Goal setting in neurorehabilitation: development of a

patient-centred tool with theoretical underpinnings.

Agata Aleksandrowicz

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Thesis declaration form

I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Signature:

Name: Agata Aleksandrowicz

Date:

Overview

This thesis focuses on goal setting in neurological rehabilitation and is presented in three parts. Part one of this volume presents a review of literature. As self-efficacy is believed to be one of the core components of self-management interventions, the review aimed to evaluate the effects of the interventions on self-efficacy in patients with acquired neurological conditions. A systematic search of four electronic databases produced 20 papers that were examined. As a result, some evidence was found in support of the effectiveness of self-management interventions on increasing self-efficacy in patients with neurological conditions. The review emphasises the need for conducting more rigorous studies in order to draw more firm conclusions on the effects of the interventions.

Part two was conducted jointly with Fouzia Siddique and it consists of an empirical paper which describes a development of a patient-centred goal setting tool with theoretical underpinnings. The design of the study followed the UK Medical Research Council framework for developing complex interventions. Perspectives of patients, carers and staff members at the inpatient neurological rehabilitation unit were explored and nine themes were identified through thematic analysis of the qualitative data. Previous reviews of literature were studied in order to identify theories relevant to goal setting. Some of the relevant theories included Social Cognitive Theory, Goal Setting Theory, Theories of Self-Regulation and Theories of Loss and Identity Reintegration. As a result, participants' perspectives, in combination with the concepts derived from the theories, informed the development of the goal setting tool.

Part three provides a critical reflection on the process of conducting this study. It discusses the process of this study from the perspective of "action research".

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Part 2: Empirical Paper

Part 1: Literature Review

Impact of self-management programmes on self-efficacy in acquired neurological disorders: a systematic review of the literature

Abstract

Aim: This review aimed to evaluate the effects of self-management interventions on self-efficacy in patients with acquired neurological conditions.

Method: Four electronic databases (MEDLINE, PsychINFO, CINAHL Plus and PubMed) were systematically searched and papers were assessed against inclusion and exclusion criteria producing 20 eligible articles.

Results: Thirteen randomised controlled trials, 2 quasi-experimental controlled design studies, 4 pre-post design studies and 1 multiple participant, two-phase single subject design study were included in the review. There was a variety of neurological diagnoses covered including Multiple Sclerosis (N=8), stroke (N=6), epilepsy (N=5) and acquired brain injury (N=1). The sample sizes varied from 10 to 216 participants. Mean age varied from 29.87 to 67.38 years. Twelve out of 20 studies found some support for the effectiveness of self-management programmes in increasing self-efficacy, although the studies were prone to biases, such as small sample sizes, lack of blinding and low power to detect effects. All but one of the studies involved some incorporation of social cognitive theory or self-efficacy enhancing strategies in their programmes.

Conclusion: The review found some evidence for the effectiveness of self-management programmes in increasing levels of self-efficacy in patients with neurological conditions. However, more rigorous studies are needed in order to draw firm conclusions regarding the effectiveness of the programmes and their application in clinical practice.

1. Introduction

The advancement in medicine over the last few decades has considerably increased life expectancy, which means that many patients now manage their long-term medical conditions at home, as opposed to staying in the hospital or other acute care services. In addition, over the years, and accelerated by the introduction of the Internet, a better educated public and the greater prominence of healthcare in the media, we have observed a paradigm shift in patient care, with a move away from a paternalistic, medical model, in which patients are passive recipients of care, to a more "informed" model, in which patients and their families take an active role in managing their health (Ahmad, Ellins, Krelle & Lawrie, 2014). This is reflected, for example, in the introduction of self-management programmes, such as an Expert Patient Programme in the UK (Department of Health, 2001).

The concept of self-management has received growing attention in the literature and clinical practice, particularly in the light of an increasing number of patients living with chronic conditions (Philips, 2012). Barlow, Wright, Sheasby, Turner and Hainsworth (2002) defined self-management as "the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and life style changes inherent in living with a chronic condition". Ahmad et al. (2014) stated that not only does self-management support provide patients with tools that help them live healthier lives, but it also reflects a change of the relationship between patients and healthcare professionals into a more collaborative one.

The lack of thorough descriptions of programme contents in many studies makes it difficult to understand the exact mechanisms of self-management programmes, which tend to consist of multiple components (Barlow et al., 2002). It is also important to distinguish between purely educational programmes from self-

management programmes, which stress the significance of active participation in managing one's own health through addressing attitudes and beliefs about behaviour change (Joice, 2012; Jones & Riazi, 2011).

Despite some limited understanding of the exact mechanisms of self-management interventions, self-efficacy is believed to be one of their core components (Lorig & Holman, 2003). According to Bandura's Social Cognitive Theory, self-efficacy is defined as beliefs about, or confidence in, one's ability to perform tasks or behaviours, as well as confidence in one's ability to cope with challenges (Ahmad et al., 2014; Bandura, 2001). The theory highlights the importance of psychological factors, such as attitudes and beliefs, as active components of behaviour change and emphasises the role of the individual in their own development (Ahmad et al., 2014; Joice, 2012). Self-efficacy beliefs can influence health outcomes by increasing motivation to pursue goals and adhere to treatment (Scobbie, Wyke & Dixon, 2009).

Lorig and Holman (2003) proposed that all self-management programmes should promote self-efficacy in managing one's condition by developing skills in problem-solving, decision making, finding and utilising resources, forming partnerships with healthcare providers, taking action and self-tailoring. However, as self-management is a new concept, it takes time for patients and healthcare professionals to shift from thinking of the therapeutic relationship as "patient and expert", to the one where patient is more empowered. This may limit the scope of some self-management programmes to enhance individuals' self-efficacy, given that healthcare professionals, on whom patients may rely on to bring about change, lead many interventions (Jones, 2006).

One of the first formal and most widely applied programmes is the Chronic Disease Self-Management Program (CDSMP) developed at Stanford Patient Education Research Center (Lorig et al., 1999), which later served as a basis for the UK's Expert Patient Programme (Department of Health, 2001). There is some evidence that self-management programmes can reduce hospitalisation and improve patient outcomes and health status in chronic disease (Lorig et al., 1999). CDSMP has been found effective in improving physical and psychological health status, quality of life, medication adherence, knowledge, self-management behaviours, cost-effectiveness and self-efficacy in patients with chronic conditions such as arthritis, diabetes and asthma (Barlow et al., 2002; Lorig, Sobel, Ritter, Laurent and Hobbs, 2001; Nolte & Osborne, 2013). This is also supported by a more recent review, which found a positive effect of self-management support on increasing self-efficacy and clinical outcomes in patients with mental health difficulties, arthritis, heart disease, lung disease, diabetes, asthma and stroke (Ahmad et al., 2014).

