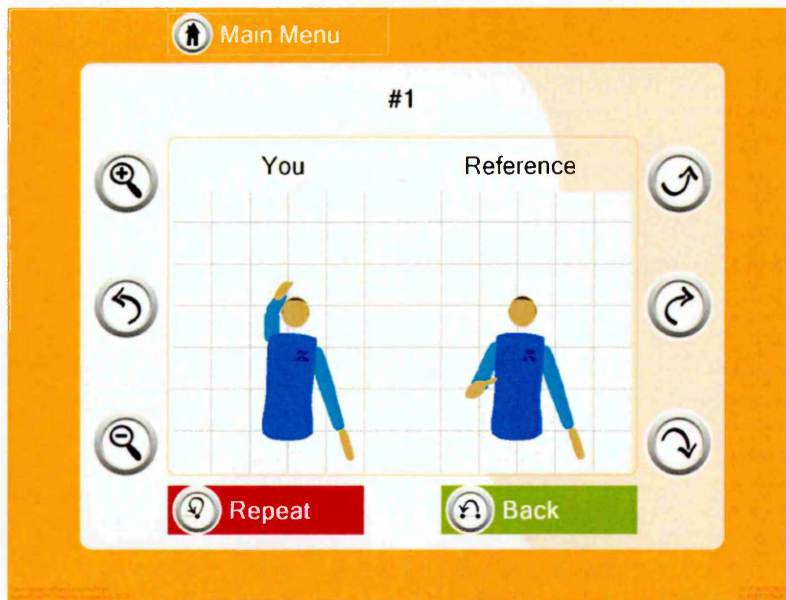


Fig 6-7: Screen shot taken by Mrs Gold of the inaccurate on-screen display during exercise.

They also said the line graph was inaccurate and confusing. However, Mrs Gold believed she may have put the sensors in the garments incorrectly (upside down).

Mrs Gold entered into the computer diary how Mr Redmond had performed on the catch the ball game but also suggested that the sensors were unreliable,

*“He [Mr. Redmond] did better on the catch the ball game, his score was 2800. The sensors didn’t seem to be recording the correct positions on the other two tasks” Mrs. Gold.*

### **Observations**

During this visit, the researcher observed Mr Redmond carry out the forward reach exercise with Mrs Gold assisting. Mrs Gold provided instructions throughout the exercises,

*“Lift your arm; higher, higher, now straighten your elbow. That’s it get it as high as your nose, up, up, up. Well done that looks good. Now bring it back down to your side, elbow in” Mrs. Gold.*

Mrs Gold gave instruction rather than feedback. She evaluated what he needed to do without telling him how or what he was doing and then told him how to improve. During this observation, neither Mr Redmond nor Mrs Gold used the optional views when replaying the video feedback.

The qualitative chart indicated that Mr Redmond had scored all of his black dots in the green zone. He described how he could see how he had got better by each attempt,

*“I’ve improved as I’ve gone along there; I think I did better than the line graph says on Wednesday” Mr. Redmond.*

The researcher asked Mrs Gold if she is helping him more with his exercises with the computer than with his previous activities (i.e. Jenga, Connect Four) she replied,

*“No not really, I think we do this instead of the Jenga and Connect Four games. I think that because it is something new, he needs some help to do the computer exercise the right way. He knows how to play Jenga now...” Mrs. Gold.*

### **6.16.2.5 Seventh visit**

#### **Analysis of Avatar Replays**

Analysis of the video replays since the previous visit (sixth visit 4 days previous) indicated that Mr Redmond had performed one set of five repetitions for the forward reach and reach sideways exercises on five occasions. It was reported that he had two attempts at the ‘catch the ball game’ on each occasion.

#### **Discussion during the Visit**

He had only missed one day since the last visit (Friday because he was at St. Luke’s). Mrs Gold explained that using the computer was now part of his daily routine where he carried out his computer exercises at 11a.m.

Mrs Gold commented in the computer diary how he had continued to improve his score on the catch the ball game and why Mr Redmond felt his performance had improved,

*“His [Mr. Redmond] best score on the ball game was 3100. He managed to lift his arm higher on the forward reach task. He felt he had improved because the avatars looked the same as each other and the graphs showed this” Mrs. Gold.*

Mrs Gold suggested that she still found the line graph confusing,

*“The graph can be confusing because the shoulder line is below the trunk line. It might be better if they were in totally separate boxes” Mrs. Gold.*

Towards the end of testing, Mrs Gold commented how she believed using the SMART system had affected Mr Redmond’s use of his affected upper-limb,

*“He has tried to do much more with his right hand than before, although he is left handed [for eating]! He uses it more for eating with his knife and fork and drinking; I don’t think he did that before he started with the computer. He’s more confident to use it now I think. He will use it because he doesn’t think he’s going to drop his cup anymore” Mrs. Gold.*

Mrs Gold also suggested that Mr Redmond finds it easier to put his wrist watch on his left hand using his affected hand (right hand); he was drinking from his cup more with his right hand; and his writing was much better. Mr Redmond suggested that he was able to sign his name confidently.

Mrs Gold explained how if Mr Redmond did not incorporate exercising his affected arm within his routine, he may neglect using it and potentially compensate by using his non-affected arm,

*“We do the exercises on it at the same time every day, so I think he is getting used to working his arm every day. He’d probably forget about it otherwise and stick with his left arm” Mrs. Gold.*

Mr. Redmond chose not to carry out the computer exercises during this visit because he was feeling too tired.

#### **6.16.2.6 Eighth (final) Visit**

##### **Analysis of Avatar Replays**

Analysis of the video replays since the previous visit (fourth visit) indicated that Mr Redmond had performed one set of five repetitions for the forward reach and reach



sideways exercises on three occasions. It was reported that he had two attempts at the 'catch the ball game' on each occasion.

During the final visit Mrs Gold reported that Mr Redmond had not performed as well over the previous week which she believed was due to the sensors not working reliably,

*"Yesterday it was in the amber for the forward reach although it had been in the green for the previous two days. He well we could figure out why this was the case or even how to get it back into the green. We didn't do anything different today so it must be the sensors I suppose" Mrs. Gold.*

## **Results of the Analysis of the Second Interviews**

### **Understanding performance**

During the second interview Mr Redmond described how he felt he knew he had performed using the feedback from the SMART system. In particular he described how he used the black dots on the qualitative chart and the line graph to understand whether he had performed 'well' compared to previous attempts,

*"The points [score on the catch the ball game] helped me know how I'd done from day to day. The graphs helped as well and the dots in the different colours. I could tell if the dots were up in the green, I'd done well. You knew if you were in the bottom lot [red zone] you weren't any good, you weren't doing any good. But as the dots were, each time you checked them as they were rising, as they got higher and the lines [on the line graph] as they got higher you could tell that you had improved today compared to yesterday" Mr. Redmond.*

His carer also described how she believed he was improving by interpreting the feedback. She also suggested that she was able to do this over a longer period (weeks) rather than day to day performance(s). When asked what on the computer system helped her to interpret Mr Redmond's performance she replied,

*"...the graphs and the score on the catch the ball game. It has tended to go up, week by week, not day by day but as I say some days are better than others but week by week I think his best score on the catch the ball game was 1200 on the first week we used it but by this week the best score was 3600, so it's gone up and err... he has never had a bad score in the last two weeks as he had in the beginning. Again with the reach forward, the dots and the graphs have been in an upward direction" Mrs. Gold.*

## **Motivation**

Mr Redmond described how he preferred the 'catch the ball' game on the system because it provided a score that was both easy to interpret and motivating,

*"I liked the catch the ball one... I felt more tempted to try again and again to get a better score. It's a good exercise because it encourages you to keep trying and get better. The more you have a go at it the more exercise you are doing" Mr. Redmond.*

His carer, Mrs Gold also commented that Mr Redmond liked the 'catch the ball' game, She suggested that she believed that this was due to the task 'being more like a game' and that because he gets a score he can tell others how well he is doing which results in him receiving praise from others,

*"He always goes for the catch the ball game because I think he considers it a game rather than a task. I think that's because he gets a score, it is easier for him to tell other people that 'I did catch the ball and I got 3100' or... 'I'm better this week I got 3600' and even though it might not make much sense to other people, they can tell it is going up and it always seems to appeal to him and he wants to do better on it each time" Mrs. Gold.*

However, the reliability of the on-screen feedback had a detrimental effect. When asked what feedback she thought Mr Redmond found useful, she suggested that he found the avatar confusing, especially when the on-screen feedback portrayed an inaccurate image. In addition, she explained that although she was able to understand that the poor results may be due to the system not working properly, Mr Redmond became concerned,

*"Yesterday he was rather crest fallen; 'I've done my best and it is still in the amber' when I knew it was just not working properly. I think it put him off using it. ...It wasn't a concern for me because I could see that what he was doing was ok but it was a concern for him. I said to him look it's just not working properly and don't worry about it; which was fine but I think it still worried him" Mrs. Gold.*

## **Incorporating the SMART system into rehabilitation.**

Mrs Gold suggested that once Mr Redmond had incorporated using the system into his daily routine, it gave him some variety within his rehabilitation program,

*“I think it would be nice to swap them round, I mean we’ve tried to do it exclusively, but in conjunction with the other things, I think it is good, so the more variety he has the better” Mrs. Gold.*

However, Mrs Gold identified the potential for using such a system in that although she valued the input from the CST, she thought that the SMART system may enable them to be less reliant on the CST to continue improving whilst still receiving feedback,

*“I think the computer would be a good follow on from a start. It is something that people can do when they are half way to where they want to be. I think it was important for him and I suppose for me as well to have the stroke team coming in doing all this work with him. But this has been great for... we don’t need them particularly to be here to carry on some improvement but still get the feedback on how he is doing” Mrs. Gold.*

### **NEADL Score**

The NEADL score did not change from the baseline measurement. However, Mrs Gold reported that he was using his affected arm/hand to hold a cup which she believed he was unable to do prior to using the SMART system.

### **6.16.3 Case Discussion**

This case study has highlighted the potential for using technology for post-stroke rehabilitation in the home. In particular, how using technology may have the potential for stroke survivors (and their carers) to continue rehabilitating in their own time whilst receiving feedback that could, without the technology, be limited and still the subjective interpretation of the stroke survivor and/or their carer.

Mr. Redmond’s environmental context impacted on his access to the SMART system in that the system was stored upstairs away from the family dog which therefore required him to be dependent on his carer to set up the system for use. Mr. Redmond was also a wheelchair user which may have caused the sensors to be affected by ferromagnetic interference resulting in inaccurate feedback. This led to reduced usage and a lack of motivation to carry out exercises (CMOC 10). However, Mr. Redmond and Mrs. Gold were able to continue using the equipment despite technical difficulties (CMOC 6).

Mr. Redmond liked the concept of receiving the objective knowledge of results feedback from the SMART system which not only enabled him to measure improvement and self-monitor but also inform others of his improvement (CMOC’s 1, 2,

3 & 4). This suggests that the provision of a 'score' may enable collaboration and positive reinforcement from others (CMOC 12). However, although Mr. Redmond described how the 'computer can't lie (like a therapist can),' the objective feedback he received was determined by the researcher. For example, by setting the parameters for the exercises, the researcher was able to determine how far into the yellow/green zone (on the qualitative chart) he would potentially reach and how easy the game (where he received a score) would be based on his observed level of ability. This would then determine whether he received positive feedback (a good score) or negative feedback (a poor score). Therefore, the setting up of the system by the researcher was key to the impact of the feedback during use.

Mr. Redmond's confidence to use the system and indeed his affected upper-limb appeared to grow with increased usage and observation of improved performance (CMOC 8 & 11). His carer described how his confidence to use his affected upper-limb for everyday tasks also increased (CMOC 9). Therefore, this may suggest that increased usage of the affected upper-limb coupled with positive feedback and reinforcement, could increase the user's confidence. This may lead to having increased confidence to carry out functional everyday activities with their affected upper-limb (CMOC 9).

This case study also highlighted some of the limitations the CST may have in providing post-stroke rehabilitation in the home, such as, their limitations in providing therapy that fits into a patient's daily routine as well as providing feedback in their absence.

### **6.17 Quantitative Outcomes: The Nottingham Extended Activities of Daily Living (NEADL) Scores**

The NEADL data was analysed by extracting the components of the measure that involve the upper-limb(s). This involved examining the scores of six of the 22 functional tasks within the measure specifically; feeding, making a hot drink, washing up, making a hot snack, managing money, and washing small items of clothing (table 6-4).

The participants varied in the number of times they used the system in the absence of the researcher (2 – 15); the overall amount of sets (4 – 20) and repetitions they carried out (8 – 100) (see table 6-3 overleaf).

Table 6-3: Participant usage of the SMART Rehabilitation Technology System

Case Study	Exercises	Number of uses (in the absence of researcher)	Usage		NEADL Scores Independence (I); Function (F)					
			Overall Sets	Overall Repetitions	Before using the SMART system. Mobility (M) Kitchen (K) Domestic (D) Leisure (L)	After using the SMART system. Mobility / Kitchen / Domestic / Leisure	Change Mobility / Kitchen / Domestic / Leisure			
<b>Mr. Brown</b>	Forward Flexion	2	4	8	I	F	I	F		
					M	4	M	4	13	0
					K	4	K	4	13	0
					D	5	D	5	13	0
				L	2	L	2	9	0	
<b>Mrs. Green</b>	Forward Flexion	9	9	68	M	0	M	0	0	0
					K	2	K	2	9	0
	Reach Sideways		9	68	D	1	D	1	5	0
					L	2	L	2	7	1 (new glasses)
<b>Mr. Gray</b>	Forward Flexion	10	10	100	M	0	M	0	1	0
					K	2	K	2	5	0
	Reach Sideways		10	100	D	0	D	0	2	0
					L	3	L	3	10	0
<b>Mr. Blackwell</b>	Forward Flexion	6	6	48	M	2	M	2	9	0
					K	4	K	4	10	0
	Reach Sideways		6	48	D	2	D	2	7	0
					L	3	L	3	9	0
	Hand to mouth		4	16						
<b>Mr. Redmond</b>	Forward Flexion	15	17	68	M	0	M	0	0	0
					K	1	K	1	3	0
	Reach Sideways		17	68	D	1	D	1	2	0
					L	2	L	2	5	0
	Catch the ball		20							

**Table 6-4: NEADL Score changes specific to the upper-limb for each participant**

<b>Case Study</b>	<b>Before using the SMART system. Independence (I) / Function (F)</b>	<b>After using the SMART system. Independence / Function</b>	<b>Change Independence / Function</b>
<b>Mr. Brown</b>	I – 5	I – 5	0
	F – 15	F – 15	0
<b>Mrs. Green</b>	I – 3	I – 3	0
	F – 11	F – 11	0
<b>Mr. Gray</b>	I – 2	I – 2	0
	F – 4	F – 4	0
<b>Mr. Blackwell</b>	I – 5	I – 5	0
	F – 8	F – 8	0
<b>Mr. Redmond</b>	I – 2	I – 2	0
	F – 5	F – 5	0

Analysis of the scores for each participant (tables 6-3 and 6-4) suggest that the irrespective of the number of attempts to use the SMART system or the number of sets and repetitions, the participants did not improve their measured functional independence over the period of using the SMART system. This may be due to the insensitivity of the outcome measure, the specificity of the computer exercises and the number of repetitions carried out.

Firstly, the NEADL may not have been responsive to change as the measure contains a number of high level tasks that involve whole body involvement such as; gardening, driving, and doing housework; therefore, if the participant is unable to walk, they will not be able to carry out the task. In addition, only six of the 22 tasks directly involve the upper-limb which may also add to the unresponsiveness of the measure. In addition, the measure does not account for environmental restrictions, such as, being unable to access the kitchen or outside area to carry out the task. For example, three of the five participants were wheel chair users and therefore were unable to confirm that they were able to carry out tasks outside of their living room i.e. washing up, washing clothes.

Secondly, the NEADL has been criticised for being gender specific (Harwood and Ebrahim 2002) as many of the tasks involve activities that may not be appealing to men. Four of the five participants in this research were men and all commented that they ‘do not do housework, making meals or washing.’ This may have affected their responses to the questions involving these tasks.

Thirdly, a key motor learning principle involves specificity (Winstein and Wolf 2009). The computer exercises prescribed during testing did not specifically match the tasks in the measure. For example, reaching forwards or sideways involves a movement that is not goal or task orientated unlike washing up, making a hot drink or feeding. An example taken from gaming technology includes playing the bowling game or the tennis game on the Nintendo® Wii™. The games do not necessarily improve one's ability to bowl in the arcade or play tennis on the court.

Finally, the maximum number of repetitions carried out by the participants throughout the testing period was 100 (Mr Gray) which may have been insufficient to facilitate functional change. Therefore, further work is required to explore the amount of repetitions users need to carry out in order to gain functional carryover.

## **6.17 Summary**

This chapter has described the systematic testing of the CMOC's with five participants and their carers using the SMART Rehabilitation Technology System for up to five weeks in their own homes. This involved the use of multiple methods of data collection including, observations, interviews, and an extended activity of daily living scale.

The exploration of the experiences of individual participants and their carers has uncovered a number of key issues and themes from the data that will allow for further refinement and synthesis of the theoretical propositions described and refined throughout this thesis.

The following chapter will therefore explore and discuss the findings and synthesise and present the findings as CMOC configurations to answer the question: *'what works for whom and in what circumstances and respects?'*

## **Section Three: Synthesising the Findings**

### **7. Chapter 7: Synthesis: ‘what work works for whom and in what circumstances and respects’**

#### **7.1 Introduction**

Chapter six subjected the hypothesised CMOC’s to systematic testing by exploring the use of computer feedback to facilitate upper-limb post-stroke rehabilitation over an extended period of time unsupervised in their home with a number of users and their carers. This provided an insight into the individual perspectives and experience of participants and their carers of community stroke rehabilitation followed by their experience undertaking rehabilitation independently and utilising feedback using the SMART Rehabilitation Technology System.

Systematic testing of the CMOC’s revealed what specific ingredients within the underpinning mechanisms work, for whom, and what circumstances are / are not conducive to the utilisation of feedback from computer-based technology for upper-limb post-stroke rehabilitation in the home, in the absence of a therapist. This has allowed for further refinement and a synthesis of the theoretical propositions described and refined throughout this thesis.

The next stage of the evaluation cycle involves the specification phase where the findings are synthesised and presented as refined CMOC configurations to answer the question: ‘*what works for whom and in what circumstances and respects?*’ (Pawson and Tilley 2004) (fig 7-1 overleaf).

The following chapter will therefore discuss and synthesise the impact of the context on the underpinning theory-driven mechanisms and how this influences the outcome(s). The refined CMOC configurations are then presented.



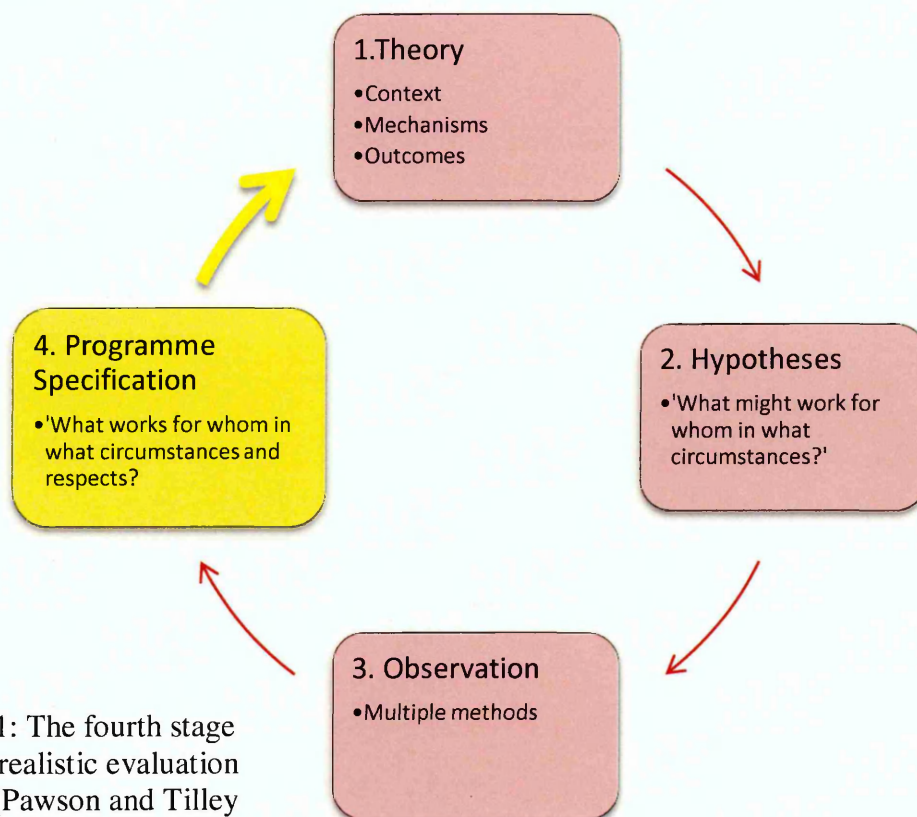


Fig 7-1: The fourth stage of the realistic evaluation cycle (Pawson and Tilley (1997)).

## 7.2 Discussion: Factors influencing the utilisation of feedback

The updated MRC framework places greater attention to the contexts in which interventions take place and that the recognition of early testing and contextual factors is essential (discussed in chapter three) (NIHR CLAHRC SY 2009; Craig *et al*, 2008; MRC 2008) (fig 3-2 p. 87). In addition, the ICF (WHO 2001) also considers the interaction between; pathology (body structure and function), impairment (signs and symptoms), activities (functionality) and participation (social integration) and has now become the main conceptual framework for understanding the chronic consequences of long-term conditions such as stroke (Gottlieb *et al*, 2001; Geyh *et al*, 2004). Indeed, the recently updated National Clinical Guidelines for Stroke (Intercollegiate Stroke Working Party 2008) have based their recommendations for the management and treatment of stroke on the ICF model (fig 7-2 overleaf).