There is some evidence to suggest that interventions aimed at increasing self-efficacy are beneficial, as efficacy beliefs are one of the strongest predictors of action (Koban & DiIorio, 2003). The findings of a recent review of literature exploring the relationship between self-efficacy and rehabilitation outcomes in stroke found support for this argument (Jones & Riazi, 2011). Self-efficacy was found to be an important factor associated with outcomes of stroke rehabilitation, with higher self-efficacy being predictive of better outcomes (e.g. Bonetti & Johnston, 2008; Hellstrom, Lindmark, Wahlberg & Fugl-Meyer, 2003; LeBrasseur, Sayers, Oullette & Fielding, 2006). It is of note that some of the studies may not be fully representative of the wider stroke population due to small sample sizes and results may differ depending on measures of self-efficacy used.

Despite the volume of evidence from the chronic disease studies, there are fewer examples of self-management programmes for people with neurological conditions, which have been included under the umbrella term of "long term conditions" as part of one of the NHS National Service Frameworks (Department of Health, 2005). With the increasing prevalence of acquired neurological conditions such as stroke, brain injury, epilepsy and Multiple Sclerosis (MS), self-management interventions have been listed as one of the evidence-based markers of good practice in working with this patient population.

Given the complexity of the sequelae of neurological conditions, such as difficulties in cognition and communication, as well as the unpredictable nature of recovery, some authors emphasise the importance of exploring social variables such as class, gender and ethnicity as factors affecting individuals' ability to engage in self-management behaviours. Despite the growing body of evidence highlighting the role of theories of behaviour change, such as self-efficacy, in self-management, Jones, Riazi and Norris (2013) stress the importance of offering individualised, more culturally sensitive approaches to self-management in stroke, rather than focusing on isolated strategies in a "one size fits all" fashion. It is recommended that self-management for complex conditions, such as stroke, should involve more holistic, whole systems approach to ensure its effectiveness and engagement of patients (Kennedy, Rogers & Bowers, 2007).

1.1   Current reviews of literature

Current reviews of literature investigating the impact of self-management programmes for neurological disorders have primarily focused on the programmes' impact on clinical outcomes and have mainly referred to one disorder at a time.

Jones, Dean, Hush, Dear and Titov (2015) reviewed the efficacy of self-management programmes in improving physical activity of people with stroke and traumatic brain injury (TBI) in the community. Despite finding only five studies fulfilling their inclusion criteria, they found positive trends in improving physical activity through participation among patients with stroke, but not TBI. Three of the five studies were based on theories of behaviour change.

Warner, Packer, Villeneuve, Audulv and Versnel (2015) reviewed the efficacy of self-management interventions in improving functional outcomes and participation in people with stroke. In two RCTs out of the nine reviewed studies, they found significant improvements in participation/functional outcomes in favour of the intervention. They also provided a comprehensive analysis of the contents of the interventions and emphasised goal setting as an important component of the programmes with the potential of bridging the gap between acute and community settings.

Lennon, McKenna and Jones (2013) reviewed 15 studies investigating the efficacy of self-management programmes for patients with stroke living in the community. They found that six out of nine reviewed RCTs showed significant effects in improving disability, confidence in recovery, quality of life, knowledge and motor ability. Social Cognitive Theory and self-efficacy informed nine of the studies and others utilised a Health Belief Model, as well as the concept of self-efficacy. Education, goal setting and problem solving where identified as the common components of the interventions. The authors concluded that there is still limited evidence in favour of self-management programmes in improving outcomes in stroke and highlighted the importance of investigating the ingredients of change in the programmes. They also stressed the limits of our understanding of the role of

self-efficacy in self-management and the need to consider its function as an outcome and/or mediator of change.

Rae-Grant et al. (2011) reviewed 39 studies of self-management interventions in neurological conditions including MS, TBI, Parkinson's Disease, stroke, headache and migraine. Thirteen of the reviewed studies were Randomised Control Trials. The authors concluded that there is limited evidence for the effectiveness of the self-management programmes for neurological conditions, due to the high risk of bias among studies. Some of the reported results included improvements in fitness, pain, stress, functional ability and self-efficacy.

All of the review articles cited above included, within their review, a number of studies prone to bias with limited power to detect statistically significant findings. The authors highlight the importance of gathering evidence from more rigorous RCTs before the integration of the programmes into routine clinical practice.

Lastly, according to a recent review by the Health Foundation (de Silva, 2011) of over 500 self-management interventions for long term conditions "there is evidence that improved self-efficacy is correlated with improved health behaviours and clinical outcomes so it is valid to examine the impact of self-management support on self-efficacy as representative of other outcomes" (p. 3). While some authors found an increase in self-efficacy following self-management interventions (Jones, Mandy & Partridge, 2009), others described programmes aimed at increasing self-efficacy without measuring it as an outcome (Caller et al., 2015). No review to date has surveyed the impact of self-management interventions in neurological conditions on patients' self-efficacy.

2. Aim

The aim of this review was to evaluate the effects of self-management interventions on self-efficacy in patients with neurological conditions.

3. Method

The list of reviewed articles was obtained by carrying out a full text, systematic search of literature of the following databases: MEDLINE (January 1946 to January 2016), PsychINFO (January 1806 to January 2016), CINAHL Plus (Cumulative Index to Nursing & Allied Health Literature; January 1991 to January 2016) and PubMed (January 1800 to January 2016). All searches included a combination of Subject Headings (marked by "/" and free-text/keyword search strategy, with the exception of CINAHL and PubMed databases which used Boolean/Phrase search only. The searches were limited to the English language.

The search terms differed somewhat depending on the database, due to differences in Subject Heading searches. All searches included "self-management" AND "self-efficacy" AND "neurological disorder" OR "neurological condition" OR "brain injury" OR "head injury" OR "epilepsy" OR "Multiple Sclerosis" OR "Stroke". The exact search terms for each database are provided in Appendix A.

3.1 Inclusion criteria

The studies were included in the review if they fulfilled the following criteria:

- Participants: adults with neurological conditions such as: stroke, acquired brain injury, Multiple Sclerosis and epilepsy

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- Intervention: Self-Management programme aimed at increasing self-management behaviours and taking more active part in managing one's condition

- Outcome: Included at least one measure of self-efficacy as outcome

- Study Design: randomised control trial (RCT) and pilot RCTs, quasi experimental design (e.g. non-randomised controlled study), pre-post longitudinal studies, single-case series

- Access: Full text accessible via University College London Library listings

3.2 Exclusion criteria

The studies were not included in the review if they fulfilled the following criteria:

- Described interventions for children or families/carers only

- Did not include a measure of self-efficacy as outcome

- Described an educational programme without the self-management aims or components

- Included patients with dementing neurological conditions (e.g. dementia, Parkinson's Disease) or a combination of neurological and other chronic conditions

- Used a qualitative or cross-sectional design

- Were review articles

- Only presented theoretical models without any empirical data

3.3   Selection process

The electronic search produced a total of 288 articles across the four databases. One article was identified through previous pilot searches and did not appear through the electronic search (Feicke, Spörhase, Köhler, Busch & Wirtz, 2014). Following the removal of duplicates, 148 titles and abstracts were screened. At this stage, 88 articles were removed due to not meeting inclusion criteria outlined above. Sixty articles were examined for a full text screening. At this stage, the main reasons for not including the studies were lack of a measure of self-efficacy as outcome and reporting a health education, rather than a self-management, programme. The final set of articles included for the review included 20 papers. Figure 1 presents a flowchart of the process of the article selection.

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┌─────────────────────────────────────┐   ┌─────────────────────────┐
│ Number of articles from original    │   │ Number of articles      │
│ search: 288                         │   │ identified through      │
│ Medline: 79                         │   │ other sources:          │
│ PsychINFO: 73                       │   │ 1                       │
│ CINAHL: 55                          │   │                         │
│ PubMed: 81                          │   │                         │
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                ▼                                       ▼
┌─────────────────────────────────────────────────────────────────┐
│ Number of articles after duplicates removed: 148                 │
└─────────────────────────────────────────────────────────────────┘
                │
                ▼
┌──────────────────────────────┐        ┌──────────────────────────────┐
│ Articles screened for titles │        │ Articles excluded: 88        │
│ and abstracts: 148           │        │  • Review articles           │
└──────────────────────────────┘        │  • Theoretical articles      │
                │                        │  • Studies describing concept│
                │──────────────────────▶ │    of self-management rather │
                │                        │    than intervention         │
                │                        │  • Cross sectional studies   │
                │                        │  • Study protocols           │
                │                        │  • Studies not describing    │
                │                        │    patients with neurological│
                │                        │    conditions                │
                │                        │  • No full text available    │
                ▼                        └──────────────────────────────┘
┌──────────────────────────────┐
│ Full text articles examined: │
│ 60                           │        ┌──────────────────────────────┐
└──────────────────────────────┘        │ Articles excluded: 40        │
                │                        │  • Studies not involving a   │
                │                        │    measure of self-efficacy  │
                │                        │  • Studies describing        │
                │                        │    development rather than   │
                │──────────────────────▶ │    effectiveness of an       │
                │                        │    intervention              │
                │                        │  • Qualitative studies       │
                │                        │    describing experience of  │
                │                        │    an intervention           │
                │                        │  • Studies involving education│
                │                        │    rather than self-management│
                │                        │    programmes                │
                │                        │  • Studies including mixed   │
                │                        │    population                │
                ▼                        └──────────────────────────────┘
┌──────────────────────────────┐
│ Studies included for a full  │
│ review: 20                   │
└──────────────────────────────┘
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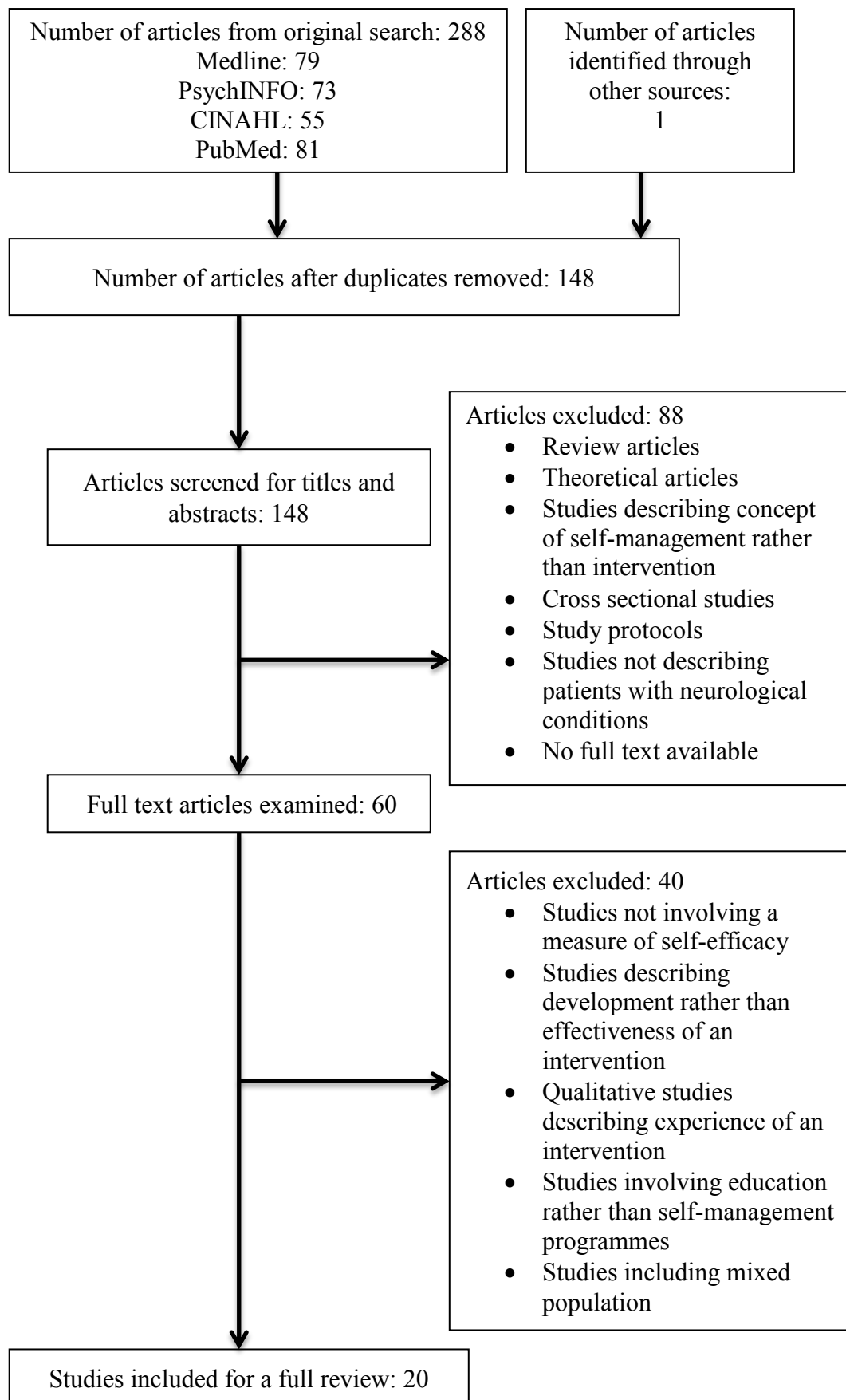
Figure 1. The flowchart of the selection process of the published papers.