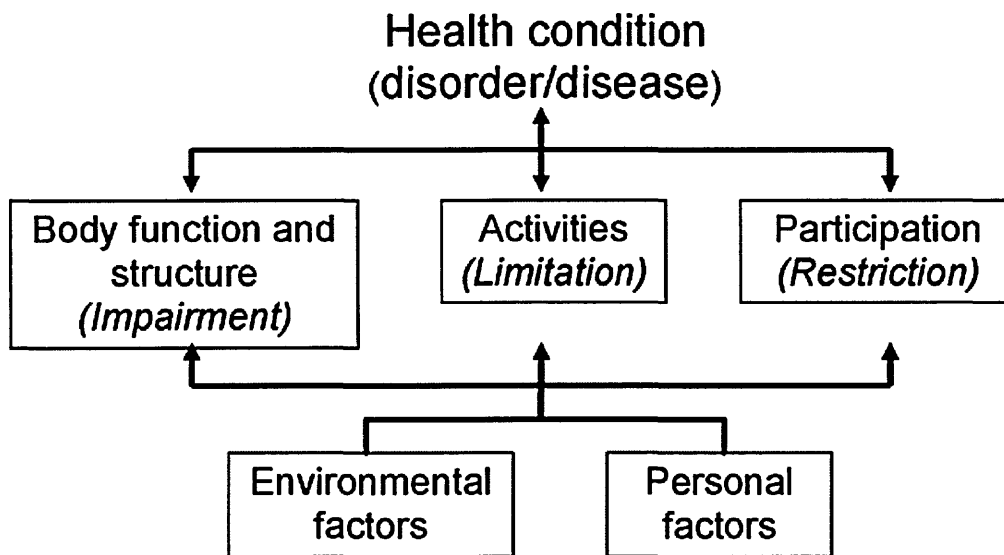


Fig 7-2: The ICF model of health (WHO 2001).

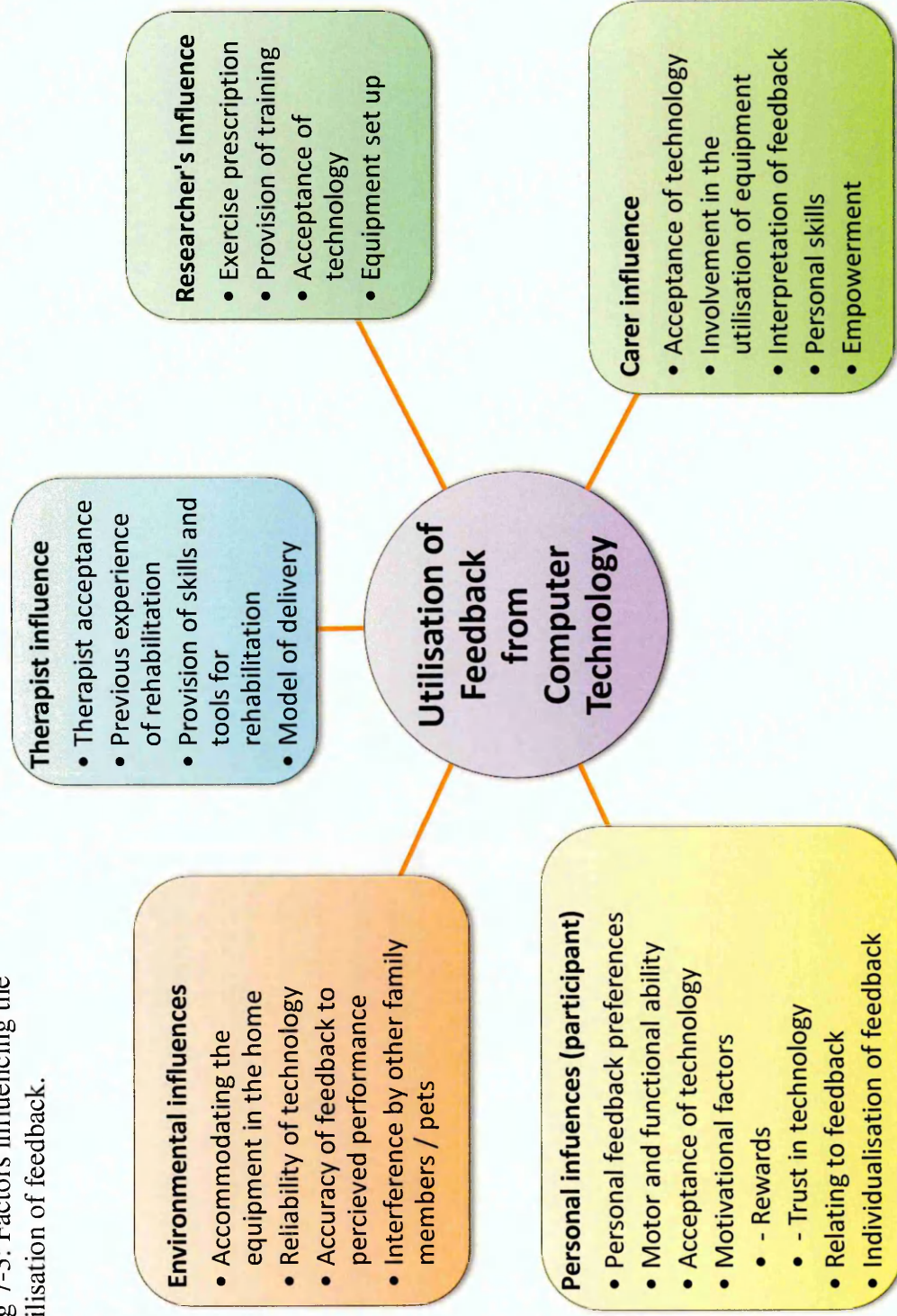
Therefore, the introduction of radical innovation and potential paradigm shifts in service delivery requires an iterative process of feasibility testing, development, and constant evaluation that includes the contextual influence and involves all stakeholders (NIHR CLAHRC SY 2009; Craig *et al*, 2008; MRC 2008) (fig 3-3 p. 87).

This research aimed to explore what components of feedback delivered by computer technology works (is favourable); for who (stroke survivors); in what circumstances (context); and respects. Therefore, in accordance with the MRC framework and the ICF, this research has exposed a number of personal and environmental contextual factors that contributed towards the participants' experience throughout the complex intervention used within this study.

Therefore the following section discusses and synthesises the influence of the personal and environmental context that influenced the utilisation of feedback from computer technology for home-based upper-limb post stroke rehabilitation. This will include specific examples from the cases involved in the systematic testing of the CMOC's in chapter six.

The following figure (overleaf) illustrates the personal and environmental factors involved (fig 7-3 overleaf).

Fig 7-3: Factors influencing the utilisation of feedback.



## **7.3 Context**

As discussed in chapter one, over recent years there has been a contextual shift in service delivery from hospital-based rehabilitation to the community. However, the provision of post-stroke rehabilitation in the context of the home has a number of limitations (see 1.6.3 p. 30). Therefore, because this research involves the exploration of the transition of one experience (feedback provided by a therapist) to another (feedback provided by a computer). The experience of receiving instruction and feedback from the CST therapist may influence opinion and/or expectations of other models of service delivery. In addition, any skills patients/stroke survivors have developed, such as learning to use exercise sheets or interpret the verbal feedback from a therapist, may only be applicable to that form of delivery. Therefore, the following section describes and discusses the pre-existing context and the influence of previous service delivery on the utilisation of feedback from computer-based technology for upper-limb post-stroke rehabilitation in the home, in the absence of a therapist.

### **7.3.1 The Pre-existing Context**

#### **7.3.1.1 CST Therapist Influence**

In order to explore the shift from face-to-face rehabilitation that is delivered by the therapist to rehabilitation that involves using technology in the absence of a therapist, participants were purposely recruited immediately after their period of community rehabilitation. This enabled the researcher to encourage the participant (and their carer) to reflect on previous experience and expose how their previous model of service delivery may have influenced their experience of using the SMART system and the feedback it provides.

#### **The Provision of Information and Feedback by the CST Therapists**

All of the five participants/carers described how they received written information from the CST therapists to enable them to continue their prescribed exercises after the therapist had left. In addition to general information sheets; such as, information about other agencies that may offer help and/or support, they were all given exercise sheets with written instructions and graphical illustrations.

However, three of the five participants either could not remember what they had been given or had thrown the exercise sheets away. In addition, all of the participants described how they relied on their carer to assist them in carrying out their exercises in the absence of the therapist. The requirement of the carer to assist with their exercises

may have been because the exercises needed another person to assist or the stroke survivor needed help with remembering how and what exercises to do. For example, Mr. Gray and Mrs. Green both said that they needed help to remember what to do and how to do them, whereas Mr Brown required his carer to physically assist him.

When asked if the CST therapist provided feedback on the exercises the participant had carried out since their last visit, one of the participants (Mr Brown) and one of the carers (Mrs Whiting) explained that they did not which may have been because the CST therapist was limited for time during each visit. Interestingly, Mr Gray suggested that because he found it difficult to detect improvements and that he ‘needed’ the CST therapist to provide feedback.

One of the reasons for receiving limited feedback on progress with the home exercise programmes maybe the CST therapists’ time and resource limitations. One of the participants (Mr. Brown) and three of the carers stated that the CST therapists were often limited for time which resulted in the CST therapist having to concentrate on the treatment they had planned for that particular session.

Mrs Blackwell explained that although the CST therapists were unable to provide daily input, she believed it was important to Mr Blackwell that the CST therapists did in order to keep him motivated and focussed on his rehabilitation. Mrs Gold also described how the inflexibility of the CST therapists disrupted Mr Redmond’s daily routine which may have limited the CST therapists’ ability to provide effective treatment. For example, if the CST therapist arrived during Mr Redmond’s sleeping time (10.00 – 11.30 am), the therapist would carry out the treatment whilst he was in bed and feeling tired.

### **7.3.1.2 Implications**

The exploration of an essential component of rehabilitation (the pre-existing provision of information and feedback) in this study has provided further knowledge and understanding of how previous experience of service delivery. More specifically, how the therapists’ delivery of feedback can influence the stroke survivor’s ability to adopt and utilise newer innovative forms of service delivery (such as the use of technology).

Findings have revealed that due to personal (i.e. poor memory) and environmental (i.e. resource limitations) contextual factors, the provision of instructions and feedback (prior to participation in this study) may not be conducive to autonomous home-based rehabilitation. As a result of these limitations, the participants and their carers who took

part in this study may have had a limited opportunity to develop the skills necessary for carrying out independent rehabilitation in the absence of a therapist. Furthermore, they may have had limited experience of carrying out self-managed rehabilitation and its essential components i.e. decision-making, resource utilisation, taking action and others (described in chapter 2).

Therefore, the CST therapists who provided rehabilitation to each of the participants prior to their involvement in this research may have influenced their *ability* to utilise the computer feedback. The rehabilitation process involves the patient learning how to rehabilitate (Wohlin-Wottrich *et al*, 2004). During the rehabilitation period, therapists play a key role in teaching their patients how to carry out the tasks that are essential for recovery, such as, identifying their own needs and wishes, setting goals to achieve, and carrying out exercises to meet their goals (Wohlin-Wottrich *et al*, 2007). An essential component of this process involves the patient understanding how they are performing, how they have performed, and what they need to do to improve. Therefore, if the patient is reliant on the therapist to provide the answers, they will not readily learn how to answer the questions themselves.

Chapter four described how the therapists provide a model of rehabilitation that may not be conducive to patients being encouraged to have the ability to answer their own questions. Paradoxically, if patients are not taught how to manage their condition independently, they may become more reliant on services and their carers placing an even greater strain on resources.

In this study, none of the participants were able to use the avatar to understand their performance which requires the participant to form a subjective opinion of their own performance. They were unable to comprehend from the avatar and how they were performing (during use of the system) or how they had performed (after using the system). Interestingly, all of the participants (and their carers) preferred the knowledge of results provided by the qualitative chart which provides the answers to the questions; '*how have I performed?*' and, '*how have I performed in relation to how the therapist expects me to perform?*' This suggests that they did not have the skills to analyse their movements or form opinions of their performance.

However, the limitations in the resources available (i.e. exercise sheets) and the variability in the therapists' patient's ability (both cognitive and physical) may prevent

the therapists from providing their patients with the skills required to analyse their performance. For example, firstly, exercise sheets do not provide the user with feedback and secondly, more severely affected stroke survivors or those who have spatial neglect may have physical and/or cognitive limitations that reduce their ability to assimilate the knowledge and skills required.

Therefore, the development and introduction of technology may provide therapists with the tools to facilitate a model of delivery that enables them to teach their patients how to analyse their performance. Furthermore, technology may enable therapists to free up some of the time spent carrying out repetitive tasks, that with the right tools could be carried out independently, which may increase the time they have to work on specialist intervention and the skills to carry out self-managed rehabilitation.

### **7.3.2 The Environmental Context**

The environmental context can be divided into firstly, the physical and social environment such as; the home, social context, and the technology system itself; and secondly, others within the environment such as the carer, and the researcher. The following section will describe how these influences impacted on the utilisation of feedback and the implications of these influences for the future use of technology.

#### **7.3.2.1 Physical Environmental Influences**

##### **Accommodating the Equipment in the Home**

The research confirmed that the utilisation of feedback may be affected by a number of (physical) environmental influences, such as; the participants' social circumstance; the reliability of the equipment; and accommodating the equipment in the home.

An essential consideration when using technology in the home is the physical and social surroundings of the user. Before the participant can interact with the technology and subsequently utilise the feedback, they have to be able to accommodate the equipment in their home; in their daily lives; and with the people they live with. This was found to be particularly relevant to the participants in this study.

Each of the participants described in the case studies had unique social circumstances, such as; their housing, their daily routines, and their ability to interact with their physical environment. For example, Mr. Gray's house was small and cluttered with objects that restricted his ability to accommodate the equipment and may have also affected the reliability of the sensors (due to ferromagnetic interference). This resulted

in inaccurate feedback, mistrust, reduced motivation to use the system, and reduced usage. However, Mr. Blackwell lived in a large uncluttered house which resulted in him being able to accommodate the equipment more easily with fewer reliability issues.

Evidence suggests that those from lower socioeconomic groups, as defined as those who have; lower levels of education, income, material ownership, and live in deprived geographical areas, are more at risk of having a stroke, are associated with lower survival rates and greater stroke severity than those from higher socioeconomic groups (Cox *et al*, 2006). In addition, socioeconomic and environmental conditions can have a detrimental impact on a stroke survivor's ability to carry out daily activities, extended daily activities and social roles (Rochette *et al*, 2001; Putman *et al*, 2007). Therefore, paradoxically, those who are most likely to suffer a stroke and require rehabilitation may be least likely to be able to accommodate technology because of their social, environmental and personal circumstances. Interestingly, this also directly affected who the CST therapists thought may be suitable to participate in the study whereby those from a less affluent area were excluded (by the CST therapist).

#### **Other Family Members and Visitors to the User's Home**

The issue of the carers' involvement is discussed in detail in section 7.3.2.2 (below). Three of the participants described how they liked to show their grandchildren the system. This leads to an interesting question regarding inclusion: by using innovative technology for their rehabilitation, younger (and possibly more technology minded) members of the family may use this as a way of interacting with older members of the family by being involved in their grandparents rehabilitation and recovery. In other words, they might find the technology as a way of helping because whilst they may not have the confidence of dealing with the stroke, they may have the confidence of assisting with the technology which may reinforce the stroke survivor's rehabilitative behaviour.

Accommodating pets within the users' household is also a consideration when deciding where to store and use the equipment. Two of the participants in this study had large pet dogs within their households which affected where the equipment could be stored. For example, Mr Redmond was concerned that his dog would chew the system or its components; therefore he chose to store the equipment in an upstairs bedroom. This has implications for gaining access to the equipment as well as setting up the equipment from its place of storage to its place of use.



### **7.3.2.2 Carers' influence**

The carers' involvement was found to be a crucial factor in enabling the people with stroke to use the system.

Three of the five participants in this study were wheelchair users and therefore had limitations in their ability to transport the equipment from its place of storage to its place of use. In addition, all of the participants were unable to independently don/doff the garments required for the placement of the inertial sensors and therefore required the assistance of the carer. This highlights how the equipment (SMART system and garments) needs further development if it is to be used independently.

The focus groups with professionals in chapter four discussed the issue of the involvement of the carer during rehabilitation. In particular, whether the carer wanted to be involved or had the time to be involved. This study found that the carers had been actively involved during the rehabilitation period with the CST therapist(s) and also embraced the concept of using the SMART system. For these motivated carers the SMART system provided a tool for the carer to be involved whilst removing the need to prompt. In other words, the SMART system acted as a 'middle man' where the carer was able to comment on the participant's performance by referring to the feedback provided by the SMART system.

However, this may not reflect the interests of a wider group of carers. For example, studies suggest that carers are often under the stress and strain of continuing with administrative tasks as well as assisting with activities of daily for the person they care for particularly with less able survivors (Bakas 2009). Therefore, future technology should account for carers (or other family members) who choose to be involved as well as carers who choose not to as well as storing the equipment in the carers home and how much the carers would need to interact with the technology outside of rehabilitation purposes.

The carers' opinion of the SMART system was a major influence for each of the participants. Acceptance of the SMART system by the carer was imperative for both practical reasons (as described above and in chapters five and six) as well as conceptual reasons. Firstly, carers had to accommodate the SMART system in their home; secondly, they had to believe that using the SMART system would benefit the participant (and cause no harm); and thirdly, they had to embrace the concept of

rehabilitating without the input of an 'expert' therapist. Therefore, if technology systems are to be used to facilitate post-stroke rehabilitation in the home in the future, the opinion of the carer is essential.

### **7.3.2.3 Researcher's Influence: Reflexivity**

The researcher's background as a Physiotherapist enabled him to use the SMART system as if he was using it in practice, similar to using another piece of equipment to facilitate rehabilitation. This involved assisting with the setting up of the equipment, providing training for the participant and their carer to use the system, and the prescription of appropriate exercises during use.

Placing the SMART system into the users' home necessitated a number of suggestions/considerations and a risk assessment (see appendix 27 p. 351). For example, the equipment needed to be stored in an area where it would not be interfered with by others (such as small children/grandchildren and pets) and large metal objects (ferromagnetic interference). In addition, the equipment also needed to be stored in an area where the peripherals such as, the garments, charger, and wires would not be hazardous during periods of non-use. This required negotiation with the participant and carer to ensure that safety considerations were met whilst ensuring the equipment was accessible and did not pose unnecessary difficulties during set up for the users which could result in reluctance to use the system.

Deciding how much training the user(s) required was also important. The researcher initially chose to give minimal training in order to remain objective. This also helped to establish how usable the system was (case study 1); however, it soon became apparent that this can influence the acceptance of the system. For example, Mr. Brown received only one session of training which may have contributed towards his reluctance to use the equipment. Therefore, the following four participants (and carers), were given as much guidance as they requested. In addition, the researcher decided to use the system as if in practice as this would allow for some reflection on the clinical utilisation of the system. However, it must be noted that the researcher did not interpret the feedback for the participants or their carers.

Prescribing exercises was a clinical decision made by the researcher. In order to set the parameters it was necessary to establish current levels of active range of movement for the upper-limb. This was achieved by examining the active range of movement

documented by the therapist in the participant profile provided by the referring therapist (appendix 19 p.339) and observing the participant(s) active range of movement prior to using the system. This was followed by identifying what exercises were most appropriate for the participant to carry out. For example, Mr. Redmond was the only participant who had sufficient active pronation/supination of the wrist and speed of movement to carry out the 'catch the ball' game on the SMART system.

However, it was also important to establish what exercises the participant wanted to carry out. Mr. Blackwell asked if he could try the hand-to-mouth exercise despite his limited range of movement. This highlights the need for variety in exercise prescription which is also a motor learning principle (Winstein and Wolf 2009). This suggests that whilst therapists play an important role in deciding what exercises their patients should carry out to meet their functional goals, the use of technology may also require them to identify what exercises may engage the user such as, games/fun activities. In addition, future technology development may incorporate exercises that incorporate a gaming element whilst maintaining the specificity of the task.

Although the process of installing the system and choosing exercises was carried out collaboratively, this influenced the amount of decision making and goals-setting by the participant. In addition, the concept of problem solving, action planning and self-monitoring were also carried out jointly. However, this firstly, enabled the researcher to model these skills for the participant, and secondly, guided and encouraged the participant to have the self-confidence to continue adopting this approach to their rehabilitation whilst using the system in the absence of the researcher.

A further consideration includes the amount of encouragement, unintended feedback and reinforcement the researcher may have provided during each visit. For example, the researcher would ask the participant how they thought they had performed (self-monitoring), how often they had used the equipment (taking action), and if they had encountered and overcome any problems since the previous visit (problem solving). This was also followed by positive encouragement (reinforcement) if these skills had been demonstrated (by the video confirmation).

The final consideration was the researcher's acceptance of the overall concept of utilising technology as a way of delivering therapy. The researcher's underpinning beliefs of 'how can I help you to help yourself' as well as his value of independence and

the potential for the SMART system to promote user engagement, were strong drivers throughout this research.

However, it must be accepted that not all therapists (or researchers) may feel this way and may view the provision of rehabilitation differently. For example, therapists may believe that they have been trained to become experts in the rehabilitation process and may wish to place their patients in a more passive role throughout the rehabilitation process. Furthermore, the researcher's Physiotherapy background may also have influenced the overall use of the equipment. It must also be noted that the findings and interpretation of the data may have also been influenced by the researcher's professional background as a Physiotherapist. For example, an Occupational Therapist may have used the equipment and prescribed exercises differently and interpreted the data from a different perspective. This research involved the use of multiple methods of data collection including interviews and observations (amongst others) and as a result, the researcher may have unintentionally introduced natural bias in the selection interpretation of the results. This has implications for the multidisciplinary utilisation of technology.

It is well recognised that members of the multidisciplinary team providing rehabilitation often have overlapping roles as a result of a range of factors including integrated practice and resource limitation (Nancarrow and Borthwick 2005). Therefore, if technology is to be integrated into mainstream therapy and is designed to be used by a range of professionals with various opinions and experience, further work is required to provide therapists from various professional backgrounds with an opportunity to learn and discuss new innovative paradigms. This includes establishing how technology can and should be clinically utilised with the wider multidisciplinary team.

### **7.3.3 Personal Context**

In addition to the individual characteristics and living situations of each participant, it was also evident that a number of personal factors also influenced the utilisation of feedback. The following section describes the personal characteristics of the participants and how this may have influenced the utilisation of computer feedback. Other personal influences such as, feedback preferences, motivation and feedback individualisation will be discussed in 7.4 (p. 245).

**Mr. Brown:** Although Mr. Brown was the most functionally independent of the users, he was the least accepting of the SMART system which was evident through his voiced opinions of using the system and the time he spent with it. He viewed the rehabilitation period passively and placed a great deal of reliance on his carer to assist at home. He also commented on how he felt that his impatient personality may impact on his expectations of recovery and would therefore not accept a model of rehabilitation that does not involve face-to-face therapy.