4. Results

Table 1 presents the summary of study designs, sample characteristics and types of interventions.

4.1   Sample characteristics

There was a variety of neurological diagnoses covered in the reviewed papers. All studies involved clinical populations: Multiple Sclerosis (N=8), stroke (N=6), epilepsy (N=5) and acquired brain injury (N=1).

The sample sizes varied from 10 to 216 participants and six of the studies involved over 100 participants. Mean age varied from 29.87 to 67.38 years.

Twelve out of 20 studies comprised a sample of over 50% females and eight of over 50% males.

Thirteen studies provided information about ethnic background of their participants. On average, 77% of the participants in eleven studies were White and one study described their sample as consisting of 99% Dutch population without further details on ethnicity (Tielemans et al., 2015). Eight studies reported that, on average, their sample consisted of 19% Black participants. Anderson, Godwin, Petersen, Willson and Kent (2013) reported using a sample consisting of 92% non-Hispanic Latino participants and 8% Hispanic-Latino participants. Four other studies had on average 3.5% Hispanic participants and one study (Fraser et al., 2015) reported a sample consisting of 11% Latino participants. Three studies reported on average 3.5% Asian sample and five studies reported 3.5% of their sample to belong to "other" category. Finally, Plow, Bethoux, Kimloan and Marcus (2014) reported 33.5% of their sample to belong to "racial minority".

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Table 1.

Summary of the sample characteristics and types of interventions.

Study (year, country, design)	Sample characteristics	Intervention	Length, way of delivery, setting, facilitator	Theoretical basis
1. Anderson et al. (2013) Pre-post, pilot USA	Stroke Phase 1: N=13; mean age: 60 (SD: 9.0); gender: 100% male Phase 2: N= 24; mean age: 62 (SD: 7.0); gender: 96% male	The Veteran's Self-Management Guide to Stroke Prevention: V-Stop Two phases: pilot (phase 1) and revised programme (phase 2). Phase 1: 2 videoconferencing clinics (30-60 minutes with a nurse practitioner), 2 videoconferencing group classes and 2 telephone counselling sessions (20-30 minutes). Phase 2: 3 group classes and 1 telephone session. Group focused on education on the risks of stroke and self-management for chronic conditions. Individual counselling focused on reinforcing/modifying individual action plans.	6 weeks Group/Individual Outpatient/ Community Nurses	Not stated

2.	Barlow et al. (2009) 2-group RCT UK	Multiple Sclerosis N=216 IG=78; mean age: 48.2 (SD: 10.1); Gender: 73% female CG=64; Mean age: 50.7 (SD: 11.7); Gender: 69% female Non-attending comparison group: CPG=74; Mean age: 54.6 (SD: 10.8); Gender: 76% female	Stanford University Chronic Disease Self-Management Course (CDSMC) Standard format for people suffering from a range of chronic conditions such as arthritis, diabetes and asthma. Delivered over six weekly, 2-hour sessions according to "Leader's manual". Focused on enhancing self-efficacy and covered topics on self-management, relaxation, depression, fatigue, communication and goal setting.	6 weeks Group Community Trained lay tutors	Social Cognitive Theory, Self-efficacy
3.	Damush et al. (2011) Pilot RCT USA	Stroke N= 63 CG=30; mean age: 67.3 (SD: 12.4); gender: 100% male CG=33; mean age: 64 (SD: 8.4); gender: 97% male	Stroke self-management programme (SSMP) Stroke specific programme based on principles of CDSMC delivered over six biweekly session via telephone (3 sessions) and in-person (3 sessions) each lasting on average 20 minutes, following standardised manual. Focused on enhancing stroke self-efficacy and self-management behaviours. Incorporated stroke specific components, such as: stroke education, managing stroke risk and adapting to new role following stroke.	12 weeks Individual Outpatient Nurse, physician assistant, master's level social scientist.	Social Cognitive Theory Self-efficacy

#	Study	Condition / Sample	Intervention	Duration / Mode	Theory
4.	DiIorio et al. (2009a) Pre-post feasibility USA	Epilepsy N=35 Mean age: 37.5 (SD: 12.6) Gender: 60% female	WebEase (Epilepsy Awareness Support and Education) Internet based self-management system. Three modules focusing on medication adherence, stress reduction and sleep. Provides a log of self-management practices allowing for planning and maintaining behavioural change. Specific components are based on individual's needs and current status.	6 weeks Individual + discussion board with other users Internet Not facilitated	Transtheoretical Model of Behavioral Change Social Cognitive Theory Motivational Interviewing
5.	DiIorio et al. (2009b) Pilot RCT USA	Epilepsy N=22 Mean age: 43 (SD: 13.51) Gender: 68.2% male IG=11 CG=11	Project EASE (Epilepsy, Awareness, Support, and Education) Telephone based epilepsy self-management programme (4 sessions) with 1 face-to-face session. Focused on facilitating social support, enhancing self-efficacy and goal setting; aimed at behaviour change. Self-management tasks included: medication, information, seizure, safety, and lifestyle management.	12 weeks (5 sessions) Individual Community Nurses	Social Cognitive Theory Self-efficacy Motivational Interviewing
6.	DiIorio et al. (2011) RCT USA	Epilepsy N=148 IG=70; mean age: 41.8 (SD: 12.9); gender: 68.6% female CG=78; mean age: 40 (SD: 13.6); gender: 78.2% female	WebEase (Epilepsy Awareness Support and Education) Internet based self-management programme. Three modules focusing on medication adherence, stress reduction and sleep. Provided a log of self-management practices allowing for planning and maintaining behavioural change. Specific components were based on individual's needs and current status.	6 weeks Individual + discussion board with other users Internet Not facilitated	Transtheoretical Model of Behavioural Change Social Cognitive Theory Motivational Interviewing