**Mrs. Green:** Mrs. Green was the oldest participant; had the longest time since her stroke; and was functionally dependent on her daughter (carer) for activities of daily living and extended activities of daily living. She also had no previous computer experience. However, this did not appear to affect her acceptance of using the system or the number of times she used it. However, due to her personal physical and cognitive limitations, she was reliant on her carer to assist with the use of the SMART system. This may suggest that although those with greater needs maybe less likely to be able to use this form of technology independently; the technology may provide a tool to enable significant others to be involved in the rehabilitation process and indeed reinforce rehabilitative behaviour.

**Mr. Gray:** Mr. Gray had the highest cognitive and communication scores (measured using the MMSE and FAST respectively) and was very familiar with using a computer. However, his low NEADL score indicated that he had poor functional independence. In addition, he also had poor active range of movement. Despite this, he carried out the most repetitions during the exercises compared to the other participants. This may suggest that those who are less cognitively impaired and/or have previous computer experience are more likely to engage with the system as a result of familiarity with the use of technology and are less cognitively impaired.

**Mr. Blackwell:** Mr. Blackwell had the most computer experience of the participants. However, he had the least active range of movement. He was very keen to try more of the exercises even though his limited range of movement made it difficult for him to carry out the exercise. For example, he requested that he could try the hand-to-mouth exercise even though he only had five degrees of elbow flexion. His previous success as a sportsman and his previous occupation may have led to him being motivated to carry out his rehabilitation and indeed take a 'lead' in the process. This concurs with Mr Gray

who was also familiar with computer technology and engaged with the use of the system.

**Mr. Redmond:** Mr. Redmond was one of the oldest users and had the poorest functional independence score. He was a wheelchair user and also terminally ill with cancer. However, he had the best active range of movement of the participants. Interestingly, he used the SMART system (in the absence of the researcher) more often than any of the other participants. This may have been a result of him being the only participant to carry out the 'catch the ball' task (a game-based activity). In addition, he was also keen to establish the SMART system into his everyday routine. This may suggest that the provision of a 'score' (quantitatively measureable feedback) may motivate users and use the technology more frequently.

The focus groups with CST therapists (chapter four) highlighted how they consider 'what type of person' their patient is during the period of rehabilitation with them. This study has also exposed that the personal context and history of the participant using the SMART system may have also influenced the utilisation of computer feedback such as the intricate preferences of the user.

However, one of the most surprising findings was that the age of the participant, their motor and functional ability, and their previous experience of using technology did not influence whether they accepted the technology within the home or as a concept. This suggests that any preconceptions of who might be suitable to use computer technology may be unfounded. For example, the one participant who the researcher thought may be the least accepting appeared to be the most accepting (Mr. Redmond).

#### **7.3.3.1 Acceptance of the Technology**

Despite the unreliability of the prototype, four out of the five participants welcomed the concept of using technology as a rehabilitation tool. Participants described how the constraints of therapy services that they had experienced such as, the lack of visits by the therapist, and the need for rehabilitation to continue beyond the twelve week period with the CST were key reasons for them choosing to participate in the study.

The participants and carers in this study also identified how technology might offer the opportunity to continue rehabilitation in the absence of a therapist in what is an ever limited service. In addition, Mrs. Gold suggested that the system would provide a variety of exercises/interventions (an essential component of motor learning) (Kalra and

Ratan 2007; Krakauer 2006; Barker and Brauer 2005). Mrs. Gold also highlighted the importance a system that could be used at any time which importantly, fits into the daily routine of the user. This would also enable the user to choose when to rehabilitate; for example, they may choose to carry out their rehabilitation sessions at a time in the day when they are less fatigued.

## **7.4 Mechanisms**

Exploring the interaction between the computer feedback and the theory-driven mechanisms underpinning the SMART system has provided new knowledge as to how specific forms of feedback ‘trigger’ mechanisms to produce outcomes. The following section details these.

### **7.4.1 Preferences for feedback through the SMART decision support**

#### **7.4.1.1 Knowledge of Results Feedback**

The use of the SMART system by the participants identified a number of feedback preferences throughout testing. All of those who took part preferred knowledge of results feedback provided by the qualitative chart displaying the results of each repetition in relation to the researcher’s expectations. Previous research has suggested that knowledge of performance is more effective than knowledge of results (Cirstea *et al*, 2006; 2007). However, these studies utilised verbal feedback only (participants closed their eyes during performance) provided by a therapist. Therefore, the participants in these studies relied on the interpretation of performance by the therapist as opposed to observing and interpreting their own performance.

This raises questions about the different contexts and levels of supervision required as well as whether stroke survivors have the skills to evaluate and interpret their own performance. In addition, when the feedback is presented through technology that includes the use of an avatar, the image may also affect the process. For example, because Mrs Green did not believe the avatar was a representation of her, she was unable to relate to it. This example leads on to the final point; the growing interest in gaming technology such as the Nintendo® Wii™; future users may have higher expectations of the interface and motivational components of rehabilitative devices. This includes the ability to personalise the on-screen display such as figures and avatars. For example, an avatar may be made to look like the user similar to the Wii Mii ([www.nintendo.com](http://www.nintendo.com)).

#### **7.4.1.2 Relating Feedback to Personal Goals**

It must be noted that the feedback provided by the qualitative chart (the users' preferred feedback) involves informing the user how they have performed in relation to the therapist's target for them to achieve.

However, one of the participants specifically described the importance for him of relating feedback to his own goal-setting (Mr Blackwell). Whilst goal-setting is an established form of individualising treatment (Intercollegiate Stroke Working Party 2008), further work is required to establish the relationship between feedback and the personal goals of the stroke survivor. This highlights how feedback needs to be meaningful to the receiver. For example, an improvement of ten degrees of shoulder flexion may be indicated on the computer; however, the user needs to be able to evaluate how a ten degree improvement relates to their goals (i.e. independent feeding) resulting in personalised feedback. Furthermore, personalised feedback may also impact on the motivation to use technology by providing feedback that displays improvement(s) that are meaningful to that person.

The SMART system used in this research involves the therapist leading the decision making on what exercises should be performed and what targets to achieve. This may therefore impact on the extent to which the stroke survivor is involved in setting goals and as a result takes ownership of the goals that have been set.

#### **7.4.1.3 The Provision of a Demonstration**

All the participants preferred to watch a demonstration of the exercise before performing it. This may reflect the 'mirror neuron hypothesis' (Rizzolatti and Craighero 2004; Buccino *et al*, 2004; 2006) which was a key finding in the study by Ertelt *et al*, (2007) who investigated the concept of 'action observation' where subjects watched a functional task on a TV screen that involved movements with varying complexity, and then immediately copied the actions.

All the users also described how they needed to be able to relate to the avatar for both movement recognition and similarities in appearance. This may also be explained by the 'mirror neuron hypothesis'. This would suggest that the avatar needs to mirror the user as well as represent the user.



## 7.4.2 Motivation

Motivation is a key determinant of rehabilitation outcome following stroke. Those with higher levels of motivation are believed to make the most improvement and adhere to rehabilitation programmes (Maclean *et al*, 2000). Motivation and rewards were heavily linked throughout the use of the equipment by the participants. For example, if the system indicated that they had performed well, they were motivated to use the system. Although it must be noted, this was often offset by the technology failing in subsequent attempts (described below). The provision of rewards has long been established in motor learning in terms of the psychological, neuroanatomical and neurophysiological effect on the learner (Schmidt and Wrisberg 2008; Nudo 2007) (see 2.9.5).

In this study, the provision of rewards to the participants impacted on their motivation to use the system. Three of the participants specifically described how obtaining positive results affected their motivation to use the system. Mrs. Green suggested that once she had managed to achieve good results, she was determined to maintain her performance which resulted in her wanting to use the system more often (increased usage). This was confirmed by her carer who reiterated that her motivation to use the system increased if Mrs. Green thought she had performed well and received positive feedback by getting her results up into the green zone on the qualitative chart. Mr Gray also described how positive feedback motivated him to use the system more often to confirm his improvements and that he was performing the exercises correctly.

However, users' motivation was offset by the system's poor reliability. For example, Mrs Green's carer described how it was disappointing and demotivating to set up the equipment and prepare her mother to use the system only for the system to not work properly. Therefore, the tensions between receiving positive feedback and poor reliability did not result in overall increased usage.

Explicit knowledge of results such as, the provision of scores with the 'catch the ball' game (Mr Redmond) also increased the determination of the user to improve. Mrs Gold suggested that Mr Redmond was motivated by being able to tell others how he was improving because he had evidence of improvements through the system. Interestingly, Mrs Gray also commented that Mr Gray also responded well when he received encouragement from other people and that he may even respond to others (outside of the therapy process) more. This highlights the importance for the user to receive feedback that can be understood by those outside of the rehabilitation process and how the

encouragement provided by others can impact on the users' motivation to engage in their rehabilitation (reinforcement).

However, if the participants received poor results to what they were expecting or the technology was unreliable or inaccurate and therefore not working correctly, this had a detrimental effect. Because Mr Brown did not know how to improve his scores, he chose not to continue using the system. Mrs Gray also described how she believed Mr Gray became despondent if his results were lower than those obtained from previous attempts. The reliability of the on-screen feedback throughout testing also led to the participants mistrusting the results (Mr Gray), not wishing to set the equipment up (Mrs Green), and not being able to interpret the feedback independently (Mr Redmond).

The impact of feedback on motivation also affected the initial set up of the equipment and any subsequent changes to the parameters for the computer exercises. It soon became apparent throughout the testing period that the parameters need to be set so that the user(s) would achieve appropriate results that reflected achievable settings. For example, it was important to set the parameters to enable the user to see the black dots on the qualitative chart as being in the middle of the amber zone. This feedback would/should portray that they have performed at a level that is expected of them.

### **7.4.3 Technology limitations**

The SMART Rehabilitation Technology System described in chapter two (2.4 p. 48) is a prototype wireless sensor system that allows for 3D real-time computer feedback ([www.theSMARTconsortium.org](http://www.theSMARTconsortium.org)). The limitations of this prototype system impacted on the participants and their carers and their ability to utilise the feedback provided.

During testing, participants had difficulties with:

- Setting up the equipment – getting the equipment ready for use.
  - Moving the computer, sensors and electrical leads from the place of storage to the place of use as well as dressing the participant in the garments housing the sensors and initiating the program.
- Stowing the equipment after use.
  - Shutting the program down, undressing the participant and stowing the equipment away safely.
- Charging the sensors when not in use.

- Ensuring that the sensors were constantly on charge ready for further use.
- Inaccurate on-screen displays.
  - Having set up the equipment, participants and carers described the frustration of receiving an inaccurate avatar image (see figs. 2-8 – 2-12 pp. 49-51).

All of the participants in this study had difficulties setting up the equipment for use and donning/doffing the garments that house the sensors. For example, they were unable to move the system from the dining room sideboard (its place of storage) to the lounge (its place of use). This resulted in them requiring assistance from their carers.

#### **7.4.3.1 Implications**

This research has provided new understanding by exposing the need for computer feedback to be both accurate and reliable. Indeed, the accuracy and reliability of the equipment used in this study influenced the utilisation of feedback which in turn, hindered the mechanisms. The on-screen display was often inaccurate and as a result, the participants (and in some instances the carers as well) became frustrated, lost patience, and trust in the feedback provided. This resulted in the participants being less willing to use the equipment and/or dismissing the feedback as an inaccurate evaluation of their performance (see chapter 6). Therefore, if similar systems are to be used in the future for mainstream rehabilitation, reliability is essential. However, in this study, although the limitations of the technology were detrimental to usage, it enabled the researcher to observe the impact of unreliability and the importance of it.

In addition, if the technology requires an amount of effort to set up and use, this may outweigh the benefits. For example, in this study, Mrs. Whiting described how she thought ‘why bother’ if there was a potential for the technology to fail and even more time and effort would be expended.

The benefits of involving the end users throughout the development of technology that are specifically designed for their use are profound (Mountain *et al*, 2010; Torsi *et al*, 2009). The inclusion of end-users experiences throughout the move from imitative to implementation enables such difficulties and obstacles to be foreseen and overcome in the earlier stages.

## 7.5 CMO Interaction

An essential element of this research explores what contextual factors help or hinder the underpinning mechanisms of the intervention. This involves observing the interaction between the context and mechanisms to produce an outcome.

Throughout the observational phase, a number of specific ingredients were identified as being key to the activation of mechanisms leading to outcomes. The following section will describe these interactions.

The ingredients that were found to be of particular importance included; receiving feedback that was perceived as being rewarding, accurate, included the results of their performance (knowledge of results feedback) that was measurable. These ingredients enabled key mechanisms to work such as motivating the users (and carers) to carry out prescribed exercises using the SMART system and having the confidence to continue using the system. This also impacted on their engagement and frequency of using the system and the subsequent reinforcement of their rehabilitative behaviour. In addition, this research also identified that the feedback should be adaptable and personalisable to the user. For example, having a facility to provide a demonstration of intended activities and the avatar ‘mirroring’ the user may be important for one user but not another.

The following figure (7-4) sets out the configuration and relationship of the ingredients (set centrally), the key mechanisms (set adjacent), and finally, further outcomes as a result of the interaction with the ingredients and activated mechanisms.

Fig 7-4: The interaction between ingredients, mechanisms and outcomes.

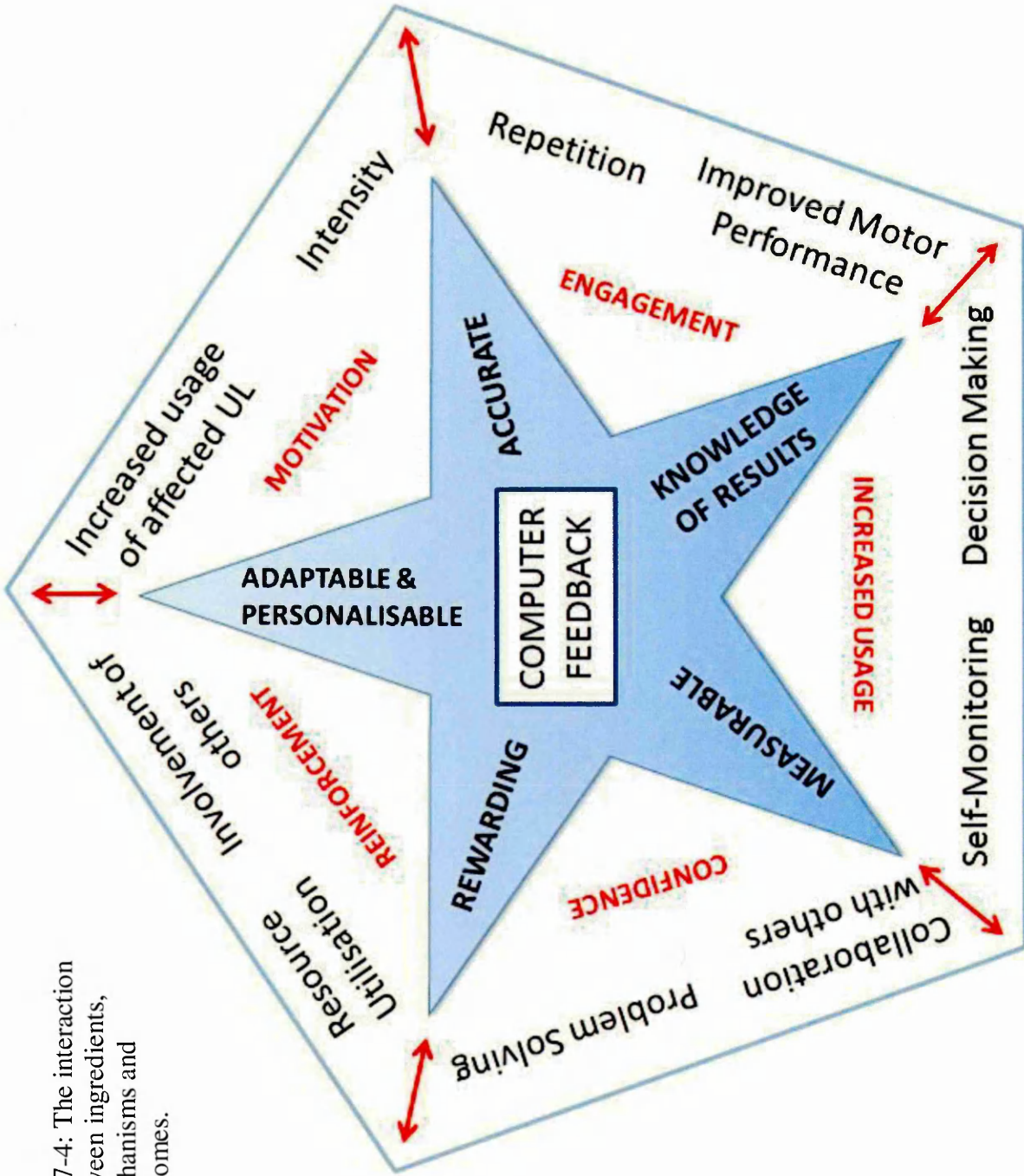


Figure 7-4 also illustrates that the interaction between the mechanisms and the outcomes are in some instances interchangeable. For example, ‘problem-solving’ can describe a mechanism for change and the outcome of change.

The ingredients activating the mechanisms described above subsequently impacted on the proposed outcomes. For example,

- The provision of knowledge of results provided confirmation of performance which motivated the user, this gave the user the confidence to use the system which led to increased usage, repetitive use and increased their familiarity of the system, and this led to improved results, reinforcement, increased motivation (fig 7-5).

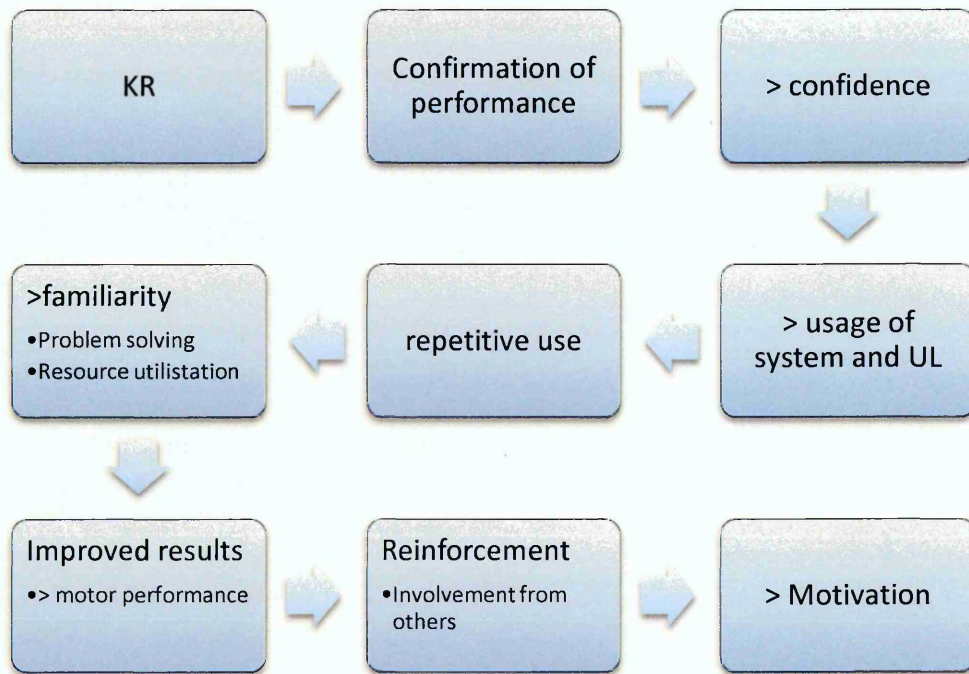


Fig 7-5: The activation of mechanisms

Further examples include:

- Measurable feedback = reinforcement = reward = > motivation = > usage = > performance = > motivation
- Accurate feedback = confidence in the system = > usage = > performance = > motivation
- Rewarding feedback = > motivation = > usage = > performance = > motivation

However, the contextual factors described previously (see 7.3 p. 234) also influenced these key ingredients. For example, the physical environment of the stroke survivor affected the accuracy of the feedback which resulted in mistrust of the system, poor motivation, and reduced usage. Therefore, although it was evident that key ingredients produced positive results, it was also evident that the context could hinder these from activating, producing undesirable outcomes. In addition to identifying essential ingredients, this research has also exposed a number of elements that hinder the mechanisms. These include:

- Inaccurate, unreliable feedback
- Poor results
- Inability to relate to the feedback / avatar
- Inadequate training / support towards the use of the system

The combination of exposing what works / does not work for whom in what circumstance and respects has identified what elements of feedback are essential for mechanisms to work and in what circumstance(s) and respects. This has enabled the refinement of theories underpinning the use of computer-based feedback for post-stroke upper-limb rehabilitation in the home. Indeed, this research has made significant refinements to the proposed CMOC's set out in table 2-3 (p. 82).

## **7.6 CMOC Refinement**

The following table (7-1) describes these refinements and is set out in CMOC form.