7.	Ehde et al. (2015) RCT USA	Multiple Sclerosis N=163 IG=75; mean age: 51 (SD: 10.1) ; gender: 89.3% female CG=88; mean age: 53.2 (SD: 10.0); gender: 85.2% female	Telephone-Delivered Self-Management Intervention Manualised intervention including a participant workbook utilising cognitive-behavioural and positive psychology strategies aimed at self-management of pain, depression, and fatigue. Included weekly telephone sessions (45-60 mins) and follow-up calls (15 mins) at 4 and 8 weeks post-treatment.	8 weeks Individual Community Masters-level social workers and doctoral-level psychologists	Cognitive-Behavioural strategies Positive Psychology
8.	Feicke et al. (2014) Quasi-Experimental Controlled Trial Germany	Multiple Sclerosis N=64 IG=31; mean age: 41.94 (SD: 11.71); gender: 87.1% female CG=33; mean age: 37.12 (SD: 7.83); gender: 69.7% female	S.MS training program (*Schulungsprogramm Multiple Sklerose)* Programme providing information about MS and its management and treatment and facilitating sharing of experiences and expression of feelings. Consisted of seven modules conducted either as part of a one-day seminar or divided to 90-minute sessions.	7 weeks Group Community Psychologists, neurologist or MS nurse	Self-management Self-efficacy
9.	Fraser et al. (2015) RCT USA	Epilepsy N=83 IG=41; mean age: 44.9 (SD: 12.5); gender: 56% female CG=42; mean age: 45.4 (SD: 12.6); gender: 55% female	PACES epilepsy self- management programme Psychoeducational intervention conducted over eight weekly 75-minute sessions. Included didactic presentations, sharing experiences and applying information by developing coping strategies and goal setting. Participants were provided with PACES workbooks.	8 weeks Group Community Rehabilitation psychologist and a peer with epilepsy	Not stated

10.	Hemmati Maslakpak and Raiesi (2014) Quasi-experimental Controlled Design Iran	Multiple Sclerosis N=80 IG=40; mean age: 29.87 (SD: 8.07); gender: 67.5% female CG=40; mean age: 30.25 (SD: 7.25); gender: 75% female	Self-Management Programme Group programme covering psychoeducation and health and emotional management of MS including role-play. Conducted over four, 2-hour sessions. Participants were provided with a self-management booklet with the contents of sessions.	4 weeks + weekly telephone over 2 months post intervention Group Community Nurses (authors)	Not stated
11.	Jones et al. (2009) Pre-post, Single Subject Design UK	Stoke N=10 Mean age: 61.5 Gender: 70% female	Interactive stroke self-management workbook Workbook created with the help of stroke survivors. Consisted of four sections aimed at addressing self-efficacy. Presented different stories of stroke survivors and allowed space to record answers and personal targets.	4 weeks Individual Community Stroke professionals	Social Cognitive Theory Self-efficacy
12.	Kendall et al. (2007) RCT Australia	Stroke N=100 IG=58; mean age: 66.38 (SD: 10.90); gender: 70.8% male CG=42; mean age: 66.36 (SD: 10.40); gender: 62% male	Chronic Disease Self-Management course with a stroke-specific session Stroke self-management programme, based on standard CDSM (described above) with an additional, stroke-specific session. Conducted over 7 weeks, each session lasting 2 hours.	7 weeks Group Inpatient Two trained health professionals	Self-efficacy

13.	McKenna et al. (2013) Feasibility RCT UK	Stroke N=24 IG=11; mean age: 62.18 (SD: 13.57); gender: 63.6% male CG=13; mean age: 67.38 (SD: 10.60); gender: 53.8% female	Bridges Stroke Self-Management Programme (Bridges SSMP) Structured, individualised programme delivered by a health professional. Involved goal-setting, recording progress, activity planning and problem-solving. Content was patient, rather than professional-driven. Participants were provided with a workbook. Each participant received one weekly session of one hour over the period of 6 weeks.	6 weeks Individual Community Health professional	Self-efficacy
14.	Miller et al. (2011) RCT USA	Multiple Sclerosis N=206 IG=102; mean age: 48.1 (SD: 9.1); gender: 72% male CG=104; mean age: 48.1 (SD: 9.7); gender: 85% female	Mellen Center Care Online-Enhanced Patient Self-Management Groups Web-based self-management programme facilitating communication between clinicians and patients. Included self-monitoring and self-management of symptoms that could be reviewed quarterly. Patients received graphical feedback of their progress.	12 months Individual Community Clinicians	Not stated
15.	Muenchberger et al. (2011) Pre-post Australia	Acquired Brain Injury N=52 Mean age: 47.29 (SD: 15.31) Gender: 62% male	Community-based self-management support (CB-SMS) - The STEPS programme ('Skills to Enable People with brain injury and their communitieS') Group programme delivered in community over six weekly sessions. One of the main components was to develop a group goal. Other components included psychoeducation, managing stress, relationships, etc. Participants were provided with a workbook supporting the programme.	6 weeks Group Community Trained local peer leader or health professional	Not stated

16.	Plow et al. (2014) Pilot RCT USA	Multiple Sclerosis N=30 IG=14; mean age: 47 (SD: 9.0); gender: 100% female CG=16; mean age: 48 (SD: 10.0); gender: 100% female	Pamphlet based self-management intervention Home-based intervention aimed at increasing physical activity in women with MS. Participants were provided with pamphlets including psychoeducational material based on participant's stages of change and barriers to engaging in physical activity to support their home exercise programme.	12 weeks Individual Community Professional	Stages of Change (Transtheoretical Model) Social Cognitive Theory
17.	Pramuka et al. (2007) Pilot RCT USA	Epilepsy N=55 Gender: 69% male IG=31; mean age: 48.89 (SD: 14.3) CG=24; mean age: 48.1 (SD: 14.3)	A psychosocial self-management program for epilepsy 6-week group programme of 2-hour weekly sessions. Topics included goal-setting, stress management, self-monitoring, relationships, rewards. The theme of self-efficacy and self-management was built into all sessions. Participants were provided with written materials.	6 weeks Group Community Two psychologists and a research associate	Self-efficacy
18.	Shevil and Finlayson (2010) Pre-post USA	Multiple Sclerosis N=35 Mean age: 52.4 (SD: 10.3) Gender: 74.3% female	Mind over Matter: Learning to Manage Cognitive Symptoms in MS Weekly 2-hour sessions over 5 weeks aimed at increasing knowledge of MS, self-efficacy in managing symptoms and confidence using cognitive management strategies. Involved homework and facilitator follow-up between sessions.	5 weeks Group Community Occupational Therapist	Not stated