Table 7-1: The Refined CMOC's

CMOC's	Plausible mechanisms: 'what'	Contexts: 'for whom' and 'in what circumstances'	Possible outcomes
CMOC 1	M1: Receiving <b>rewarding, KR</b> feedback from the system might improve the user's confidence by confirming performance.	<p>C1: A system that:</p> <ul style="list-style-type: none"> <li>• <b>Is reliable, accurate and robust.</b></li> <li>• <b>Can be adapted and personalised to the individual personal, environmental and social context of the stroke survivor</b></li> <li>• <b>Is accessible in the home setting</b></li> <li>• <b>Is used by the stroke survivor who does not believe they will become more socially isolated as a result of carrying out rehabilitation and subsequent ADL's,</b></li> <li>• <b>Can be used independently of the therapist.</b></li> </ul>	<p>O1: Adoption and development of a self-management approach to rehabilitation (behaviour change).</p> <ul style="list-style-type: none"> <li>- Independent rehabilitation, self-evaluation and self-monitoring of recovery.</li> </ul>
CMOC 2	M2: By receiving <b>KR and KP</b> feedback, users might feel confident to be able to interpret their performance and changing their movements to improve subsequent performance(s).	<p>C2: A system that:</p> <ul style="list-style-type: none"> <li>• <b>Is reliable, accurate and robust.</b></li> <li>• <b>Can be adapted and personalised to the individual personal, environmental and social context of the stroke survivor</b></li> <li>• <b>Can be used independently by the stroke survivor in the home.</b></li> <li>• <b>Is provided in an environment where the user is provided with adequate resources and support.</b></li> </ul>	<p>O2: Development of self-management skills.</p> <ul style="list-style-type: none"> <li>- Problem-solving.</li> </ul>
CMOC 3	M3: By receiving <b>rewarding KR</b> feedback, users might feel confident in making decisions, utilising resources, and taking action.	<p>C3: A system that:</p> <ul style="list-style-type: none"> <li>• <b>Is reliable, accurate and robust.</b></li> <li>• <b>Can be adapted and personalised to the individual personal, environmental and social context of the stroke survivor</b></li> <li>• <b>Provides feedback to the stroke survivor during and after use.</b></li> <li>• <b>Is provided in an environment where the user is provided with adequate resources and support.</b></li> </ul>	<p>O3: Users take ownership of their condition.</p> <ul style="list-style-type: none"> <li>- Making decisions, utilising resources, and taking action.</li> </ul>



CMOC 4	<p>M4: By receiving <b>measurable, rewarding KR</b> feedback, users might engage with significant others such as, the therapist and carer.</p>	<p>C4: A system that: A system that:</p> <ul style="list-style-type: none"> <li>• <b>Is reliable, accurate and robust.</b></li> <li>• <b>Can be adapted and personalised to the individual personal, environmental and social context of the stroke survivor</b></li> <li>• <b>Involves significant others.</b></li> </ul>	<p>O4: Users involve others in their rehabilitation through choice.</p> <ul style="list-style-type: none"> <li>- Collaborate with significant others.</li> </ul>
CMOC 5	<p>M5: By receiving <b>meaningful</b> feedback, users might be motivate to set specific, measurable, realistic, and time specified goals (targets) to achieve that are confirmed by the computer feedback.</p>	<p>C5: A system that:</p> <ul style="list-style-type: none"> <li>• <b>Is reliable, accurate and robust.</b></li> <li>• <b>Can be adapted and personalised to the individual personal, environmental and social context of the stroke survivor</b></li> <li>• <b>Allows stroke survivors who continue to have a desire to continue the recovery process to set goals in relation to the feedback provided in collaboration with a therapist.</b></li> </ul>	<p>O5: Increased motivation and self-management.</p> <ul style="list-style-type: none"> <li>- Goal-setting.</li> </ul>
CMOC 6	<p>M6: By receiving feedback, users might feel confident to <b>recognise inaccurate feedback and</b> problem-solve by overcoming technical problems encountered that impact on the feedback provided.</p>	<p>C6: An environment where:</p> <ul style="list-style-type: none"> <li>• The user is provided with adequate resources, training and support</li> <li>• <b>The performance of the equipment is not adversely affected.</b></li> <li>• <b>The equipment is easily accessible for the user.</b></li> </ul>	<p>O6: Development of self-efficacy.</p> <ul style="list-style-type: none"> <li>- Perseverance in adversity.</li> </ul>
CMOC 7	<p>M7: By receiving <b>measurable, rewarding</b> feedback, users might be motivated to use the SMART system as a result of positive reinforcement.</p>	<p>C7: A system that provides feedback that can be described and/or observed by significant others.</p>	<p>O7: Increased usage of the affected upper-limb, intensity, and repetition.</p>
CMOC 8	<p>M8: By receiving <b>rewarding</b> feedback, users might be motivated to carry out intense, repetitive, specific, salient practice.</p>	<p>C8: A system that:</p> <ul style="list-style-type: none"> <li>• <b>Is reliable, accurate and robust</b></li> <li>• <b>Can be adapted and personalised to the individual personal, environmental and social context of the stroke survivor</b></li> <li>• <b>Is provided in an environment where the user is provided with adequate resources and support.</b></li> </ul>	<p>O8: Improved motor and functional performance.</p>

CMOC 9	<p>M9: By receiving <b>rewarding</b> feedback, users might be more confident and motivated to carry out repetitive practice and increase their usage of their affected upper-limb.</p>	<p>C9: A system that encourages the stroke survivor to carry out computer exercises repetitively.</p>	<p>O9: Increased use of the affected upper-limb in ADL's and social participation.</p>
CMOC 10	<p>M10: The delivery of <b>rewarding</b> feedback might engage the users.</p>	<p>C10: A system that:</p> <ul style="list-style-type: none"> <li>• Is reliable, accurate and robust.</li> <li>• Can be adapted and personalised to the individual personal, environmental and social context of the stroke survivor</li> <li>• Is provided in an environment where the user is provided with adequate resources and support.</li> </ul>	<p>O10: Increased repetition through the use of the SMART system.</p>
CMOC 11	<p>M11: The delivery of <b>concurrent</b> feedback might engage the users and enable them to learn implicitly through trial and error.</p>	<p>C11: A system that:</p> <ul style="list-style-type: none"> <li>• Is reliable, accurate and robust.</li> <li>• can be adapted and personalised to the individual personal, environmental and social context of the stroke survivor</li> <li>• Is provided in an environment where the user is provided with adequate resources and support.</li> </ul>	<p>O11: Improved performance on the computer exercises.</p>
CMOC 12	<p>M12: Providing <b>measurable, rewarding KR</b> feedback through technology may enable significant others to take a more active role in the rehabilitation process and reinforce behaviour.</p>	<p>C12: A system that:</p> <ul style="list-style-type: none"> <li>• Is reliable, accurate and robust.</li> <li>• Can be adapted and personalised to the individual personal, environmental and social context of the stroke survivor</li> <li>• Allows stroke survivors to utilise the feedback in the presence of significant others.</li> </ul>	<p>O12: Significant others are involved in their rehabilitation through choice.</p>

## 7.7 Summary

This chapter has discussed and synthesised the observational phase of this PhD programme that involved the use of the SMART Rehabilitation Technology System to answer the question, *'what works for whom and in what circumstances and respects?'*

This research has exposed the limitations in current service provision and how this may impact on the innovative use of technology systems for upper-limb post-stroke rehabilitation. However, the use of the SMART system in this study demonstrated the potential to provide those who are involved in the rehabilitation process with a means of interpreting and analysing improvements in motor behaviour. Furthermore, these systems may offer choice; the choice to carry out rehabilitation when the user wishes.

The synthesis has revealed that the mechanisms underpinning the utilisation of feedback from computer technology for upper-limb rehabilitation in the home are influenced by the pre-existing, personal and environmental contextual factors surrounding the user. Furthermore, the synthesis has also identified the key ingredients of computer-feedback and how these activate specific mechanisms to produce anticipated and unanticipated outcomes.

In addition, the utilisation of computer-feedback is dependent on the technology being robust and fit for purpose as well as the practicalities of using technology in the home setting. Therefore, further work is required to; develop the technology so that it is able to deliver feedback that is reliable and accurate and contains the specific ingredients identified; investigate the clinical utility of technology for home-based stroke rehabilitation, and the extent to which it might encourage utilisation by the end user.

The following chapter will discuss the implications of this research and recommendations as well as the limitations of this research and recommendations for further research.

## **Chapter 8: Final Discussion, Recommendations and Conclusion**

### **8.1 Introduction**

Using a realistic evaluation framework, this research has conducted an in-depth evaluation of how the contextual factors surrounding the utilisation of computer-based feedback for upper-limb, post-stroke rehabilitation impacts on the theory-driven mechanisms underpinning the intervention resulting in context-mechanism-outcome configuration theory refinement. This has also included the exploration of a paradigm shift from therapist led rehabilitation where feedback is provided face-to-face to a more patient led model of rehabilitation where feedback is provided by a computer in the absence of a therapist.

The findings have revealed that the mechanisms underpinning the utilisation of feedback from computer technology for upper-limb rehabilitation in the home are triggered by key ingredients (described in chapter seven). However, the pre-existing, personal and environmental contextual factors surrounding the user can also impact on these mechanisms and influence the outcome(s).

This final chapter will firstly; describe how this research builds on existing theory; secondly, describe the refinement of theory and the creation of new knowledge; thirdly, discuss the implications of the findings of this study; and fourthly, provide recommendations for the development and future use of technology for post-stroke rehabilitation. Consideration is then given to the study limitations and in light of this, identifies recommendations for further research. This is then followed by final conclusions.

### **8.2 Final Discussion**

Due to the current limited knowledge underpinning the use of technology for upper-limb post-stroke rehabilitation in the context of the home, this complex intervention required multiple research methods and the utilisation of a realistic evaluation methodological framework (described on page 16). The methodological framework used in this thesis gave an important innovative dimension to the research study since this methodology has not been used in the development of technology for rehabilitation. Fundamentally, RE involves refining the underpinning existing theory / theories of an intervention which are set out in context-mechanism-outcome configurations (Pawson and Tilley 2004).

This thesis therefore followed the RE cycle illustrated in fig 0-1 (p. 18) to firstly; describe the context of service delivery and how this is changing; secondly, describe the mechanisms underpinning the use of the SMART Rehabilitation Technology System; thirdly, detail the underpinning theories of the intervention and set out the theoretical outcomes of utilising the feedback from the SMART system; and finally, hypothesise '*what might work for whom and why*' and systematically test the hypotheses to explore, '*what works for whom and in what circumstances and respects.*'

This highlighted that as a result of increasing demand for stroke services, there is a need for further consideration for the delivery of new, innovative service models to increase the amount of time patients spend in therapy within the context of home-based rehabilitation (DoH 2010, 2011) (chapter one).

This research involved the use of computer technology to provide feedback for users carrying out post-stroke upper-limb rehabilitation in the home and in the absence of a therapist. The key components of the intervention were scrutinised to reveal the underpinning components of the intervention, the underpinning theories, ingredients, and propositions. This led to the development and description of mechanisms, contexts and possible outcomes to form CMOC's to be tested. This uncovered what particular aspects of each of the theories may be activated under certain contexts leading to proposed outcomes (chapter two).

Testing and validating the embryonic hypotheses (CMOC's) by gaining the perspectives of practitioners revealed how currently, the rehabilitation experience is led by the therapist who establishes a model of delivery that is individual to the stroke survivor within their personal and social environment (chapter four). However, this model of service delivery may not be conducive to self-managed rehabilitation.

Initial testing using the SMART Rehabilitation Technology System (chapter five) revealed how the utilisation of feedback may be affected by the pre-existing, personal and environmental context of the user. In addition, this initial testing also confirmed the need to explore how the interaction between others involved in the rehabilitation process; namely, the carer/close family member and how the therapist may also influence the utilisation of feedback. Further testing (chapter six) explored the experiences of individual participants

and their carers and uncovered a number of key issues and themes from the data that allowed for further refinement and a synthesis of the theoretical propositions. The synthesis described in chapter seven then draws on the findings of this research to answer the question, *'what works for whom and in what circumstances and respects?'*

The synthesis described how the mechanisms underpinning the utilisation of feedback from computer technology for upper-limb rehabilitation in the home are influenced by the pre-existing, personal and environmental contextual factors surrounding the user. Furthermore, the synthesis has also identified the key ingredients of computer-feedback and how these activate specific mechanisms to produce anticipated and unanticipated outcomes.

Furthermore, although this research focuses on the use of computer-based feedback, rehabilitative behaviour change and self-managed rehabilitation, the findings extend beyond rehabilitation physiotherapy. The identification and refinement of CMOC's and the interaction between the underpinning ingredients, the mechanisms and how this may lead to self-management outcomes such as; decision-making, increased self-efficacy, problem solving, collaboration and involving others and utilising resources may have wider implications. For example, there are unanswered questions as to whether self-management outcomes within the context of independent home-based rehabilitation have an influence on other areas of recovery such as emotional well-being and/or the health and well-being of the carer(s).

### **8.2.1 Refining Theory**

This research identified the three key theoretical areas of the intervention which included a number of underpinning theories (see table 2-2 p.80). These underpinning theories exposed the elements of these theories that were required to be 'activated' in order for the mechanisms to work and the desired outcome(s) to be achieved. However, as described in chapter two, prior to this research these theories had not been tested in the context of utilising computer-feedback for post-stroke upper-limb rehabilitation in the home and in the absence of a therapist. Furthermore, it was unclear how the utilisation of feedback within this context would interact with these elements to trigger mechanisms to produce outcomes.

### 8.2.1.1 Theoretical Areas

The theoretical areas underpinning the intervention, ‘the utilisation of computer-feedback for post-stroke upper-limb rehabilitation in the home and in the absence of a therapist’ identified were; the theoretical approach to post-stroke rehabilitation incorporated within the SMART system (see 2.8 p. 55), and the use of feedback for post-stroke rehabilitation. However, the SMART system used in this study was designed to encourage a change in behaviour towards self-managed rehabilitation (as an outcome of using the system). Therefore, elements of the SMART system were also underpinned by self-management and behaviour change theories.

The theoretical ‘areas’ identified are underpinned by theories; these include, neuroplasticity, motor learning, motivation and operant conditioning, feedback theories, self-regulation, social cognition, goal-setting, and self-efficacy.

Existing literature suggests that in order for post-stroke rehabilitation to improve function, independence and quality of life, the theories underpinning post-stroke rehabilitation are based upon the ability of the neuronal network to plastically adapt and reorganise (Kreisel *et al*, 2007; Kalra and Ratan 2007). These include key elements such as; independent practice, intensity, problem-solving, goal setting, specificity, repetition, salience, and implicit and explicit learning, feedback content and schedules, and rewards. (Kalra and Ratan 2007; Krakauer 2006; Barker and Brauer 2005; Van Vliet and Wulf 2006; Langhorne *et al*, 2009).

Chapter two highlighted that extrinsic feedback provided through technology that does not provide physical assistance or tactile stimulation and is provided in the absence of a therapist may improve motor and functional performance in the post-stroke upper-limb. In addition, concurrent feedback, knowledge of performance (KP), knowledge of results (KR) and explicit feedback may be key components in the promotion of improved performance (Parker *et al*, 2011). However, existing literature also highlighted the heterogeneity in studies that have explored the use of feedback in post-stroke rehabilitation (see 2.2.3 p41).

This suggests that careful consideration should be made as to what form and method of delivery of feedback is given. In other words the provision of feedback should not be a ‘one size fits all’ component of rehabilitation (Van Vliet and Wulf 2006; Parker *et al*, 2011).

In addition, to date, there has been minimal research on self-management interventions for stroke and it is unclear what self-management should actually involve (Jones and Riazi 2011). Nevertheless, efforts are being made to identify components of self-management (Lorig and Holman 2003; 2004; Jones 2006) and how self-management principles can be integrated into therapeutic approaches for post-stroke rehabilitation (Johnston *et al*, 2007; Jones *et al*, 2009; Kendall *et al*, 2007) including the use of innovative technology (Huijbregts *et al*, 2009; Mountain *et al*, 2010). However, little is known as to how the desired outcome of self-managed rehabilitation can be achieved through the use of technology for post-stroke upper-limb rehabilitation and in particular, how the mechanisms underpinning and the context surrounding this intervention impacts on the outcomes (see 2.10 p71).

This research has provided new knowledge by exposing the interaction between the feedback delivered through computer technology, the mechanisms underpinning the intervention, the context, and how this leads to variable outcome(s). For example, section 7-5 (p250) describes how particular elements of feedback such as; rewarding, knowledge of results feedback, are required to facilitate motivation (increased usage, intensity, and repetition). This leads to improved performance, reward, confidence and self-efficacy, and the reinforcement of rehabilitative behaviour change.

The identification of the interaction between feedback, mechanisms and outcome(s) has also exposed how underpinning theories may work in combination with other theories to produce an outcome within a given context. For example figure 7-5 (p252) illustrates how; KR (feedback theory) provided confirmation of performance (self-efficacy) which motivated the user (Social Cognition Theory), this gave the user the confidence (self-efficacy) to use the system which led to increased usage, repetitive use (motor-learning) and increased their familiarity and use of the system (resource utilisation), and this led to improved results (motor learning), reinforcement and increased motivation (Social Cognition Theory).

As described in chapter seven, there are key elements that are required to work together to create desirable outcomes. These are; the inclusion of the key ingredients to trigger mechanisms (see figure 7-4 p. 251) and a conducive context. This research has exposed these ingredients and highlighted elements of the context that can negatively impact on the



underpinning mechanisms such as; the previous experience of rehabilitation, the environment, and the technology itself. This adds further refinement and understanding of what elements of feedback are necessary within the constraints of using technology for home-based upper-limb rehabilitation.

Therefore, this research programme has created new knowledge and a refinement of the theories underpinning the utilisation of computer-based feedback for upper-limb post-stroke rehabilitation in the home and in the absence of a therapist.

This thesis has demonstrated how RE can be utilised as a methodological framework to explore the interaction between the mechanisms underpinning the intervention, the context and the expected and unexpected outcomes. This has exposed the intricacies of ‘what works for whom and in what circumstances and respects’ for introducing technology into post-stroke upper-limb rehabilitation.

By exploring the interaction between; the theories underpinning the mechanisms, the pre-existing, personal and environmental context and the theoretical outcomes, new knowledge has been created by uncovering what ‘ingredients’ of feedback are essential to the activation of these mechanisms and what elements of the context are conducive and what elements hinder the mechanisms. In other words, what ingredients of feedback are necessary to activate essential mechanisms, and in what context, to produce a desired outcome.

This has revealed what elements of theories work in what circumstances and how the desired outcomes (self-management / self-managed rehabilitation and behaviour change) may be reliant on particular forms of feedback to trigger mechanisms within a conducive context.

The identification of the contextual influence(s) and the key ingredients that are required to trigger mechanisms to produce desired outcomes have allowed for the refinement of CMOC’s (described in table 7-1 p. 254). This completes the final stage of the RE cycle where the refined theory-driven CMOC’s can be further tested (fig 8-1 overleaf).

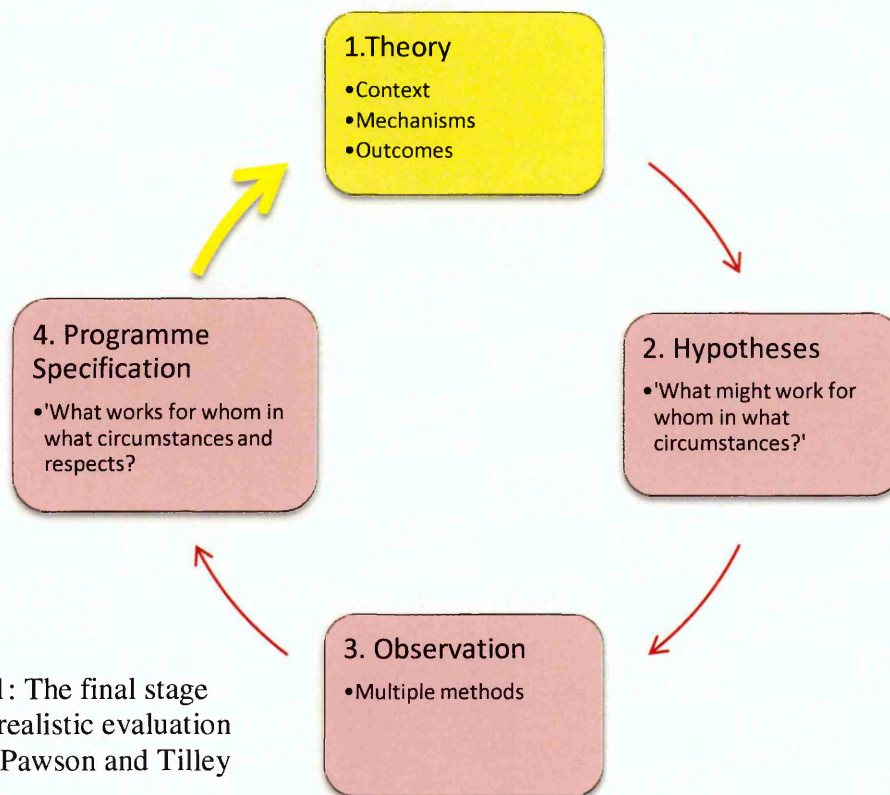


Fig 8-1: The final stage of the realistic evaluation cycle (Pawson and Tilley (1997)).

### 8.3 Implications and Recommendations

This research has identified the elements of feedback that are necessary to trigger mechanisms which may lead to desired outcomes (self-managed rehabilitation). If the use of technology to facilitate self-managed rehabilitation in the context of the home is to gain a foothold, the feedback provided should include the elements of feedback highlighted by this research in a conducive context.

The discovery of these elements may therefore result in the development of technology; therapy education and the subsequent adoption of technology and a self-management paradigm; long-term self-managed rehabilitation; and importantly, improvements in the physical and psychosocial aspects of recovery.

#### 8.3.1 Stroke Survivors and their Carers

Chapter one (1.4 p24) describes how stroke survivors are invariably left with physical and psychological changes that can profoundly affect their physical and functional ability (Pound *et al*, 1998; Ones *et al*, 2005) personal identity (Clarke & Black 2005), their

relationship with others (Dowswell *et al*, 2000), and their participation in society (Cott *et al*, 2007; Desrosiers *et al*, 2006; Mayo *et al*, 2002; Rochette *et al*, 2007). In addition, caregivers are also at risk of physical and psychological impairment (Bakas 2009).

By facilitating elements of self-management and self-efficacy through the use of technology, stroke survivors may address some of the psychosocial impact of stroke. For example, by carrying out independent rehabilitation in the home, a stroke survivor may feel more confident to problem solve, make decisions, involve others (i.e. showing good results), set goals, and be motivated to continue recovery in the longer-term whilst being less reliant on their carers. However, as described above (8.3) further research is required to establish the wider and longer-term outcome(s) of self-managed rehabilitation through the use of technology (8.4).

### **8.3.2 The Pre-Existing Context: Service Delivery**

A key aspect of this research is the shift from service delivery involving rehabilitation that is delivered in the home by a therapist to rehabilitation that utilises technology in the absence of a therapist. This research programme has highlighted how the stroke survivors participating in this study had limited opportunity to develop the skills necessary for carrying out independent rehabilitation in the absence of a therapist (see 7.3.1.2). Therefore, if innovative models of service delivery are to be adopted to cope with the ever demanding need for rehabilitative services, a significant shift to promote a model of rehabilitation that encourages self-managed rehabilitation over the longer-term is required.

Current models of service delivery are based on a hierarchical approach which stems from governmental policy; strategic health authority coordination; primary care trust commissioning; and finally rehabilitation delivery (NAO 2010). This top-down approach continues through to therapist intervention whereby practitioners lead the rehabilitation sessions and maintain control over their patients (Ballinger *et al*, 1999; DeJong *et al*, 2004; Hartvelt and Hegarty 1996; Wohlin Wottrich *et al*, 2004). The implementation of efficiency targets and clinical outcomes to justify finances and manpower ensures governance and accountability; however, in the current climate this resource and labour intensive model of delivery is both financially unsustainable and may not facilitate long-term benefits.

Health services in the next decade are faced with: reduced finances; ever higher patient expectations; an ageing population; advances in technology and the growing information technology age; the reduction in mortality and a subsequent rise in morbidity due to advances in acute care, and a changing workforce (NAO 2010; Nancarrow *et al*, 2006). Therefore, the predicted need to release £15 – £20 billion through efficiency savings from 2011 to 2014 whilst keeping quality as the overriding principle presents a challenge to service providers (DoH 2010).