#	Study	Population/Sample	Intervention	Details	Theory
19.	Suh et al. (2015) Pilot RCT USA	Multiple Sclerosis N=68 IG=34 Mean age: 50.1 (SD: 8.1) Gender: 88.2% female CG=34 Mean age: 48 (SD: 9.4) Gender: 76.5% female	Social Cognitive Theory-Based Physical Activity Intervention Behavioral intervention delivered by newsletters and phone calls aimed at increasing physical activity in persons with MS who were physically inactive and had middle levels of self-efficacy, as determined in previous study. Included self-monitoring and goal setting.	6 weeks Individual Community Researcher	Social Cognitive Theory
20.	Tielemans et al. (2015) RCT Netherlands	Stroke N=113 IG=58; mean age: 55.2 (SD: 8.9); gender: 55.2% female CG=55; mean age: 58.8 (SD: 8.7); gender: 60% male	Restore4stroke Self-Management Intervention "Plan Ahead!" Intervention for stroke survivors and their carers, comprising seven 2-hour sessions over a period of 10 weeks. Aimed at teaching proactive action planning, emotion management, social relationships, and participation in society. Participants were provided with a workbook.	10 weeks Group Outpatient Psychologist or occupational therapist	Not stated

Note: IG- Intervention Group; CG- control group, CPG-Comparison group

4.2   Design

Across the 20 studies, 13 were randomised controlled trials, six of which were described as pilot/feasibility trials, two studies used a quasi-experimental controlled design, four studies used a longitudinal, pre-post design and one study described a multiple participant, two-phase single subject design. The majority of studies (N=12) were conducted in the United States, three in the UK, two in Australia, one in Germany, one in Netherlands and one in Iran.

4.2.1   Power calculation

Only five out of 13 RCTs (Ehde et al., 2015; Miller et al., 2011; Pramuka, Hendrickson, Zinski & Van Cott, 2007; Suh, Motl, Olsen & Joshi, 2015; Tielemans et al., 2015) and one quasi-experimental study (Hemmati Maslakpak & Raiesi, 2014) described power calculations. This questions the extent to which scientific conclusions can be drawn from the studies regarding the generalisability of the findings and the strength of the effects. Two other authors (Jones et al., 2009; McKenna, Jones, Glenfield & Lennon, 2013) provided explanations as to why power calculations were not conducted, i.e. due to a single-case design and a feasibility study. These studies are prone to multiple biases.

4.2.2   Randomisation

All but two RCTs (DiIorio, Reisinger, Yeager & McCarty, 2009b; Plow et al., 2014) clearly described their randomisation procedures. The most common randomisation method involved the use of random number generator or table, two studies used opaque sealed envelopes and one used two-dice roll.

4.2.3 Inclusion/exclusion criteria

Nineteen studies had explicitly stated inclusion/exclusion criteria. Eleven studies included severe cognitive and/or language difficulties in their exclusion criteria. Patients with severe cognitive difficulties were excluded on the basis of the score of Mini Mental State Examination (in Anderson et al., 2013 and in McKenna et al., 2013), Cognitive Screener (in Ehde et al., 2015), IQ score or Montreal Cognitive Assessment (MoCA; in Hemmati Maslakpak & Raiesi, 2014), Multiple Sclerosis Neuropsychological Screening Battery for Multiple Sclerosis (in Shevil and Finlayson, 2010) and clinical judgment (in Jones et al., 2009; Tielemans et al., 2015). Two studies (Damush et al., 2011; Shevil and Finlayson, 2010) included patients with mild-moderate cognitive difficulties in their studies.

Patients with severe speech/communication difficulties were excluded on the basis of National Institutes of Health Stroke Scale (NIHSS; in Anderson et al., 2013), shortened version of the Aphasia Scale of the Dutch Aphasia Foundation (in Tielemans et al., 2015) and speech and language clinician's assessment (in Kendall et al., 2007 and in Jones et al., 2009). Damush et al. (2011) also used the NIHSS to screen language ability and included patients with moderate language difficulties in their study. Patients with significant language deficits were excluded.

Four studies excluded patients with severe depressive symptoms/ psychiatric illness on the basis of the diagnosis of depression or emotionalism (in Jones et al., 2009), Patient Health Questionnaire-9 score of over 15 (PHQ-9; in Ehde et al., 2015), Chicago Multiscale Depression Inventory score (in Shevil and Finlayson, 2010) and clinical judgment (in Tielemans et al., 2015). Ehde et al. (2015) included patients with moderate depressive symptoms as indicated by the PHQ-9 score between 10-14.

4.3   Characteristics of the programmes

4.3.1   Programme components

Nineteen different programmes were delivered in the 20 reviewed studies. Most articles described novel self-management interventions, one study described a previously established Chronic Disease Self-Management Course (CDSMC; Lorig et al., 1999) and two studies described a version of CDSMC adapted for stroke. Common components of the programmes included psychoeducation, stress management, facilitation of relationships and social support, and enhancement of self-efficacy via goal setting, problem solving and action planning. Most studies provided detailed information about the contents of the interventions, including examples of module titles or discussed topics. Tielemans et al. (2015) did not provide a detailed description of their intervention, but the details can be found in their previous paper which they referenced (Tielemans et al., 2015). Two other studies (Barlow et al., 2009; Kendall et al., 2007) also did not provide details of their interventions; however, as they used standardised CDSMC, the details can be found elsewhere.

4.3.2   Duration

Most programmes were delivered over 4-8 weeks (N=15). Four studies described 10-12-week-long interventions and one study described an intervention that took place over a course of 12 months.

4.3.3   Mode of delivery

Fifteen studies described programmes that were delivered face-to-face, two of which also included an additional telephone contact. Three studies described

programmes that were purely web-based and two studies used telephone only or telephone and videoconference-based intervention.

There was a balance of group and individual programmes. Nine studies described programmes that were delivered as part of a group programme, eight studies described programmes that were provided to participants on an individual basis and three studies described a combination of individual and group approaches.

4.3.4 Place of delivery

Seventeen programmes were delivered in the community or with outpatients, one was delivered in an inpatient setting and two programmes were delivered via the Internet.

4.3.5 Programme facilitation

Healthcare professionals, including nurses, psychologists, occupational therapists, social worker, physician's assistant and neurologist, facilitated the majority of programmes. A researcher or a scientist facilitated three programmes, a professional and a peer leader facilitated two programmes and a trained lay tutor facilitated one programme. One of the web-based programmes (WebEase) was not facilitated at all.

4.3.6 Theoretical underpinnings

Eleven programmes involved explicit reference to Social Cognitive Theory and/or self-efficacy (Bandura, 2001) as a theoretical basis of the intervention. Two programmes utilised Transtheoretical Model of Behaviour Change (Prochaska & DiClemente, 1982) and two programmes used Motivational Interviewing (Miller & Rollnick, 2002). Finally, one of the programmes was based on cognitive-behavioural and positive psychology strategies. However, more detailed consideration of the

theoretical basis of these approaches was not described. Seven studies showed no consideration of a theoretical basis of the administered interventions.