Radical innovation is now considered to be an essential way of delivering the changes that are required to meet the challenges faced in healthcare. Therefore, initiatives that focus on patient-centered care that involves contemporary ways of providing long-term self-care for chronic conditions are at the forefront of service redesign (Bunt and Harris 2009). However, if technology is to be incorporated into mainstream rehabilitation, significant adjustments to the current model of delivery are required.

The UK government has recently announced a major overhaul of the National Health Service to provide effective healthcare for service users whilst removing the bureaucracy in healthcare (DoH 2010). In addition, the *'Innovation, Health and Wealth: accelerating adoption and diffusion in the NHS'* document published by the Department of Health (2011) sets out an integrated set of measures and a delivery agenda that will support the adoption and diffusion of innovation across the NHS. Therefore, service delivery will focus on empowerment: empowering and liberating practitioners to innovate and focus on improving healthcare services and enabling patient choice. The white paper *'Equity and Excellence: Liberating the NHS'* (DoH 2010) highlights the ever growing move towards a 'bottom-up' approach in the delivery of health interventions and the continued changing landscape of healthcare.

However, if service delivery is to adopt a bottom-up approach that involves patient choice, empowerment and innovation, all stakeholders including strategic health authorities; primary care trusts; and finally the professionals who deliver services to service users are required to embrace change. Therefore, further work is required to facilitate the transition of research into clinical practice by drawing together research, innovation, and the practicalities of clinical implementation.

### 8.3.2.1 Facilitating Change

It is recognised that there is a need for a stronger relationship between scientific and academic communities with industry. The five Academic Health Science Centres (AHSCs) established in 2009 aim to create partnerships between healthcare and academia. However, in recognition that more needs to be done to spread innovation across the whole of the NHS, the Innovation Health and Wealth report (DoH 2011) announced a new wave of academic and health partnerships to align education, clinical research, informatics, innovation, training and education and healthcare delivery. In support of the AHSCs, Academic Health Science Networks (AHSNs) that are due to be initiated in 2012/13 will focus on ‘improving patient and population health outcomes by translating research into practice and developing and implementing integrated health care service’ (DoH 2011 p. 19). It is expected that the AHSNs will work closely with AHSCs and other National Institute for Health Research (NIHR) units, centres, collaborations, education clusters (HIECs) and innovation hubs.

An example of translating innovation into healthcare and in particular, the focus on the self-management of long-term conditions includes the Collaborations for Leadership in Applied Health Research and Care (CLAHRC). These were introduced in response to The Cooksey Review (2006) which recognised gaps in the translation of health research into new products and treatment approaches, and in the implementation of new approaches to clinical practice (The Cooksey Review 2006).

In particular, the South Yorkshire collaboration (one of nine in England) aims to,

*‘Become internationally recognised in the field of self-management of long-term conditions through applied research, health technology innovations, and translation of knowledge into quality patient care’ (NIHR CLAHRC SY 2009 p9).*

This demonstrates a clear drive for the development and implementation of the self-management of long-term conditions through radical innovation and the translation of research knowledge into service delivery. Whilst there are significant future challenges in healthcare and service delivery; enabling cultural and behavioural change and the way in which practitioners and service users approach rehabilitation may therefore, have

significant implications towards cost-savings and importantly, the ability to self-manage a long-term condition which may lead to longer-term benefits.

With the removal of the hierarchical approach, restructuring of healthcare finances, and increased focus on long-term quality of care (DoH 2010); innovative technology may provide therapists with the tools to adopt an approach that allows them to facilitate a model of care that provides their patients with the skills to carry out self-managed rehabilitation. However, if technology is to be embraced and incorporated into mainstream therapy, further work is required to establish the benefits to all stakeholders.

This shift will require further technology development; further work to establish the clinical utilisation of technology; pre and post registration therapy education; and further research to establish the efficacy of using technology for post-stroke rehabilitation.

### **8.3.3 Technology Development**

This research has highlighted the key ingredients that are necessary in activating the mechanisms underpinning the utilisation of computer-based feedback (see 7.5 p. 250) as well as the issues involved in testing early prototype technology and how developing technology systems need to be reliable, robust and accurate.

In addition, developing technology needs to account for the clinical needs of the practitioners as well as the end users themselves. For example, there are a number of adaptations that should be available to make a computer system usable such as, increasing the font size and the provision of an easily manipulated mouse; however, this research focused on the utilisation of feedback and what influenced it.

#### **8.3.3.1 Including Key Ingredients**

The views of the participants and their carers in this research led to a number of recommendations for improvements to the technology and the feedback it provides. This involves including the key ingredients highlighted in 7.4 and 7.5.

**The technology needs to be adaptable and personalised to the user:** In order to improve the users' ability to relate to the avatar, the graphical interface needs to be individualised to

the user. For example, the user may wish to alter the avatar image to look like them (i.e. male / female) and therefore, make it both recognisable and easier to relate to.

In addition, further developments that include feedback should be capable of being tailored towards the user's specific goals to enable the feedback to become 'meaningful' to the user (see chapter 6). For example, if the user's goal is to be able to use their affected arm to feed themselves, the feedback provided could indicate how they have performed in relation to that task.

**The avatar should 'mirror' the user:** The avatar image needs to have an option where the user is able to see the image as a mirror.

**All of the exercises should have a demonstration:** The system should include a video demonstration of the exercise that the user has selected to carry out. This will provide the user with a clear reminder of what is required without the need for further instruction from another person.

**The feedback needs to be accurate (i.e. displaying exactly how the user is moving) and reliable:** The system should provide feedback that is accurate and reliable which will therefore, increase the trustworthiness and acceptance of the feedback provided.

**The feedback needs to be measurable:** The system should provide feedback that can be 'measured' or scored which will enable the user to quantify improvements and share their results with others.

**The feedback needs to be rewarding:** In order to maintain motivation, the system should provide feedback that is rewarding.

#### **8.3.3.2 Form of Feedback to be Delivered**

**The feedback should include knowledge of results:** The feedback presented should include knowledge of results that relate and compare to the desired performance set by the therapist in conjunction with their patient. However, future systems may also benefit from providing knowledge of performance which will provide the therapist with feedback that can be analysed and used to guide the further rehabilitation of the stroke survivor. For example, the therapist should be able to replay the feedback and discuss with their patient how and what they both feel they need to do to improve.

In the early stages of rehabilitating, the system should incorporate prescriptive feedback whereby a system would provide a description of performance followed by what the learner needs to do to improve performance. However, as the learner develops their capabilities, the system should provide less frequent feedback to avoid dependency on the feedback. In addition, as the user adopts a self-managed approach to their rehabilitation, they may also improve their ability to utilise knowledge of performance feedback.

### **8.3.3.3 Accessibility**

**Intelligent system development:** The development of software that either automatically progresses the user by changing the settings depending on the user's current performance or allows a therapist to change the settings from a remote location would enable the user to move through stages of improvement without the need for therapists to physically change the settings in the location it is being used. This may also provide the user with levels of achievement, similar to the levels achieved on a gaming device and reduce the workload of the therapist.

**Inclusion of a therapy portal:** During the design of the SMART system, it was intended that the system could be used remotely (telehealth). However, using the system in this way is yet to be explored. Nevertheless, this would enable therapists to monitor their patients remotely which would reduce the need to travel to and from their patients freeing up more time to treat more patients.

**Accessibility requirements:** Although a further development of the garments were tested; further developments of the garments and testing of new attachment solutions over a sustained period of time is required to establish the long-term use and reliability.

### **8.3.3.4 Clinical Adaptability**

From a clinical utility perspective technology systems need to incorporate greater clinical adaptability, such as, including greater variety of exercises into the programme(s). For example, the PhysioTools ([www.physiotools.com](http://www.physiotools.com)) exercise sheets used currently (and by the therapists in this study) has over 16000+ activities that can be selected and subsequently prescribed by the therapist. This enables therapists to choose from a vast library of activities what to prescribe making their therapy specific to the requirements of the patient. Therefore, if therapists are to incorporate technology into their practice, they will require



and even expect the technology to be a better alternative to what is currently available to them.

With the growing interest in gaming technology such as the Nintendo® Wii™; future users may be more receptive to computer interaction; however, they may also have higher expectations in terms of the interface and motivational components of rehabilitative devices. Therefore, if future systems are to be embraced they will have to meet the rising expectations of system users and therapists for both usability and clinical utility.

### **8.3.4 Therapy Education**

The delivery of face-to-face feedback provided by a therapist is unsustainable; therefore, therapists are required to provide their patients with the skills to continue their rehabilitation independently by learning to use information/instruction and feedback from other means (such as technology). This will require a radical shift away from the face-to-face ‘hands-on’ only approach highlighted by the therapists that participated in this study (see chapter 4) to a paradigm that involves patients being guided by therapists through the rehabilitation process from the acute – sub-acute – chronic stages providing patients with the skills to carry out self-managed rehabilitation over the longer-term.

However, therapists may not have the skills or tools to adopt a model of delivery that incorporates the self-management of stroke nor the inclination to use technology as part of their therapeutic intervention.

If therapists are to embrace and accept the concept of self-management through the utilisation of technology; significant efforts are required to (re)train the workforce. The ‘*Innovation, Health and Wealth: accelerating adoption and diffusion in the NHS*’ document published by the Department of Health (2011) sets out a drive towards ensuring innovation is ‘hard-wired’ into educational curricula,

*‘The NHS must build innovation and the concept of adoption and spread into undergraduate and post graduate curricula’ Prof. Norman Williams, RCS (DoH 2011 p. 23).*

Whilst there are already initiatives towards self-management training for both stroke practitioners and stroke survivors ([www.bridges-stroke.com](http://www.bridges-stroke.com)), further work is required to

establish how practitioners may use technology as a tool to establish self-managed rehabilitation. This includes transferring cutting edge research into pre and post registration therapy education and into clinical practice.

Therapy education at pre and post registration will firstly, enable new aspiring practitioners to embrace innovative methods of delivering therapy; and secondly, post registration training will enable experienced practitioners to reflect on the practicalities of using technology as well as the potential for leadership in the use and implementation within service delivery.

However, as discussed earlier, all stakeholders will be required to gain an understanding of the benefits and possible drawbacks of using technology for post-stroke rehabilitation. For example, the latest NHS reform (DoH 2010) suggests that in the future General Practitioners may control the budget within their Primary Care Trust and will therefore; make key decisions as to what and where the finance should be invested.

### **8.3.5 Clinical Utilisation**

There are a number of clinical utility questions regarding how therapists may use technology within mainstream service delivery. In particular, how and when do therapists provide their patients with the skills to use technology independently? It is this researcher's opinion that technology systems could be used both during conventional service delivery whereby the therapist provides the technology and uses it as a tool to facilitate rehabilitation in addition to face-to-face input. For example, a therapist may prescribe exercises to carry out between face-to-face therapy sessions and then analyse the person's performance as part of their session (teaching the patient how to analyse performance). Technology might be introduced gradually as the patient becomes more familiar with the rehabilitation process (fig 8-2 overleaf). This may also enable longer-term rehabilitation (after service delivery has ceased).

This approach is now being tested and implemented within the care-pathway using the second generation of a personalized self-management system for post-stroke rehabilitation (SMART 2) ([www.thesmartconsortium.org.uk/Smart\\_2/index.php](http://www.thesmartconsortium.org.uk/Smart_2/index.php)).

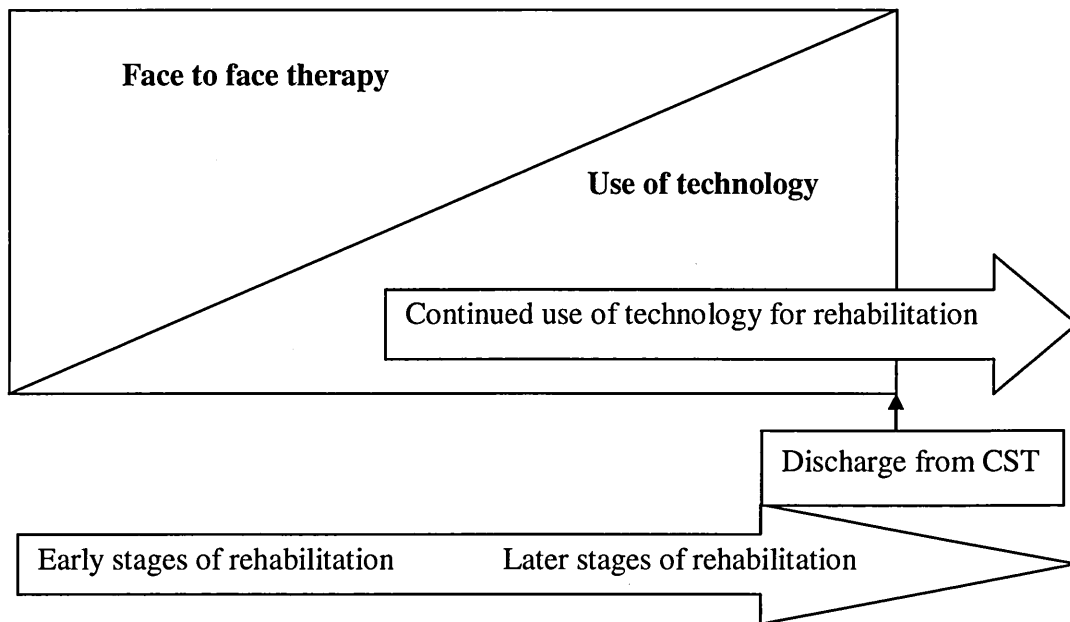


Fig 8-2: Postulated integration of computer technology for post-stroke rehabilitation in the home.

However, there are unanswered questions as to what forms of feedback is required from the therapists perspective. For example, do therapists require knowledge of performance and/or knowledge of results? Therefore, further work is required to explore the clinical requirements of the practitioners involved in post-stroke rehabilitation.

This research has demonstrated the potential for using an innovative form of delivering rehabilitation that involves longer-term care through a self-management paradigm that may also have cost saving implications. Furthermore, because this research has involved a user-centred approach, it has also highlighted the possible acceptance and barriers to this form of delivery. However, it has also uncovered the intricacies and the future challenges that face the usability of technology, the clinical utility and the further development of technology and further research that is required.

#### 8.4 Further Research

In order to continue the cycle set out in figure 0-1, the refined CMOC's should be tested again with the refinements in place. This would involve changes to service delivery, therapy education, and the technology (as described previously). This would allow for

further testing of the theoretical underpinnings of this intervention and the exclusion of the problematic non-conductive elements highlighted in this study.

This research has also uncovered a number of key areas that require further exploration.

Further research is required to develop the potential use of technology. This should include the exploration and efficacy of various forms of feedback as well as the development of technology, the clinical utilisation of technology for upper-limb post-stroke rehabilitation in a number of settings, and the use of other systems to deliver feedback that are already familiar devices, such as, televisions. This would alleviate the problems associated with storing equipment within the household and transferring equipment from its place of storage to its place of use.

Chapter two highlighted the paucity of robust evidence about the efficacy of various forms of extrinsic feedback and methods of applying feedback. Therefore, research is required to investigate the efficacy of various methods of delivering extrinsic feedback as well as the form(s) of feedback within each method. In addition, there are unanswered questions surrounding the impact of context on various forms of feedback. For example, this research has revealed that in the context of using technology in the home, the participants and carers preferred knowledge of results feedback; however, this may not be the case in other contexts where technology could be placed such as, a community day centre or a hospital, where a therapist may be present and is able to provide support and interpret the feedback for the user.

The development of reliable and accurate technology is essential if systems are to become a clinical tool for therapists. This research has uncovered the impact poor reliability has on the utilisation of technology; therefore, work is required to improve the graphical interface (described above), the sensor technology, and peripherals that are required to use the system i.e. garments for housing the sensors during use. In addition, further work is required to develop the potential for remote monitoring through telehealth, such as, connecting the equipment (securely) to the internet where therapists can monitor and feedback to users from their community office location(s).

Alongside the development of technology through user involvement, further research is then required to explore the clinical utilisation of technology in practice. This includes:

- How therapists implement a self-management paradigm into clinical practice.
- The therapists' acceptance of using technology for post-stroke rehabilitation in the home.
- The prescription of technology i.e. how and what aspects of rehabilitation should be performed for who and when.
- The potential for remote monitoring.
- How the use of technology should be integrated into therapy.
- The efficacy of using technology i.e. conventional therapy versus conventional therapy + technology.

Finally, further research is required to explore whether the adoption of technology that incorporates the necessary ingredients (highlighted in this research) and is used in a conducive context, may or may not facilitate a self-management paradigm; long-term self-managed rehabilitation; and importantly, improvements in the physical and psychosocial aspects of recovery.

## **8.5 Study Limitations**

This study has evaluated and subsequently refined the theories underpinning the use of feedback and technology; the feasibility of utilising feedback provided by computer technology in the absence of a therapist, and the contextual influences that may impact on the theory-driven mechanisms underpinning the utilisation of feedback in the context of the home. However, there were a number of study limitations.

Firstly, this study involved a limited number of users, thus limiting the generalisability of the results. However, this approach enabled the researcher to observe the use of the SMART system over a prolonged period of time, and therefore allowed for a deeper exploration and a thick description of the underlying influences and contexts in which the system was used.

Secondly, in order to access the participants and their carers, the researcher was ethically required to use the CST therapists as gatekeepers. This in itself resulted in those who chose to participate in the study were already 'selected' by the preconceptions of the CST therapist(s). This was evident in that all of the potential participants that were passed on to

the researcher passed the screening assessments and agreed to participate. Had this not been the case, the researcher would have been able to analyse who and why potential participants did not go on to become actual participants.

Thirdly, the poor reliability of the SMART system resulted in the researcher being unable to examine the computer data for changes in range of movement. This would have provided further understanding of the efficacy of using the computer for upper-limb rehabilitation. Nevertheless, because the focus of this research was the utilisation of the feedback, the poor reliability added to the findings by providing an insight into the effect of this upon the participants (and their carers), and therefore highlights the importance for technology to be reliable and accurate.

Finally, by using the system over a prolonged period, the researcher was able to establish a good rapport with the participants and their carers. However, this may have affected how they responded to the researcher. For example, they may have been more reluctant to discuss negative aspects of using the system and the feedback it provides because they may have felt that they would have let the researcher down. In order to overcome this issue, the researcher reminded the participants and their carers throughout testing that if technology is going to improve in the future, they needed to reveal their dislikes and recommendations for improvement.

## **8.6 Conclusion**

This research has refined the theory underpinning the utilisation of computer-based feedback for post-stroke upper-limb rehabilitation in the home and in the absence of a therapist. This answers the question, '*work works for whom and in what circumstances and respects.*'

This research has provided new knowledge by exposing a number of key elements that are crucial for the development and potential utilisation of technology in what is an inevitable shift towards the use of innovative methods of delivering post-stroke rehabilitation. These include the feasibility of utilising technology in the home over a prolonged period of time; the specific ingredients that are essential for the activation of underpinning mechanisms; the impact of the context on the mechanisms; the usability issues that are involved; and

importantly, the need for a shift in service delivery and improvements in the reliability and accuracy of the technology.

This research has demonstrated the potential for using home-based computer technology as means of providing feedback in the absence of a therapist over a prolonged period. In addition, this research has shown how the participants and their carers were able to utilise the feedback and crucially, gain some understanding of their performance both during and after carrying out numerous rehabilitation sessions. Furthermore, the participants and their carers were also able to reflect on personal preferences as well as how they believe this form of therapy may be integrated into mainstream therapy, which provided valuable insights into the potential clinical utilisation of technology.

This research has therefore provided new knowledge by exploring the influence of contextual issues surrounding the use of computer technology in the home setting and how the utilisation of feedback is dependent on the limitations of the context in which it is used and the technology. In particular, this research has exposed what elements of feedback are essential. Therefore, if technology is to be used in mainstream therapy, service providers are required to consider the impact and variance of the context, the reliability and accuracy of the technology and importantly, what forms of feedback is provided to facilitate the users' understanding of performance.

In addition, this research suggests that therapists provide a model of service delivery that is led by their empirical knowledge, which may not be conducive to motor learning and self-management. This may therefore limit their ability to utilise computer-based feedback to facilitate self-managed rehabilitation. Therefore, work is required to educate therapists in the provision of therapy that includes newer innovative methods of delivering feedback that facilitates independent rehabilitation. This will place less demand on services whilst empowering stroke survivors and close family members to carry out and continue their recovery beyond the acute and sub-acute period.

## **Broadcasting**

### **Journal paper:**

Parker J, Mountain GA and Hammerton J. (2011) A review of the evidence underpinning the use of visual and auditory feedback for computer technology in post-stroke upper-limb rehabilitation. *Disability and Rehabilitation: Assistive Technology*, **6**: 465-472.

### **Book Chapter:**

Parker J, Mountain GA and Hammerton J (2010) An Investigation into Stroke Patients' Utilisation of Feedback from Computer-Based Technology, In: P Langdon, J Clarkson and P Robinson (Eds), *Designing Inclusive Interactions*. London: Springer-Verlag. Pp 167-176.

### **Peer Reviewed Presentations:**

Mountain GA, Mawson SJ, Parker J, Nasr, N and Wright PC (2010) Methodological considerations in the evaluation of technologies, drawing upon the experiences of the SMART projects AAATE workshop, Assistive technology- technology transfer. October 2010, Sheffield.

Parker J (2009) An Investigation in to Stroke Patients' Utilisation of Feedback from Computer-based Technology, In: Recent advances Assistive Technology and Engineering (RAatE), Nov 30<sup>th</sup> - Dec 1<sup>st</sup> 2009, Coventry

Parker J (2009) An Investigation in to Stroke Patients' Utilisation of Feedback from Computer-based Technology. Health and Social Care Seminar Series; Sheffield Hallam University. 11<sup>th</sup> September 2009.

Parker J (2009) An Investigation in to Stroke Patients' Utilisation of Feedback from Computer-based Technology. 'Cutting Edge' PhysioFirst Education Day; East Midlands Conference Centre, Nottingham; 23<sup>rd</sup> April 2010.

Parker J (2010) A Preliminary Investigation into Stroke Patients' Utilisation of Feedback from Computer-Based Technology for Home-Based Rehabilitation. The 5th Cambridge Workshop on Universal Access (UA) and Assistive Technology (AT): CWUAAT 2010. Fitzwilliam College, University of Cambridge, 22<sup>nd</sup> – 26<sup>th</sup> March 2010.