Damush et al. (2011) provided an example of the theoretical basis of their intervention on four components of self-efficacy: mastery experiences, vicarious experiences, verbal persuasion and physiological feedback (Bandura, 1982). For example, learning from other stroke patients was associated with the concept of social modelling/vicarious experiences and discussing and diminishing symptoms linked to the reinterpretation of physiological feedback.

4.3.7   Comparison groups

The most common comparison condition was providing patients with education materials or educational intervention without the self-management component that controlled for other effects, such as therapist's attention (N=5) and providing standard rehabilitation offered through health system (N=4). Other authors used a waitlist control (N=2) and treatment-as-usual with a delayed treatment option or provision of intervention materials after the completion of the study (N=3).

4.4   Outcome measures used

Fourteen different measures of self-efficacy were administered across 20 studies. The measures and outcomes of the interventions are described in Table 2.

4.4.1   Chronic Disease Self-Efficacy Scales

Six studies used a form of the Self-efficacy for Managing Chronic Disease measure (SMCD; Lorig et al., 1996), which measures one's confidence in managing chronic disease across different dimensions, such as obtaining help and information, communicating with physicians, managing disease in general, managing symptoms, and managing depression. Kendall et al. (2007) reported using the 29 items of the

Table 2.

Descriptions of outcome measures, assessment time points and the results of the interventions.

Study (year, country, design)	Self-efficacy measure used	Assessment time points	Results
Anderson et al. (2013)	The Self-efficacy for Managing Chronic Disease (Lorig et al., 1996) 6-Item Scale measuring participants' self-efficacy across several domains common in chronic diseases, such as controlling symptoms of pain and fatigue, emotional distress and visiting doctors. Rated on a 1-10 scale.	Baseline, 12 weeks, 18 weeks	Phase 1: Significant increase (p<0.01) in participants' self-efficacy from baseline to 12 weeks, not sustained at 18 weeks. Phase 2: High self-efficacy scores at baseline with no significant change over time.
Barlow et al. (2009)	1) "Self-management self-efficacy scale" (Lorig et al., 1996) A combination of Lorig's self-efficacy scales.10-item scale measuring self-efficacy for managing disease (5 items) and symptoms (5 items) rated on a scale 1-7. 2) Liverpool Self-Efficacy Scale (Airlie, Baker, Smith &Young,2001) 11-item, MS-specific self-efficacy scale rated on a scale 1-4.	Baseline, 4 months, 12 months	Significant increase in Self-management self-efficacy (effect size 0.30, p = 0.009, for the IG) at 4 months. Improvements maintained, but no further significant change at 12-month follow-up. Non-responders found to have had significantly lower self-management self-efficacy at 12-month baseline.
Damush et al. (2011)	Self-efficacy Scales (Lorig et al., 1996) Scales measuring patient's confidence to manage stroke symptoms (Cronbach alpha coefficient=0.82) and communicate with physician (Cronbach alpha coefficient =0.93) rated on a 1-10 scale.	Baseline, 3 months, 6 months	Significant increase in communicating with the physician scale scores at the second follow-up: IG increased in confidence and CG decreased (p<0.04, effect size=-0.59)

DiIorio et al. (2009a)	Epilepsy Self-Efficacy Scale (ESES; DiIorio & Yeager, 2003) 33-item scale measuring confidence in ability to manage epilepsy, rated on 0-10 scale.	Pre and post intervention.	Significant improvement in self-efficacy scores (p<0.001) between pre and post test scores.
DiIorio et al. (2009b)	Epilepsy Self-Efficacy Scale (ESES; DiIorio & Yeager, 2003) Reported internal consistency reliability coefficients ranging from 0.89 to 0.94.	Baseline, 3 months.	Participants in IG showed higher levels of self-efficacy at follow-up, that did not reach significance (p=0.097).
DiIorio et al. (2011)	Epilepsy Self-Efficacy Scale (ESES; DiIorio & Yeager, 2003) 24 items of the original 33-item measure were used to focus on measurement of medication, stress, and sleep issues. The reliability of responses in this sample was α= 0.92.	Baseline, 6 weeks, 12 weeks.	Self-efficacy scores of the non-completers of the course decreased over time, whereas the scores of those who completed the intervention increased (p=0.013). No significant changes in self-efficacy between IG and CG groups over time.
Ehde et al. (2015)	University of Washington Self-Efficacy Scale (Amtmann et al., 2012) Assesses one's confidence in the ability to manage MS and keep it from interfering with important activities. Originally developed to be used with patients with MS and spinal cord injury.	Baseline, post-treatment (9-11 weeks post randomisation), 6 months, 12 months	Significant increase over all time points in both IG and CG, with higher scores at 12 months in IG. No significant differences between IG and CG. Effect size post treatment was -.41, at 6 months -.27 and at 12 months -.42

Feicke et al. (2014)	FERUS (Jack, 2007) Questionnaire for measuring resources and self- management ability, comprises seven scales including a self-efficacy scale.	Baseline, post intervention, 6 months	Significant effect of group on all scales of FERUS questionnaire including self-efficacy in favour of IG (p= 0.014, effect size 0.102). Self-efficacy slightly increased in IG over time and decreased in CG.
Fraser et al. (2015)	Epilepsy Self-Efficacy Scale (ESES; DiIorio, Faherty, Manteuffel, 1992) Measures epilepsy management efficacy, Cronbach's alpha has been reported at .90.	Baseline, 8 weeks, 6 months	Significant improvement in self-efficacy in favour of the IG at treatment completion (p<0.001, effect size 0.59). No further increase for IG at 6 months, but increase in self-efficacy for CG with no significant differences between the groups at 6-month follow-up.
Hemmati Maslakpak and Raiesi (2014)	Multiple Sclerosis Self-Efficacy Scale (MSSE; no reference) Described as a14-item scale measuring four dimensions of independence, control of worry and anxiety, personal control, and social self-esteem. Rated on a six-point Likert scale. Reliability of the scale established at 0.74.	Pre and post intervention.	Significant changes between IG and CG after the intervention (p<0.001). Self-efficacy increased in the IG and decreased in CG. Significant differences between IG and CG post treatment for independence, anxiety and worry and personal control dimensions (P<0.001).