Parker J (2010) An Investigation in to Stroke Patients' Utilisation of Feedback from Computer-based Technology. Strategic Promotion of Ageing Research Capacity (SPARC) – KT Equal. University of Strathclyde, 28<sup>th</sup> June 2010.



Parker J (2011) The application of Realistic Evaluation: 'What works for whom, and in what circumstances and respects?' 2<sup>nd</sup> Friday Seminar Series; Sheffield Hallam University. 9<sup>th</sup> December 2011.

Parker J (2011) The utilisation of extrinsic feedback from computer-based technology for post-stroke upper-limb rehabilitation in the home: A realistic evaluation. The National Physiotherapy Research Network (NPRN) Event; Sheffield Hallam University 12<sup>th</sup> July 2011.

Parker J (2011) Using technology in rehabilitation following stroke: What does the patient say? 'Innovations in Telehealth and Rehabilitation' Association of Chartered Physiotherapists Interested in Neurology; Yorkshire and Humber Regional Network. Sheffield Hallam University, Robert Winston Building, 5th February 2011.

**Poster presentations:**

Parker J (2008) An Investigation in to Stroke Patients' Utilisation of Feedback from Computer-based Technology, In: Recent advances Assistive Technology and Engineering (RAatE) conference Dec 1<sup>st</sup> 2008. Coventry. Poster presentation.

Parker J (2008) An Investigation in to Stroke Patients' Utilisation of Feedback from Computer-based Technology, In: Faculty of Health and Wellbeing Research Day. SHU, 17<sup>th</sup> Dec 2008. Sheffield. Poster presentation.

Parker J (2010) An Investigation into Stroke Patients' Utilisation of Feedback from Computer-Based Technology, In: International Conference on Support for Self-management of Health (ICCSMOH) May 11-13 2010. Sterling Scotland. Poster presentation.

Parker J (2010) An Investigation into Stroke Patients' Utilisation of Feedback from Computer-Based Technology. Faculty of Health and Wellbeing Research Day, Sheffield Hallam University. 17<sup>th</sup> June 2010.

## **Section 4: References and Appendices**

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Appendix 1: A Summary of Papers Reporting Comparable Technology Systems to the SMART System

Citation, study design, Level of evidence	Subjects, Age, Chronicity and Numbers (N)	Intervention	Results
Edmans <i>et al.</i> , (2009) Single case studies Level III CASP Score 3	13 acute stroke survivors • Mean age 72.8 yrs. • A = control phase • B = treatment phase • Hospital setting	AB/BA – (n = 5): A - 1 hour virtual reality training (VRT) 5 days; B – 1hour sessions of attention control training, 5days. ABA – (n = 2): 1hour sessions of attention control training, 5days - 1 hour VRT, 5 days. rAB – (n = 6): 1hour sessions of attention control training, 3 – 10 days - 1 hour VRT, 5 - 12 days.	No significant difference in the real and virtual hot drink making ability during all control and intervention phases. Measured by the number of errors made, assistance required and tasks completed.
Rand <i>et al.</i> , (2009) Case series, ABA design (A = no treatment) Level III CASP Score 2	6 stroke survivors • Mean age 63.7 yrs. • 5 – 96 months post-stroke • Hospital setting	10 one hour sessions, 3 weeks using the Virtual Mall (VMall).	Improvements were found during the intervention phase only in the FMA and WMFT (mean 0.22 and 0.30 – on a scale of 0-1.0).
Yavuzer <i>et al.</i> , (2008) RCT Level I CASP Score 7	20 sub-acute stroke inpatients (10 controls) • Mean age 61.1 yrs • Mean time since stroke 3.9 months • Hospital setting	Exp gp – 30 mins Playstation eye-toy games and conventional therapy. Control gp – Observation of games only and conventional therapy.	Improved FIM self-care score ( $p < .018$ ) compared to control gp. No significant differences between the groups for Brunstrom stages for the hand and upper extremity.
Piron <i>et al.</i> , (2008) RCT Level I CASP Score 5	47 chronic stroke survivors (20 controls) • Mean age 60 • Mean time since stroke 15 months • Hospital setting	Exp gp – Reinforced Virtual Feedback in a Virtual Environment (RFVE). Control gp – Conventional therapy Both gps: 1 hr, 5days per week, 4 weeks.	FM (upper extremity), FIM, showed significant improvements for both groups for the groups ( $p < 0.05$ ).
Broeren <i>et al.</i> , (2008) CCT Level II CASP Score 3	16 chronic stroke survivors (11- exp gp and 11 controls; 6 participated in both groups starting with control) 1. Mean age 68 yrs. 2. Mean time since stroke 66 months 3. Community day centre	Exp gp: VR therapy 3 times per week for 45 minutes for a 4 week period and conventional therapy. Control gp: Conventional therapy only.	9% improvement in Box and Block Test with exp gp - no change in control group. No changes in manual ability using ABILHAND measure. Increase in speed of hand path ratio (the quotient between actual hand trajectory and straight line distance to targets ( $p = <0.5$ )).

Abbreviations: UL = Upper limb; RCT = Randomised Control trial; CCT = Clinical Control trial; MAS = Modified Ashworth Scale; FM = Fugl-Meyer upper extremity; FIM = Functional Independence Measure; FMA = Fugl-Mayer Assessment; UEFI = Upper Extremity Functional Index; BDI = Beck Depression Inventory; Scale; MMSE = Mini Mental State Examination; MAL-AAU = Motor Activity Log – Actual Amount of Use; MAS = Modified Ashworth Scale; FRT = Functional Reach Test

## Appendix 2: A Summary of a Review of the Evidence Underpinning the Use of Feedback for Computer Technology in Post-Stroke Upper-Limb Rehabilitation

Citation, study design.	Subjects, Age, Chronicity & Numbers (N)	Intervention	Results
Yavuzer <i>et al.</i> , (2008) RCT CASP Score: 8	40 sub-acute stroke survivors <ul style="list-style-type: none"> <li>• mean age 63.2y</li> <li>• mean time since stroke 5.5mo</li> </ul>	Exp gp - Mirror therapy for the UL. Control gp - Conventional stroke rehabilitation 5 days a week, 2 to 5 hours a day, for 4 weeks per day without additional verbal feedback	Improved the scores of the Brunnstrom stages for the hand and upper extremity and the FIM self-care score improved more in the mirror group than in the control group after 4 weeks of treatment ( $p < .01$ ) and at the 6-month follow-up ( $p < .05$ ). No significant differences between the groups for increases in spasticity using the MAS.
Piron <i>et al.</i> , (2007) CCT CASP Score: 3	38 acute stroke survivors <ul style="list-style-type: none"> <li>• mean age 61y</li> </ul>	Exp gp - virtual tasks 1 hour per day, 5 days per week over 5 to 7 weeks Control gp - Conventional therapy	FM & FIM ( $p = < .001$ & $.001$ respectively)
Gilmore & Spaulding (2007) RCT CASP Score: 5	10 acute stroke survivors <ul style="list-style-type: none"> <li>• mean age 68.9y</li> <li>• mean time since stroke 4.5wks</li> </ul>	Exp gp - Videotaped feedback + OT 10 treatment sessions Control gp - OT only 10 treatment sessions	No significant differences between the groups in the subtests of the Klein-Bell Activities of Daily Living Scale and their scores on the Canadian Occupation Performance Measure.
Mautucci & Echouse (2001) CCT CASP Score: 3	40 participants <ul style="list-style-type: none"> <li>- 16 chronic stroke survivors</li> <li>- Age 50-70 yrs.</li> </ul>	Gp 1 - n = 24, 42 attempts x 3 Gp 2 - n = 8, Practice only Gp 3 - n = 8, Reaching with real-time auditory feedback. 18 attempts, 3 times per week for 6 weeks with feedback.	Improvement in path performance was only achieved with feedback group ( $P < 0.05$ )

Abbreviations: UL = Upper limb, RCT = Randomised Control trial, CCT = Clinical Control trial, MAS = Modified Ashworth Scale, FM = Fugl-Meyer upper extremity FIM = Functional Independence Measure

## **Appendix 3: Focus Group Moderator Guide**

### **Welcome**

- Introduce myself
- Thank for volunteering
- Introduce the project (SMART)

### **Introduction**

- Not a test – no right or wrong answers/perspectives
- Interested in hearing your perspectives on the delivery of information and extrinsic feedback to patients carrying out rehabilitation at home.

### **Confidentiality**

- The discussion will be confidential
- I'll be asking you to sign a consent form and the background information sheet before we start
- Discussion will be audio-taped
- Storage of audio-tape
- The background information sheets will be uniquely coded and locked away
- Ask the group to refrain from discussing comments made within the focus group outside.

### **Ground Rules**

- One only person speaks at a time
- You do not have to speak in a particular order
- You do not have to agree with another person's view / opinions
- I may have to redirect the discussion with questions
- Does anyone have any questions?

### **Discussions**

- I realise that each patient and their carer are individual but for the purpose of this discussion may I ask that you think broadly, using general terms

### **Conclusions**

- Thanks for taking part
- If there are any concerns regarding the discussion please feel free to speak to me afterwards

I will be in touch to ask of your opinion following my analysis.

## Appendix 4: The Nottingham Extended Activities of Daily Living Scale (NEADL)

Answers:	Not at all	With help	Alone with difficulty	Alone easily
Questions:	0	1	2	3
<b>Mobility</b>				
<i>Do you:</i>				
• Walk around outside?				
• Climb stairs?				
• Get in and out of the car?				
• Walk over uneven ground?				
• Cross roads?				
• Travel on public transport?				
<b>In the kitchen</b>				
<i>Do you:</i>				
• Manage to feed yourself?				
• Manage to make yourself a hot drink?				
• Take hot drinks from one room to another?				
• Do the washing up?				
• Make yourself a hot snack?				
<b>Domestic tasks</b>				
<i>Do you:</i>				
• Manage your own money when you are out?				
• Wash small items of clothing?				
• Do housework?				
• Do your own shopping?				
• Do a full clothes wash?				
<b>Leisure activities</b>				
<i>Do you:</i>				
• Read newspapers or books?				
• Use the telephone?				
• Write letters?				
• Go out socially?				
• Manage your own garden?				
• Drive a car?				

Scoring 0-3 from left to right.

Lincoln NB and Gladman JRF (1992) The Extended Activities of Daily Living scale: a further validation. *Disability and Rehabilitation*, 14(1): 41-43.

## Appendix 5: Ethical Approval



### **National Research Ethics Service**

#### **South Yorkshire Research Ethics Committee**

1st Floor Vickers Corridor  
Northern General Hospital  
Herries Road  
Sheffield  
S5 7AU

Telephone: 0114 226 9153  
Facsimile: 0114 256 2469  
Email: joan.brown@sth.nhs.uk

05 September 2008

Mr Jack Parker  
PhD Student  
Sheffield Hallam University  
213 Collegiate Hall  
Collegiate Crescent Campus  
Sheffield  
S10 2BP

Dear Mr Parker

**Full title of study:**            **The extent to which stroke survivors can utilise extrinsic feedback from computer-based technology to facilitate rehabilitation in the home.**

**REC reference number:**    **08/H1310/63**

The Research Ethics Committee reviewed the above application at the meeting held on the 28 August 2008. Thank you for attending to discuss the study.

#### **Discussion**

It was queried how you would deal with participants who, because of their condition, were unable to understand the participant information sheet (PIS) or sign the consent form. You explained that participants who were unable to give consent were part of the exclusion criteria and you hoped to be able to explain the PIS in face-to-face meetings with the participants or via the telephone. The committee accepted this clarification.

You were asked to explain the recruitment procedure and clarified that the patients and carers would be sourced from the Community Stroke Teams (CST) in both North and South Sheffield. You had already visited the South Sheffield CST to see how it worked and the clinical lead from the Team believed he could provide the potential participants. The Teams would introduce the research and ask participants if they were interested. Participants would be recruited at the point of their discharge from the CST. The committee accepted this explanation.

You were asked to clarify the number of home visits involved because there appeared to be several and there was conflicting information on the application form. You clarified that the number of follow-up visits could vary and would be dependent upon how much help the participant needed in order to be able to use the computer technology. The majority of visits would be purely to support participants with the computer system rather than for the gathering of data. The committee accepted this clarification.

This Research Ethics Committee is an advisory committee to Yorkshire and The Humber Strategic Health Authority  
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the National Patient Safety Agency and Research Ethics Committees in England



You were asked to explain how the computer system worked and explained it was a new system that had been developed. It was a wireless motion tracking system and consisted of a fabric sleeve containing an inertial tracking device which sat on the wrist and upper arm. Participants' movements were orientated to their trunk and 3D images appeared on the computer screen. They could watch the movements back on the screen and compare them to normal movements. It would be possible for them to detect changes/improvements in their movements. The computer recorded angles and degrees of movement. You would be using the ENVIVO package to analyse the qualitative data and you confirmed you had been on a training course provided by the University in relation to the use of the package. The committee accepted this explanation.

I was pointed out that Point 4 on the consent form for both participants and carers needed rewording and the start date on the application form needed amending.

#### **Ethical opinion**

Members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

#### **Ethical review of research sites**

The favourable opinion applies to the research sites listed on the attached form.

#### **Conditions of the favourable opinion**

The favourable opinion is subject to the following conditions being met prior to the start of the study.

- Submit amended consent form for participants (Version 2 with a new date) – Point 4 to read as follows: "I agree to the researcher visiting my home for the purpose of the study".
- Submit amended consent form for carers (Version 2 with a new date) – Point 4 to read as follows: "I agree to the researcher visiting my home for the purpose of the study".
- The study start date on the application forms reads "17 September 2007" – confirm actual study start date in writing

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

Management permission at NHS sites ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

#### **Approved documents**

The documents reviewed and approved at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Application		23 July 2008
Investigator CV		21 July 2008
Protocol	1	17 July 2008
Covering letter		

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Letter from Sponsor		21 July 2008
Peer Review		24 June 2008
Peer Review		
Questionnaire: Validated - The Nottingham EADL Scale		
Letter of invitation to participant	1	17 July 2008
Participant Information Sheet: Health Professionals	1	17 July 2008
Participant Information Sheet: Carers	1	17 July 2008
Participant Information Sheet	1	17 July 2008
Participant Consent Form: Health Professionals	1	17 July 2008
Participant Consent Form: Carers (Awaiting Version 2)	1	17 July 2008
Participant Consent Form (Awaiting Version 2)	1	17 July 2008
GP Letter	1	17 July 2008
Letter of invitation to participants - health professionals	1	17 July 2008
Letter of invitation to participants - carers)	1	17 July 2008
Risk assessment questionnaire	1	17 July 2008
Focus group topics - health professionals	1	17 July 2008
Interview schedule - carers	1	17 July 2008
Interview schedule - participants	1	17 July 2008

#### Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

#### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

#### After ethical review

Now that you have completed the application process please visit the National Research Ethics Website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

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

- Notifying substantial amendments
- Progress and safety reports
- Notifying the end of the study

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

This Research Ethics Committee is an advisory committee to Yorkshire and The Humber Strategic Health Authority

The National Research Ethics Service (NRES) represents the NRES directorate within  
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We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email [referencegroup@nres.npsa.nhs.uk](mailto:referencegroup@nres.npsa.nhs.uk).

<b>08/H1310/63</b>	<b>Please quote this number on all correspondence</b>
--------------------	---

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

Yours sincerely

*J Brown*

*JP* **Jo Abbott**  
**Chair**

**Enclosures:** List of names and professions of members who were present at the meeting and those who submitted written comments

"After ethical review – guidance for researchers" SL-AR2

Site approval form (SF1)

**Copy to:** Mr Brian Littlejohn, Sheffield Hallam University, Howard Street, Sheffield, S1 1WB

Mr R Dixon, Manager, Sheffield Health & Social Research Consortium, Fulwood House, Old Fulwood Road, Sheffield

## Appendix 6: Research Governance Approval



Sheffield Health & Social Research Consortium

2<sup>nd</sup> October 2008

Mr Jack Parker  
12 Patterdale Close  
Dronfield  
Derbyshire  
S18 8PW

Fulwood House  
Old Fulwood Road  
Sheffield  
S10 3TH

Tel: 0114 2718804  
Fax: 0114 2716736  
Email: [shsrc@shsc.nhs.uk](mailto:shsrc@shsc.nhs.uk)  
[www.shsrc.nhs.uk](http://www.shsrc.nhs.uk)

Dear Mr Parker,

**Consortium Ref: ZK11**

**Full Project Title: The extent to which stroke survivors can utilise extrinsic feedback from computer-based technology to facilitate rehabilitation in the home**

Please find enclosed two copies of an Honorary Contract for your involvement in Sheffield Primary Care Trust, in order to regularise your position with the Trust. Please note that the copy of the contract marked 'file copy' should be signed and dated by you on the last page and returned to the Consortium.

You now have **Research Governance approval from this Consortium** to carry out research as described in documentation you have supplied to us.

We also advise you of the following conditions which apply to all receiving Research Governance Approval through the Consortium:

1. Please inform us of the actual project start date immediately you do start and at that time inform us also of the expected end date.
2. In order to comply with the NHS Research Governance Framework, please copy the Consortium into all future project monitoring forms that you send to the relevant Research Ethics Committee, including the "Declaration of End of Study".
3. The Consortium recommends the attached format for maintenance of your project site file to ensure all documentation is readily accessible.
4. You will also need to seek approval for every future change to protocol or project title and I suggest you do this by sending us a draft of the submission you will also have to make to the NHS REC and that you do so at the same time as that submission to the REC. See the following web reference for details:  
[www.nres.npsa.nhs.uk/applicants/review/after/amendments.htm](http://www.nres.npsa.nhs.uk/applicants/review/after/amendments.htm)
5. The Consortium recommends the attached amendment log in order to track amendment submissions to, and approvals from, the relevant REC and R&D office(s)
6. As Chief Investigator, you have an obligation to report all research-related adverse events directly to the Consortium.

A multi-agency consortium of NHS  
Trusts, Universities and the City  
Council in Sheffield



The University  
of Sheffield



Sheffield Hallam University

7. As Chief Investigator, you are reminded of your obligations in relation to the Mental Capacity Act 2005. See the following web reference for details:  
[www.rdforum.nhs.uk/docs/mca\\_guidance.doc](http://www.rdforum.nhs.uk/docs/mca_guidance.doc)
8. You are reminded to familiarise yourself with our partner organisation(s) Information Governance policies and procedures regarding the storage of patient-identifiable data
9. You need to seek Consortium approval for any additions to your research team not already included in documentation sent to us. For this purpose, please send a short CV, preferably in the format required by the NHS REC.
10. This Research Governance approval is given on the understanding that the findings of the research will be appropriately disseminated in peer-reviewed journal(s) and to research participants and any organisations representing their interests.

We wish you every success with the project and please feel free to contact us if you need further assistance from the Consortium.

Yours sincerely



Dr Robert Dixon  
Consortium Manager

Enc: Two copies of honorary contract  
Site file guidance  
Amendment log

Cc: Dr Jonathan Boote  
Project File

Ecc: Prof Wesley Vernon

## Appendix 7: NRES Amendment Approval



### National Research Ethics Service

#### South Yorkshire Research Ethics Committee

1st Floor Vickers Corridor  
Northern General Hospital  
Herries Road  
Sheffield  
S5 7AU

Tel: 0114 226 9153  
Fax: 0114 256 2469  
Email: joan.brown@sth.nhs.uk

25 February 2009

Mr Jack Parker  
PhD student  
The Centre for Health & Social Care Research  
Faculty of Health & Wellbeing  
213 Collegiate Hall  
Collegiate Crescent Campus  
Sheffield  
S10 2BP

Dear Mr Parker

**Study title:** The extent to which stroke survivors can utilise extrinsic feedback from computer-based technology to facilitate rehabilitation in the home.  
**REC reference:** 08/H1310/63  
**Amendment number:** No.1  
**Amendment date:** 12 February 2009

The above amendment was reviewed at the meeting of the Sub-Committee of the REC held on 18 February 2009.

#### Ethical opinion

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

#### Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Protocol	2	09 February 2009
Recruitment Flow Chart	1	09 February 2009
Letter of invitation to carers	2	09 February 2009
Notice of Substantial Amendment (non-CTIMPs)		12 February 2009
Letter of invitation to participant	2	09 February 2009

This Research Ethics Committee is an advisory committee to Yorkshire and The Humber Strategic Health Authority  
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### **Membership of the Committee**

The members of the Committee who were present at the meeting are listed on the attached sheet.

### **R&D approval**

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

### **Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

<b>08/H1310/63:</b>	<b>Please quote this number on all correspondence</b>
---------------------	---

Yours sincerely



**Mrs Joan Brown**  
**Committee Co-ordinator**

Enclosures                      List of names and professions of members who were present at the meeting and those who submitted written comments

Copy to:                         Mr Brian Littlejohn, Sheffield Hallam University, Howard Street, Sheffield, S1 1WB

   Mr R Dixon, Manager, Sheffield Health & Social Research Consortium, Fulwood House, Old Fulwood Road, Sheffield

This Research Ethics Committee is an advisory committee to Yorkshire and The Humber Strategic Health Authority

The National Research Ethics Service (NRES) represents the NRES directorate within  
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## Appendix 8: Research Governance Amendment Approval



Sheffield Health & Social Research Consortium

10 March 2009

Mr Jack Parker  
The Centre for Health and Social Care Research  
Faculty of Health and Wellbeing  
32 Collegiate Crescent  
Collegiate Crescent Campus  
Sheffield S10 2BP

Fulwood House  
Old Fulwood Road  
Sheffield  
S10 3TH

Tel: 0114 2718804  
Fax: 0114 2716736  
Email: [shsrc@shsc.nhs.uk](mailto:shsrc@shsc.nhs.uk)  
[www.shsrc.nhs.uk](http://www.shsrc.nhs.uk)

Dear Mr Parker,

**Consortium Ref: ZK11**

**Full Project Title: The extent to which stroke survivors can utilise extrinsic feedback from computer-based technology to facilitate rehabilitation in the home**

**REC Proposed Amendment Version 2, dated 09 February 2009**

I am writing in response to a letter received on 9 March 2009 from you dated 5 March 2009 with details of the above proposed amendment. I can confirm on behalf of Sheffield Primary Care Trust that you have Research Governance approval from this Consortium to implement the above amendment, for which I note you have received a favourable opinion from an NHS REC.

For the benefit of our partner organisation research lead to whom I am copying this letter, I summarise the essential changes as follows:

- Changes to the protocol: Recruitment (p12) and Inclusion / exclusion (p14)
- Changes to the application form: Question A20 and A23
- Change to the covering letters

Yours sincerely

Dr Robert Dixon  
Consortium Manager

cc: Project File

ecc: Prof Wesley Vernon





## Appendix 9: Audit



SHARPENS YOUR THINKING

21 August 2009

Jack Parker  
The Centre for Health and Social Care Research  
Faculty of Health and Wellbeing  
33 Collegiate Crescent  
Sheffield  
S10 2BP

Dear Jack

**Re: Project Audit**  
**Project Title: An Investigation into Stroke Patients Utilisation of feedback from computer based technology**

Please find enclosed the report of the audit that was undertaken by Prof Ann Macaskill and Brian Littlejohn on the above project on 20 August 2009. You will see that the report corresponds to the Sheffield Health and Social Research Consortium's "Guidance for Maintenance of an Investigator Site File".

The audit team was satisfied with the contents of your site file, are confident that your study is being undertaken to the standards laid out in the Department of Health's Research Governance Framework for Health and Social Care and would commend your approach to including the PhD material in the file.

Please do not hesitate to contact me if you have any queries about the amendments you are asked to make. We hope you found the audit a useful experience. Please keep this letter and the report in your site file.

Best wishes for the remainder of the study.

Yours sincerely



Brian Littlejohn  
Research Support Team  
Enterprise Centre  
Sheffield Hallam University, Science Park, Unit 6  
Howard Street, Sheffield, S1 1WB  
Tel: 0114 225 4050  
Email: [b.littlejohn@shu.ac.uk](mailto:b.littlejohn@shu.ac.uk)

### Enterprise Centre

Sheffield Hallam University City Campus Howard Street Sheffield S1 1WB UK  
Telephone +44 (0)114 225 5000 Fax +44 (0)114 225 3524 E-mail [business@shu.ac.uk](mailto:business@shu.ac.uk)  
[www.shu.ac.uk/business](http://www.shu.ac.uk/business)



This project is part-funded by the  
European Regional Development Fund

## **Appendix 10: Letter of Invite (Health Professionals)**

Mr Jack Parker  
The Centre for Health and Social Care Research  
Faculty of Health and Wellbeing  
33 Collegiate Crescent  
Collegiate Crescent Campus  
Sheffield  
S10 2BP

Dear Health Professional,

### **Re: An Investigation into Stroke Patients' Utilisation of Feedback from Computer-Based Technology.**

I am a PhD student at Sheffield Hallam University. My study aims to explore the use of some equipment that we have developed which uses technology to give feedback to stroke survivors and therapists. We now want to test out this equipment to see if stroke survivors, carers and therapists can make use of the feedback/information the equipment provides during the rehabilitation process.

I would like to invite you to take part in my study. Please read and consider the information sheet provided. If you wish to ask any questions regarding your involvement, please do not hesitate to contact me. If you would like to take part in the study please contact me by email or telephone by 20<sup>th</sup> February 2009.

Yours sincerely

**Mr Jack Parker**

BSc (Hons) MCSP

**Email:** jack.parker@student.shu.ac.uk

**Tel:** 07791 587896

## **Appendix 11: Information Sheet (Health Professionals)**

### **Health Professionals Information Sheet.**

#### **PART 1**

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

#### **What is the title of the study?**

An investigation into stroke patients' utilisation of feedback from computer-based technology.

#### **What is the purpose of the study?**

We want to find out the best way of using technology to assist with rehabilitation following a stroke.

As part of this investigation, I am exploring the extent to which stroke survivors can utilise the feedback provided by computer-based technology to facilitate rehabilitation in the home. I am conducting this study over 3 years as part of my PhD. It will involve various Health Professionals in the Community Stroke Team, stroke survivors and their carers.

Firstly, we want to find out what current practice and provision of information and extrinsic feedback is given to clients and carers, in order to facilitate home-based rehabilitation when not in face-to-face contact with the therapist.

Secondly, we have developed some equipment using orientation sensors and computer technology that will give feedback to clients and therapists. We now want to test out this equipment to see if clients can make use of the feedback/information the equipment provides during the rehabilitation process.

#### **What have I been chosen?**

You have been asked to take part because you are part of a team that provides community stroke rehabilitation. In particular, you provide treatment that aims to alter the physical behaviour of patients in your care.

#### **Do I have to take part?**

It is up to you whether or not to take part. If you do decide to take part you will be given this information sheet to keep and asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason.

**Do I have to take part?**

Participation is entirely voluntary.

**What do I have to do?**

If you decide you would like to take part, the researcher would like to conduct a group discussion (focus group) about the current practice and provision of information and extrinsic feedback that is given to clients and carers, in order to facilitate home-based rehabilitation when not in face-to-face contact with the therapist. This will be in your place of work and should last for approximately 1 ½ hrs. It is hoped that the discussion will be video/tape-recorded and notes will be taken during the discussion.

**What will happen to the audio recordings?**

All information will be kept strictly confidential. The recordings will be stored securely. You may withdraw your consent before, during and after the recording or ask for it to be edited or deleted if necessary. You can stop the recording for any reason. You can listen or see the finished recording. They will not be used for any other purposes and by anyone else outside the research team. After the study ends, the recordings will be stored in a secure, locked university space for another 3 years.

**Expenses**

With your permission all your involvement in the study will take place in your place of work at a time of your convenience. Therefore there should be no costs for you.

**Are there any risks or disadvantages to taking part in this study?**

We do not anticipate that there will be any risks or disadvantages to taking part. However, you are being asked to give up some time for the group discussion.

**What are the possible benefits of taking part?**

We think that you will find the discussions interesting and the information you provide will help with the development of the equipment will enhance therapy outcomes as well as relieving therapy staff of some of the burden of routine treatment, allowing them to concentrate on more complex interventions.

**PART 2**

### **What if relevant new information becomes available?**

Sometimes during the course of a research project, new information becomes available about the treatment that is being studied. If this happens, your research physiotherapist will tell you about it and discuss whether you want to or should continue in the study. If you decide to continue in the study you will be asked to sign an updated consent form.

Also, on receiving new information your research physiotherapist might consider it to be in your best interests to withdraw you from the study. They will explain the reasons for this.

If the study is stopped for any other reason, you will be told why.

### **What if there is a problem?**

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action but you may have to pay for it. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms should be available to you.

### **What if I want to get more information?**

Please contact me at the address below if you have any questions regarding the study. For more information you may also like to look at the booklets produced by Involve, a national advisory group funded by the DoH, which supports active public involvement in NHS, public health and social care research. They can be contacted at:

Involve  
Wessex House  
Upper Market St  
Eastleigh  
Hampshire  
SO50 9FD  
Tel. 023 8065 1088  
[www.invo.org.uk](http://www.invo.org.uk)

### **Will my taking part in the study be kept confidential?**

All information which is collected about you during the course of the research will be kept strictly confidential. You will be identified by a code number rather than a name. The audio tapes will be stored securely. People from regulatory authorities may look at our records to check that the study is being carried out correctly. Your name will not be disclosed.

**What will happen to the results of the study?**

You will be informed of the results of the study on completion if you wish. I intend to publish the findings of the study in a healthcare journal or present them at professional conferences.

**Who is organising and funding the research?**

The sponsors of the study are the Engineering Physical Sciences Research Council.

**Who has reviewed the study?**

The study will have received ethical approval by Sheffield Research Ethics Committee.

Please do hesitate to contact me if you have any questions or queries regarding the study and thank you for taking time to read the information sheet and considering your involvement.

**Contact Details:**

If you have any questions or wish to contact the researcher;

Mr Jack Parker BSc (Hons) MCSP

The Centre for Health and Social Care Research

Faculty of Health and Wellbeing

33 Collegiate Crescent

Collegiate Crescent Campus

Sheffield

S10 2BP

## Appendix 12: Therapists' Details

<b><u>Name:</u></b>
<b><u>Address (work):</u></b>
<b><u>Profession:</u></b>
<b><u>Grade:</u></b>
<b><u>Year Qualified:</u></b>
<b><u>Qualification:</u></b>
<b><u>Additional Qualifications:</u></b>
<b><u>Length of time working with Stroke as a specialty:</u></b>

## Appendix 13: Focus Group Topics with Health Professionals

**Objective:** To establish what forms of information and extrinsic feedback is routinely given to patients and carers, in order to facilitate home-based rehabilitation when not in face-to-face contact with the therapist and gain the opinion of practitioners on the potential use of the SMART Rehabilitation Technology System with stroke survivors.

**Question:** What is the opinion of expert practitioners in the the potential use of the SMART Rehabilitation Technology System with stroke survivors?

- What do you think are the positives and negatives for using the SMART Rehabilitation Technology System?

**Question:** What is the opinion of expert practitioners in the delivery of information and extrinsic feedback to patients carrying out rehabilitation when the therapist is not in face-to-face contact with the patients?

- What information is routinely given to patients, to facilitate home-based rehabilitation when not in face-to-face contact with the therapist?
  - What form does this take?
  - Do you vary what you give for different patients?
  - Have you received any feedback/opinion on this information from the patient/carer?
    - Practical/personal considerations
- What extrinsic feedback being routinely given to patients, to facilitate home-based rehabilitation when not in face-to-face contact with the therapist?
  - What form does this take?
  - Do you vary what you give for different patients?
  - Have you received any feedback/opinion on this information from the patient/carer?
    - Practical/personal considerations
- What help and information is routinely given to carers/family members to assist the home exercises prescribed for the patients?
  - Are the patients and carers able to follow the exercises/activities given?
    - If not, why? What are the problems with it?
    - Is there anything that you think would help?
  - How do you know if they are improving?
    - How does this usually correlate to how they think they are improving/not improving?
  - What do you like about current provision?
  - What do you not like about current provision?
    - What would you change about it?
  - Do you know of or think the patients or carers receive any other information and extrinsic feedback from other sources?
    - Do you recommend any to them?
- Do you vary what feedback you give to patients when you are treating them?
  - What are the reasons (if any) for giving different feedback?



## Appendix 14: Institutional Ethical Approval

Research proposal review form: July 08

Faculty of Health and Wellbeing  
Faculty Research Ethics Committee  
Health and Social Care Division

### Research Proposal Review Form

#### Review Summary

**Name of researcher:** Jack Parker

Project title: An Investigation into Stroke Patients' Utilisation of Feedback from Computer-Based Technology.

Name of supervisor: Gail Mountain

Code for Decision:

**Satisfactory Review with some advice**

Signature of Reviewer: Peter Allmark

Date: 13/08/08

Feedback :

This is a pilot project associated with a larger doctoral project to be undertaken in the NHS. That larger project has already had ISR and is due to go through NHS ethics. As such, the scientific side of the project seems robust and I have not dealt with it further here. I also believe it only needs one further review so I have dealt with it myself rather than send it out to an additional two reviewers. The ethical issues of recruitment, confidentiality, consent and so forth are satisfactorily dealt with here also. The information sheets are good. Under the "What if there is a problem?" section you should add the name and details of your supervisor as an alternative to contacting you. I think the GP letter is unnecessary.

**Faculty of Health and Wellbeing Research Ethics Committee  
Health & Social Care Research Ethics Review Group  
Report Form**

Title: An Investigation into Stroke Patients' Utilisation of  
Feedback from computer-Based Technology.

Principal Investigator: Jack Parker

Recommendation:

Acceptable:

✓
---

Not acceptable, see comments:

--

Acceptable, but see comments:

--

Comments:

Please see advice on attached review sheets.

Signature : Peter Almark ..... Date: 13/8/08 .....

Peter Almark,  
Chair  
HSC Research Ethics Review Group

*Please remember that an up-to-date project file must be maintained for the duration of the project and afterwards. The project file might be inspected at any time.*

**Note:** Approval applies until the anticipated date of completion unless there are changes to the procedures, in which case another application should be made.

## **Appendix 15: Letter of invite (participant)**

Mr Jack Parker  
The Centre for Health and Social Care Research  
Faculty of Health and Wellbeing  
33 Collegiate Crescent  
Collegiate Crescent Campus  
Sheffield  
S10 2BP  
Tel: 07791 587896 (mobile)  
01246 291866 (home)

Dear [stroke survivor],

### **Re: An Investigation into Stroke Patients' Utilisation of Feedback from Computer-Based Technology.**

I am a PhD student at Sheffield Hallam University. My study aims to explore the use of some equipment that we have developed which uses technology to give feedback to stroke survivors and therapists. We now want to test out this equipment to see if stroke survivors, carers and therapists can make use of the feedback/information the equipment provides during the rehabilitation process.

I would like to invite you to take part in my study. Please read and consider the information sheet provided. If you wish to ask any questions regarding your involvement, please do not hesitate to contact me. The researcher will contact you soon to discuss your potential involvement.

Yours sincerely

Mr Jack Parker  
BSc (Hons) MCSP

## **Appendix 16: Information Sheet (Participant)**

### **PART 1.**

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Part 1 of this information sheet tells you the purpose of this study and what will happen to you if you take part. Part 2 gives you more detailed information about the conduct of the study. Talk to others about the study if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

#### **What is the title of the study?**

An investigation into stroke patients' utilisation of feedback from computer-based technology.

#### **What is the purpose of the study?**

As part of my PhD I am exploring the extent to which stroke survivors can utilise the feedback provided by computer-based technology to facilitate rehabilitation in the home. I am conducting this study over 3 years and it will involve various Health Professionals who you may have already met in the Community Stroke Team, your carer and yourself.

Following a stroke, you may need therapy to help you improve your movements.

We want to find out the best way of using technology to assist with rehabilitation following a stroke. We have developed some equipment using technology that will give feedback to participants and therapists. We now want to test out this equipment to see if participants, carers and therapists can make use of the feedback/information the equipment provides during the rehabilitation process.

#### **Why have I been invited?**

You have been invited to participate in this study because you have had a stroke that has affected your arm.

#### **Do I have to take part?**

It is up to you whether or not to take part. If you do decide to take part you will be given this information sheet to keep and asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. If you decide not to take part or you withdraw later on, it will not affect the standard of care you receive from any health or social care service.

### **What will happen to me if I take part?**

If you decide to take part, you will be involved in the study for 8 weeks. The researcher will visit you at home initially to ask you some questions about what information you find useful that helps you improve your physical ability when your therapist is not there. This will take no longer than 90 minutes.

Following this, you will be invited to use some technology that may help you do some arm exercises. To begin with, the researcher will show you how to use the equipment and take some measurements from the computer, after this you will then be invited to use the equipment for up to 6 weeks to be agreed with you and keep a simple diary to note down any comments about using the system each time you use it. The researcher will visit you up to 4 times in the first week with the equipment to monitor your use of the equipment and answer any questions you may have. These visits will last no longer than 90 minutes. The frequency of these visits may then decrease if agreed with you. At the end of your 6 weeks the researcher will take some more measurements from the computer and ask you some questions about your experiences using the equipment. In order to record your views accurately we would like to make audio recordings of your responses to the equipment. The recordings will be of you using and talking about your experiences.

### **What will happen to the audio recordings?**

All information will be kept strictly confidential. The recordings will be stored securely. You may withdraw your consent before, during and after the recording or ask for it to be edited or deleted if necessary. You can stop the recording for any reason. You can listen or see the finished recording. They will not be used for any other purposes and by anyone else outside the research team. After the study ends, the recordings will be stored in a secure, locked university space for another 3 years.

### **Expenses**

With your permission all your involvement in the study will take place in your home. Therefore there should be no costs for you.

### **What if I change my mind during the study?**

You are free to withdraw from the study at any time without affecting your management. You will not have to give any reasons for your withdrawal.

### **Are there any risks or disadvantages to taking part in this study?**

We do not anticipate that there will be any risks or disadvantages to taking part. You are being asked to give up some time in order to use the equipment and to give us your views on your experience of testing it. The exercises you will be asked to do are designed to assist your rehabilitation. With your permission, your GP will have been informed of your participation in the study and will give the researcher their approval for you to take part.

**What are the possible benefits of taking part?**

We think you will find the use of the equipment interesting. You may find that the use of the system encourages you to do the therapist prescribed exercises. You may find that your use of the system improves your movement ability. The information we get from this study will help us to refine the devices for rehabilitation following a stroke. We hope that it will help people in the future who have had a stroke.

**What will happen to the information from the study?**

All information will be kept entirely confidential. No individual will be identifiable in the report. You will be informed of the results of the study if you wish but they may not be fully analysed for a couple of years.

**PART 2**

**What if relevant new information becomes available?**

Sometimes during the course of a research project, new information becomes available about the treatment that is being studied. If this happens, your research physiotherapist will tell you about it and discuss whether you want to or should continue in the study. If you decide to continue in the study you will be asked to sign an updated consent form.

Also, on receiving new information your research physiotherapist might consider it to be in your best interests to withdraw you from the study. They will explain the reasons for this.

If the study is stopped for any other reason, you will be told why.

**What if there is a problem?**

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action but you may have to pay for it. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way

you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms should be available to you.

**What if I want to get more information?**

Please contact me at the address below if you have any questions regarding the study. For more information you may also like to look at the booklets produced by Involve, a national advisory group funded by the DoH, which supports active public involvement in NHS, public health and social care research. They can be contacted at:

Involve  
Wessex House  
Upper Market St  
Eastleigh  
Hampshire  
SO50 9FD  
Tel. 023 8065 1088  
[www.invo.org.uk](http://www.invo.org.uk)

**Will my taking part in the study be kept confidential?**

All information which is collected about you during the course of the research will be kept strictly confidential. You will be identified by a code number rather than a name. The audio tapes will be stored securely. People from regulatory authorities may look at our records to check that the study is being carried out correctly. Your name will not be disclosed.

**What will happen to the results of the study?**

You will be informed of the results of the study on completion if you wish. I intend to publish the findings of the study in a healthcare journal or present them at professional conferences.

**Who is organising and funding the research?**

The sponsors of the study are the Engineering Physical Sciences Research Council.

**Who has reviewed the study?**

The study will have received ethical approval by Sheffield Research Ethics Committee.

Please do hesitate to contact me if you have any questions or queries regarding the study and thank you for taking time to read the information sheet and considering your involvement.

**Contact Details:**

If you have any questions or wish to contact the researcher;

Mr Jack Parker BSc (Hons) MCSP  
The Centre for Health and Social Care Research, Faculty of Health and Wellbeing  
33 Collegiate Crescent, Collegiate Crescent Campus  
Sheffield, S10 2B

## **Appendix 17: Letter of invite (carer)**

Mr Jack Parker  
The Centre for Health and Social Care Research  
Faculty of Health and Wellbeing  
33 Collegiate Crescent  
Collegiate Crescent Campus  
Sheffield  
S10 2BP  
Tel: 07791 587896 (mobile)  
01246 291866 (home)

Dear [carer],

**Re: An Investigation into Stroke Patients' Utilisation of Feedback from Computer-Based Technology.**

I am a PhD student at Sheffield Hallam University. My study aims to explore the use of some equipment that we have developed which uses technology to give feedback to stroke survivors and therapists. We now want to test out this equipment to see if stroke survivors, carers and therapists can make use of the feedback/information the equipment provides during the rehabilitation process.

I would like to invite you to take part in my study. Please read and consider the information sheet provided. If you wish to ask any questions regarding your involvement, please do not hesitate to contact me. The researcher will contact you soon to discuss your potential involvement.

Yours sincerely

Mr Jack Parker

BSc (Hons) MCSP



## **Appendix 18: Information Sheet (carer)**

### **Carers Information Sheet**

#### **PART 1**

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

#### **What is the title of the study?**

An investigation into stroke patients' utilisation of feedback from computer-based technology.

#### **What is the purpose of the study?**

As part of my PhD I am exploring the extent to which stroke survivors can utilise the feedback provided by computer-based technology to facilitate rehabilitation in the home. I am conducting this study over 3 years and it will involve various Health Professionals who you may have already met in the Community Stroke Team, the person you care for and yourself.

Following a stroke, the person you care for / live with may need therapy to help you improve your movements, ability or speech.

We want to find out the best way of using technology to assist with rehabilitation following a stroke. We have developed some equipment using orientation sensors and computer technology that will give feedback to clients and therapists. We now want to test out this equipment to see if clients, carers and therapists can make use of the feedback/information the equipment provides during the rehabilitation process.

#### **Why have I been invited?**

You have been asked to take part because you care for or live with someone who has had a stroke.

#### **Do I have to take part?**

It is up to you whether or not to take part. If you do decide to take part you will be given this information sheet to keep and asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason.

#### **What if I do not wish to take part?**

If you decide not to take part or you withdraw later on, it will not affect the standard of care the person you care for / live with receive from any health or social care service in any way.

**What will happen to me if I take part?**

If you decide to take part, you will be involved in the study for 8 weeks. The researcher will visit you at home to ask you some questions about the treatment the person you care for / live with receives at the moment. This will take no longer than 90 minutes. The researcher will be asking you what information you find useful that helps the person you care for / live with improve their physical ability when they are not in face-to-face contact with their therapist. Following this, the person you care for / live will be using some computer equipment to carry out some arm exercises in the home. This will be for a period of up to 6 weeks. After the 6 weeks the researcher would like to ask you some questions to gain your perspectives on the use of the equipment over the time they have been using it.

With your permission, the interviews will be recorded by a tape –recorder.

**What will happen to the audio recordings?**

All information will be kept strictly confidential. The recordings will be stored securely. You may withdraw your consent before, during and after the recording or ask for it to be edited or deleted if necessary. You can stop the recording for any reason. You can listen or see the finished recording. They will not be used for any other purposes and by anyone else outside the research team. After the study ends, the recordings will be stored in a secure, locked university space for another 3 years.

**Expenses**

With your permission all your involvement in the study will take place in your home. Therefore there should be no costs for you.

**What if I change my mind during the study?**

You are free to withdraw from the study at any time without affecting your management. You will not have to give any reasons for your withdrawal.

**Are there any risks or disadvantages to taking part in this study?**

We do not anticipate that there will be any risks or disadvantages to taking part. However, you are being asked to give up some time to be interviewed at home.

**What are the possible benefits of taking part?**

The information you give us will help us design a system that will enable people with who have had a stroke cope better at home. We hope that in the future this will benefit people who have had a stroke as well as make good use of healthcare resources.

## **PART 2**

### **What if relevant new information becomes available?**

Sometimes during the course of a research project, new information becomes available about the treatment that is being studied. If this happens, your research physiotherapist will tell you about it and discuss whether you want to or should continue in the study. If you decide to continue in the study you will be asked to sign an updated consent form.

Also, on receiving new information your research physiotherapist might consider it to be in your best interests to withdraw you from the study. They will explain the reasons for this.

If the study is stopped for any other reason, you will be told why.

### **What if there is a problem?**

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action but you may have to pay for it. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms should be available to you.

### **What if I want to get more information?**

Please contact me at the address below if you have any questions regarding the study. For more information you may also like to look at the booklets produced by Involve, a national advisory group funded by the DoH, which supports active public involvement in NHS, public health and social care research. They can be contacted at:

Involve  
Wessex House  
Upper Market St  
Eastleigh  
Hampshire  
SO50 9FD  
Tel. 023 8065 1088  
[www.invo.org.uk](http://www.invo.org.uk)

**Will my taking part in the study be kept confidential?**

All information which is collected about you during the course of the research will be kept strictly confidential. You will be identified by a code number rather than a name. The audio tapes will be stored securely. People from regulatory authorities may look at our records to check that the study is being carried out correctly. Your name will not be disclosed.

**What will happen to the results of the study?**

You will be informed of the results of the study on completion if you wish. I intend to publish the findings of the study in a healthcare journal or present them at professional conferences.

**Who is organising and funding the research?**

The sponsors of the study are the Engineering Physical Sciences Research Council.

**Who has reviewed the study?**

The study will have received ethical approval by South Yorkshire Research Ethics Committee. Please do hesitate to contact me if you have any questions or queries regarding the study and thank you for taking time to read the information sheet and considering your involvement.

**Contact Details:**

If you have any questions or wish to contact the researcher;

Mr Jack Parker BSc (Hons) MCSP

The Centre for Health and Social Care Research

Faculty of Health and Wellbeing

33 Collegiate Crescent

Collegiate Crescent Campus

Sheffield

S10 2BP

## Appendix 19: Therapist's Participant Profile

### Part A: Participant Suitability

Please tick the corresponding box yes or no.

<b>Name:</b>		
<b>Address:</b>	<b>Tel:</b>	
<b>Suitability Criteria</b>	<b>Yes</b>	<b>No</b>
1. Do they have a definitive diagnosis of stroke?		
2. Are they able to speak English?		
3. Do they have a co-resident carer?		
4. Do they have severe communication, perceptual or cognitive disorders?		
5. Do they have visual impairment?		
6. Do they have any shoulder subluxation or arm pain that affects their AROM?		
7. Are they medically unstable or have other neurological, neuromuscular, or orthopaedic disorders that would interfere with UL task performance?		
8. Are they receiving further rehabilitation in the home?		

If questions 1-3 are ticked 'yes' please continue onto part B.

### Part B: Participant Profile

<b>Age:</b>	<b>Gender:</b>
<b>Stroke onset:</b>	
<b>Site of lesion:</b>	
<b>PMH / Co-morbidities:</b>	
<b>AROM (affected arm):</b>	
<b>Shoulder Flexion:</b>	<b>Elbow Flexion:</b>
<b>Abduction:</b>	<b>Extension:</b>

**Level of functional ability:**

**Carer Profile:**

**Name:**

**Age:**

**Gender:**

**Participant's General Practitioner (G.P)**

With permission from the participant, advice will be sought from the participant's G.P. to ensure their medically suitability and safety. This will be via a letter that will be sent prior to their involvement in the study.

**G.P. Details:**

**Name:**

**Address of surgery:**

**Checklist:**

<b>Have you:</b>	<b>YES</b>	<b>NO</b>
Introduced the study to the participant and carer?		
Given the patient and carer an information pack (white envelope)?		
Explained screening process to the participant? (MMSE and FAST)?		
Filled in suitability criteria (parts A and B)?		
Gained verbal consent from participant and carer for suitability criteria (parts A and B) to be given to Jack and for Jack to telephone to arrange a visit and screen them (MMSE and FAST)? * <b><u>PLEASE INITIAL YES OR NO</u></b>		

MMSE – Mini-mental state examination      FAST – Frenchay Aphasia Screening Test

**If these are all ticked 'yes' please email Jack Parker (jack.parker@student.shu.shu.ac.uk) or call him on 07791 587896 to collect.**

**Thank you for your help!**

## Appendix 20: Letter to G.P.

Mr Jack Parker  
The Centre for Health and Social Care Research  
Faculty of Health and Wellbeing  
33 Collegiate Crescent  
Collegiate Crescent Campus  
Sheffield  
S10 2BP  
Tel: 07791 587896 (mobile)  
01246 291866 (home)

Name and Address of participant's G.P.

Dear Dr.

I am carrying out a study as part of my PhD that aims to explore the extent to which stroke clients can utilise extrinsic feedback from computer-based technology to facilitate rehabilitation in the home.

In collaboration with a number of universities; we have developed some equipment using orientation sensors and computer technology that will give feedback to clients who have had a stroke and therapists. We now want to test out this equipment to see if clients can make use of the feedback/information the equipment provides during the rehabilitation process. I am hoping that this study will help inform technology development and future practice.

The study is being funded by the Engineering Physical Sciences Research Council (EPSRC).

As part of the research, I am conducting interviews with participants and their co-residing carers. Following this I will be providing the participants with computer equipment for them to use in their homes for 6 weeks under my guidance.

My inclusion criteria for participants are those who have had a single definitive diagnosis of stroke, able to speak English and are able to give informed consent to the participation of the study.

My exclusion criteria involves persons who have severe communication, perceptual or cognitive disorders, visual impairment; apraxic, shoulder subluxation or arm pain; medically unstable and other neurological, neuromuscular, or orthopaedic disorders that would interfere with task performance and are unable to give informed consent to the participation in the study.

If there are any reasons why you would recommend that XX should not participate, I would be grateful if you could let me know within two weeks of receiving this letter. If I do not hear from you, I will presume that you are in agreement.

I would like you to know that XX has agreed to take part in the above study.

Yours sincerely,


Mr J. Parker BSc (Hons) MCSP

## Appendix 21: The MMSE

### Mini-Mental State Examination (MMSE)

Patient's Name: \_\_\_\_\_ Date: \_\_\_\_\_

**Instructions:** Ask the questions in the order listed. Score one point for each correct response within each question or activity.

Maximum Score	Patient's Score	Questions
5		"What is the year? Season? Date? Day of the week? Month?"
5		"Where are we now: State? County? Town/city? Hospital? Floor?"
3		The examiner names three unrelated objects clearly and slowly, then asks the patient to name all three of them. The patient's response is used for scoring. The examiner repeats them until patient learns all of them, if possible. Number of trials: _____
5		"I would like you to count backward from 100 by sevens." (93, 86, 79, 72, 65, ...) Stop after five answers. Alternative: "Spell WORLD backwards." (D-L-R-O-W)
3		"Earlier I told you the names of three things. Can you tell me what those were?"
2		Show the patient two simple objects, such as a wristwatch and a pencil, and ask the patient to name them.
1		"Repeat the phrase: 'No ifs, ands, or buts.'"
3		"Take the paper in your right hand, fold it in half, and put it on the floor." (The examiner gives the patient a piece of blank paper.)
1		"Please read this and do what it says." (Written instruction is "Close your eyes.")
1		"Make up and write a sentence about anything." (This sentence must contain a noun and a verb.)
1		"Please copy this picture." (The examiner gives the patient a blank piece of paper and asks him/her to draw the symbol below. All 10 angles must be present and two must intersect.) 
30		TOTAL



# Frenchay Aphasia Screening Test Administration Form

**Materials required:**

Picture card with attached reading cards, pencil and paper, stop watch, or watch with second hand.

**Check:**

Patient is wearing spectacles, if needed. Patient can hear you adequately (raise voice if necessary).

**Comprehension**

Show patient card with river scene. Say: 'Look at the picture. Listen carefully to what is said and point to the things I tell you to.' Score 1 for each correctly performed. If instructions require repeating, score as error. Unprompted self-correction may be scored as correct. Score range 0–10.

**Instructions**

(a) *River scene*

Practice item: 'Point to the river'. Do not score this item. Repeat until patient understands what is required.

- 1 Point to a boat
- 2 Point to the tallest tree
- 3 Point to the man and point to the dog
- 4 Point to the man's left leg and then to the canoe
- 5 Before pointing to a duck near the bridge, show me the middle hill

(b) *Shapes*

Practice item: 'Point to the circle'. Repeat until patient understands task.

- 1 Point to the square
- 2 Point to the cone
- 3 Point to the oblong and the square
- 4 Point to the square, the cone and the semicircle
- 5 Point to the one that looks like a pyramid and the one that looks like a segment of orange

**Expression**

- (a) Show patient the river scene and say: 'Tell me as much about the picture as you can.' If the patient does not appear to understand, say: 'Name anything you can see in the picture.' Score range 0–5.

**Score**

- 0 Unable to name any objects intelligibly
  - 1 Names 1–2 objects
  - 2 Names 3–4 objects
  - 3 Names 5–7 objects
  - 4 Names 8 or 9 objects or uses phrases and sentences, but performance *not* normal (e.g. hesitations, inappropriate comments, etc.)
  - 5 Normal – uses phrases and sentences, naming 10 items
- (b) Remove picture card from view and inform patient that you are now going to attempt something a little different. Then ask him to

name as many animals as he can think of in 1 minute. If patient appears doubtful, explain that you want the names of any kind of animal, wild or domestic, and not just those which may have been seen in the picture. Commence timing as soon as patient names first animal and allow 60 seconds. Score range 0–5.

**Score**

- 0 None named
- 1 Names 1–2
- 2 Names 3–5
- 3 Names 6–9
- 4 Names 10–14
- 5 Names 15 or more

**Reading**

Check that the patient is wearing correct spectacles for reading purposes. Show patient river scene and first reading card. Ask him to read the sentence to himself, not aloud, and do whatever it instructs him to do. Proceed in the same manner with the remaining four reading cards. Score range 0–5.

Score 1 for each correct.

**Writing**

Show patient river scene and say: 'Please write as much as you can about what is happening in the picture.' If he does not appear to understand say: 'Write anything that you can see in the picture.' If dominant hand is affected ask patient to attempt with non-dominant hand. Encourage if he stops prematurely. Allow a MAXIMUM of 5 minutes. Score range 0–5.

**Score**

- 0 Able to attempt task but does not write any intelligible or appropriate words
- 1 Writes 1 or 2 appropriate words
- 2 Writes down names of 3 objects or a phrase including 2 or 3 objects
- 3 Writes down names of 4 objects (correctly spelled), or 2 or 3 phrases including names of 4 items
- 4 Uses phrases and sentences, including names of 5 items, but *not* considered 'normal' performance, e.g. sentence is not integrating people and actions
- 5 Definitely normal performance, e.g. sentence integrating people and actions

**Interpretation**

The presence of aphasia is indicated if the patient scores below the following cut-off points. (Referral to speech therapy for full assessment is suggested.)

Age	Raw Score
Up to 60	27
61+	25

## **Appendix 23: Researcher's Participant Profile**

### **Participant Profile**

Age:

Gender:

Height:

Weight:

Type of residence and adaptations:

Married / live with partner:

Family (live with or nearby):

Current / Previous Occupation:

Computer experience:

Hobbies / Interests:

Daily / Weekly activities:

### **Carer Profile**

Current / Previous Occupation:

Computer experience:

Hobbies / Interests:

Daily / Weekly activities:

## **Appendix 24: Interview 1 with Participants and Carers**

**Aim:** Gather opinion on information and extrinsic feedback being given to patients and carers, in order to facilitate home-based rehabilitation when not in face-to-face contact with the therapist.

**Objective:** To establish what forms of information and extrinsic feedback is routinely given to patients and carers, in order to facilitate home-based rehabilitation when not in face-to-face contact with the therapist.

### **Interview 1 with Participants**

- What were you given by the CST to help you get better?
  - Was it useful?
  - Did it help you?
- If you were given exercises or movements to do like arm exercises or transfers, how did you know if you were doing them right?
- How did you know if you were improving or not?
  - What makes you think this?
- Did you get help from anyone or anywhere else?
  - Did that help you?
- What did you like about what you were given?
- What did you not like about what you were given?
  - How would you change it?
  - Why did you not like it?

### **Interview 1 with Carers**

**Objective:** To establish what forms of information and extrinsic feedback is routinely given to patients and carers, in order to facilitate home-based rehabilitation when not in face-to-face contact with the therapist.

**Aim:** Gather opinion to determine what help and information is routinely given to carers/family members to assist the home exercises prescribed for the patients.

- What were you given by the CST to help you understand what exercises/activities the person you care for should do after the therapist had gone?
  - Were you able to understand and remember what the therapists wanted them to do?
  - Was it useful?
  - Did it help you?
- Did you give the person you care for any help with their exercises/activities?
  - How did you do this?
- Did you get help from anyone or anywhere else?
- How did you know if they were improving or not?
  - What makes you think this?
- What did you like about what you were given?
- What did you not like about what you were given?
- How would you change it?

## **Appendix 25: Interview 2 with Participants and Carers**

### **Interview 2 with Participants**

**Objective:** To investigate participants and carers' utilisation and behaviour following the delivery of extrinsic feedback from computer-based technology in the home.

**Aim:** Gather opinion to determine if there are preferences of different types of extrinsic feedback.

- Were you able to recognise your movement on the computer screen?
- On the computer, what helped you to know how you were doing with your exercises?
- Which exercise(s) helped you know how you were doing the most?
  - What was it about this exercise over the others?
- On the computer, what did not help you to know how you were doing with your exercises?
- Did you prefer the avatar or the graphs?
  - Why that over the other?

**Aim:** To gather opinion to determine how the extrinsic feedback from the computer is perceived by the participants.

- Do you think the computer indicated that you were getting better, staying the same or getting worse?
  - What makes you think this?

**Aim:** To gather opinion to determine if stroke survivors can utilise the feedback provided and alter their motor-patterns appropriately.

- What did you think of the replays of you doing the exercises?
- Were you able to see any differences in the way you moved compared to the avatar?
  - Did you try and change any of your movements because of what you saw on the screen?
- Would you prefer to see what you are doing whilst you are doing it or after you've completed your task?
- What did you think of the results graphs?
  - Did you know if you had improved?

**Aim:** To gather opinion to determine how participants perceive the feedback from the computer in relation to function and participation.

How do you think the feedback from the computer compares to how you are doing in your everyday activities?

## **Interview 2 with Carers:**

**Aim:** To investigate participants and carers' utilisation and behaviour following the delivery of extrinsic feedback from computer-based technology in the home.

- What did you like about the feedback from the computer?
- On the computer, what helped you to know how they were doing with their exercises?
- What did you not like about the feedback from the computer?
- On the computer, what did not help you to know how they were doing with their exercises?

•

**Aim:** Gather opinion to determine how carers' perceive the feedback from the computer in relation to function and participation.

- Do you think the computer indicated that they were getting better, staying the same or getting worse?
  - What makes you think this?

How do you think the feedback from the computer compares to how they are doing in their everyday activities?

## Appendix 26: Development of the Garments

In September 2009 three new garments were developed to eradicate these issues. As part of a Master's project, a designer conducted a series of focus groups and interviews with stroke survivors and therapists. This led to eleven alterations for the chest garment, twelve for the wrist garment and four for the upper arm garment. In addition, the final alterations were evaluated with participant four of this research (case study four).

The participant in case study four confirmed that the requirements set out had been met. In addition, it should be noted that the participant in case study three and four had minimal active movement but were still able to don and doff the garments successfully. The upper-arm garment was made with a rigid plastic casing and dense foam inner. It fastens in place with a tough, seat-belt material strap with a Velcro inner and now has an arrow to enable the user to align the sensor with elbow to ensure correct positioning (fig a). The following images show the final designs.

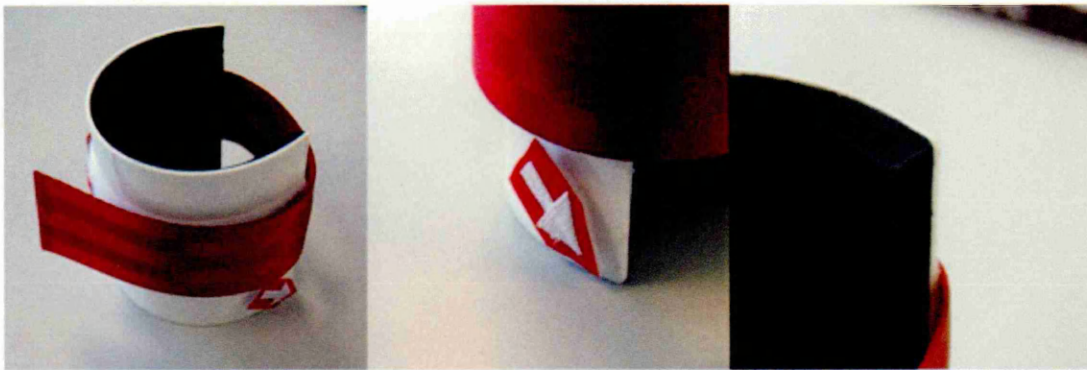


Fig a. Upper-Arm Garment

The chest garment was made with a dense foam neck and trunk strap which was colour coded to help the user orientate where their head and arms go. The garment is fastened with a seat-belt material strap and two clips to allow for opening and closing with either arm. The sensor is housed in between the clips and is not affected by differing anatomy (fig b).

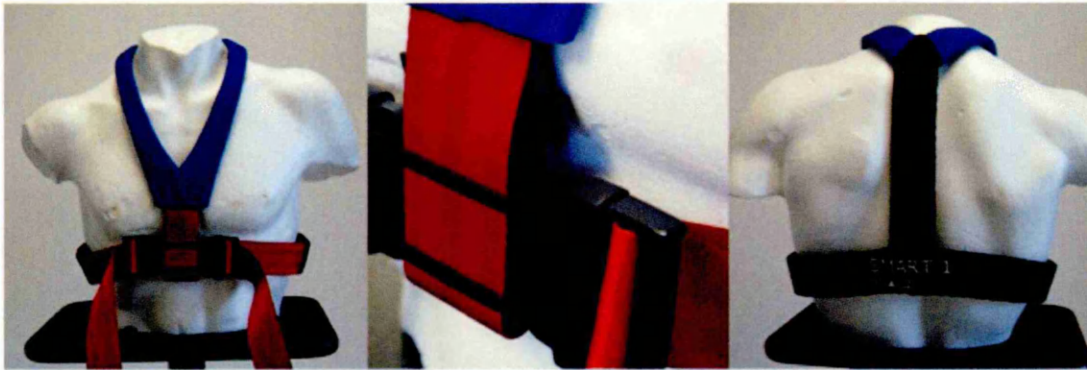


Fig b. Chest Garment

The wrist garment makes use of a rigid plastic shell to house the sensor which is held in place with ergonomically shaped dense foam and a ‘chameleon tail’ strap. The strap is designed to remain straight and then wraps around itself using material designed to tighten and grip to adjacent material (fig c). The garment also has an arrow to illustrate which way up the garment should be placed on the wrist. Importantly, the sensor does not need to be removed for charging in all of the garments. This eliminates the possibility of the participant or carer removing the sensor for charging and then replacing the sensor upside down or back to front which would significantly distort the screen images.

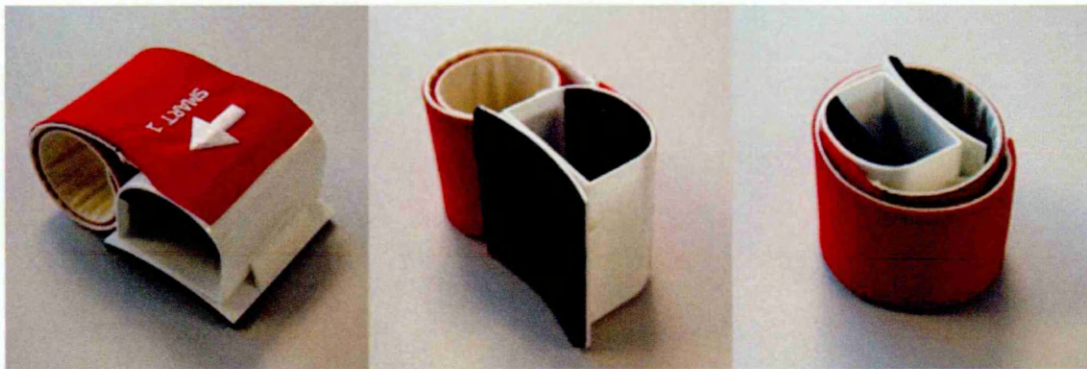


Fig c. Wrist Garment



## **Appendix 27: Risk Assessment from SMART 1**

This risk assessment was carried out by SMART 1 (copy).

### **RISK ASSESSMENT QUESTIONNAIRE<sup>8</sup>**

Please complete the following questions and submit with your protocol. If any questions are not applicable please state N/A.

**Does your proposed study involve the use of any apparatus or equipment (for example, equipment to record balance)?**

Yes.

**If yes, please describe briefly below.**

The equipment consists of a laptop computer, touch-screen, and wireless motion sensors, simple clothing to attach sensors to the body and battery charging leads.

**Are there any risks you can think of associated with the apparatus or equipment and how will you ensure safety (to the participants and to yourself)?**

There may be risks associated with tripping over the power cord for the equipment. This will be minimised by ensuring that the equipment is set up in a safe place with power cord close to the socket. Researchers will set up the equipment in the first instance and will give instructions for safe use. Sensors are battery powered and run at a low voltage so there is no risk of electric shock. Participants may forget how to use the equipment or be anxious about any malfunction. Researchers will leave comprehensive instructions for the equipment and will leave mobile telephone numbers so that they can be contacted in the event of any problem. They will make further home visits if and when contacted.

**If you are conducting face-to-face data collection, in what environment will the research take place (for example, participant's home, clinical setting)?**

In the participants' homes and at meeting rooms in the office(s) of the CSTs.

**Are there any risks you can think of associated with the research environment and how will you ensure safety (to the participants and to yourself)?**

Researchers may notice unsafe devices and fixtures in the home and where this happens they will be brought to the attention of participants. The equipment will be located in a safe and secure place and instructions given on how to use it. Where participants are brought into the university transport will be provided and researchers will meet participants in the entrance to the building and escort to the meeting room. Where researchers are visiting clients' homes researchers will give times and location of visit to support staff at the research centre to enable contact.

**Will you be interviewing participants individually?**

Yes

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<sup>8</sup> This form is used by MA/MSc students. However, it can also be used for most projects undertaken by doctoral students and staff.

**If yes, do you consider there to be any psychological consequences as a result of in-depth interviews?**

It is unlikely that there will be any psychological consequences of the interviews. The topics for discussion will focus on the use of the equipment in the home.

**What steps will you take to ensure that participants are not left feeling distressed/upset after the interview?**

The researchers are mature and experienced interviewers and will be sensitive to any distress shown by participants. They will allow sufficient time for participants to talk through any matters arising from research and if necessary will assist participants to be left in the company of family member, friend or carer.

**Can you identify any additional risks to your participants or to yourself as the researcher, not already mentioned?**

NO