Jones et al. (2009)	1) General Self Efficacy Scale (GSES; Schwarzer and Jerusalem, 1995) 10-item scale of high internal consistency (between 0.75 and 0.91; Scholz, Benicio Gutiérrez, Shonali & Schwarzer, 2002). 2) Stroke Self-Efficacy Questionnaire (SSEQ; Jones Reid & Partidge, 2008) 13-item measure of confidence in the ability to perform functional tasks such as walking, getting comfortable in bed, as well as some self-management tasks.	Weekly for 14 weeks	Significant increase in stroke self-efficacy for all participants across three data points. No significant changes in general measure of self-efficacy.
Kendall et al. (2007)	The Self-efficacy Scale (Lorig et al., 1996) 29 items of the original 33-item scale were used, assessing help and information, communication with physicians, managing symptoms and managing disease in general. Reported internal consistency ranging from .77 to .92 and test-retest coefficients ranging from.72 to .89.	3, 6, 9, 12 months post stroke	Significant differences in self-efficacy levels across all times between IG and CG (p=0.003), including pre-intervention, where CG showed lower levels of self-efficacy. No overall significant change in self-efficacy for either group over time. Significant positive main effect of self-efficacy on stroke specific quality of life (as a covariate).
McKenna et al. (2013)	1) Self-efficacy Scale (SES; Lorig et al., 1996) 2) Stroke Self Efficacy Questionnaire (SSEQ; Jones et al., 2008)	Baseline, 6 weeks, 3 months	IG showed higher, significant increase in self-efficacy scores at 6 weeks than CG. Both IG and CG showed decline in scores on SSEQ at 3 months and CG showed improvement on SES, that did not reach significant levels.

Miller et al. (2011)	MS Self-Efficacy Scale (MSSE; Schwartz, Coulthard-Morris , Zeng, Retzlaff, 1996) Control subscale used. Measures confidence in the ability to manage e symptoms, reactions to disease-related symptoms impact of the disease on life activities.	Baseline, 12 months.	No significant improvements in self-efficacy over time or between groups. CG showed no change in mean self-efficacy, whereas IG showed some increase between baseline and end-point.
Muenchberger et al. (2011)	Self-Efficacy Scale (Lorig, Chastain , Ung, Shoor & Holman, 1989) 5-item scale with reported sound psychometric properties measuring confidence in managing one's condition. Originally developed for patients with arthritis.	Baseline, 3 months post completion, 6 months post completion.	No significant changes in self-efficacy over time.
Plow et al. (2014)	1) Self-efficacy scale (Marcus, Rakowski & Rossi, 1992; Marcus, Selby, Niaura & Rossi, 1992) 5-item scale measuring confidence in exercising despite barriers, such as bad weatherReported internal consistency of 0.84. 2) The Self-Efficacy for Managing Chronic Disease (Lorig et al., 1996) Measures confidence in self- managing symptoms and emotions to engage in activities as desired. Reported internal consistency of 0.87.	Baseline, 12 weeks, 24 weeks.	No significant changes in self-efficacy. Mean self-efficacy decreased in both groups over time.

	Measure	Time points	Results
Pramuka et al. (2007)	Epilepsy self-efficacy scale (ESES; DiIorio & Yeager, 2003) 33-item scale measuring confidence in managing epilepsy, focuses on awareness an planning regarding self-management techniques. Reported internal consistency between 0.89 and 0.94. The measure was chosen to match the dimensions of self-efficacy covered by the intervention.	Baseline, 1 month.	No significant improvements in self-efficacy; trends in improved direction. Significant positive correlations with self-efficacy and locus of control, overall psychological functioning and overall quality of life.
Shevil and Finlayson (2010)	Cognitive Management Self-Efficacy Questionnaire (CMSEQ) Non-standardised measure specifically developed for the purposes of this study. 13-item scale measuring confidence that reflected management strategies of the programme. Reported internal consistency of 0.95	Baseline, post intervention, 6 weeks after intervention.	Significant changes in self-efficacy over time (p<0.0001). Improvement maintained at 6-week follow-up. Effect size 1.08.
Suh et al. (2015)	The Exercise Self-efficacy Scale (EXSE; McAuley, 1993) 6-item scale measuring one's belief in their ability to engage in moderate physical activity 3 times per week for 20 minutes or more.	Pre and post intervention.	No significant improvement in self-efficacy in either group.
Tielemans et al. (2015)	General Self-Efficacy scale (GSES; Schwarzer & Jerusalem, 1995) Dutch version of the 10-item scale.	Baseline, post intervention, 3 months follow-up, 9 months follow-up.	No significant changes on self-efficacy in either group.

original 33-item scale in their study with stroke patients. McKenna et al. (2013) and Plow et al. (2014) did not specify whether they used a full 33-item scale, the subscales of it, or a short 6-item scale and Anderson et al. (2013) used a 6-item form. Barlow et al. (2009) and Damush et al. (2011) used a combination of two subscales of SMCD in their study with patients with Multiple Sclerosis and stroke patients respectively.

Muenchberger, Kendall, Kennedy and Charker (2011) used a scale of self-efficacy (Lorig, Chastain, Ung, Shoor & Holman, 1989), which was originally developed for patients with arthritis, in their study with patients with acquired brain injury. The authors did not clarify whether they adapted the scale for patients with brain injury.

4.4.2   General Self-Efficacy Scales

Jones et al. (2009) used the General Self-Efficacy Scale (GSES; Schwarzer & Jerusalem, 1995) in their study with stroke patients. The scale measures one's confidence in coping with difficult tasks and stressful life events and has been translated to 33 languages. Tielemans et al. (2014) used a Dutch version GSES in their study with stroke patients.

Feicke et al. (2014) used the FERUS Questionnaire (Jack, 2007) in their study with patients with Multiple Sclerosis. FERUS has been developed in Germany and is a questionnaire for measuring resources and self-management. It assesses different domains of self-management abilities and includes a self-efficacy scale.

4.4.3   Disease-specific measures.

Ten studies used disease-specific measures of self-efficacy.

4.4.3.1 Epilepsy-specific measures. All of the studies that investigated patients with epilepsy (N=5) used the Epilepsy Self-Efficacy Scale (ESES; DiIorio & Yeager, 2003), with one study (Fraser et al., 2015) using a previous version of it (DiIorio, Faherty, Manteuffel, 1992). ESES measures one's confidence in their ability to manage epilepsy across various dimensions such as medication, sleep or mood.

4.4.3.2 Multiple Sclerosis-specific measures. Four out of eight studies investigating patients with Multiple Sclerosis used measures of self-efficacy specific to this condition. In addition to a chronic disease self-efficacy measure, Barlow et al. (2009) also administered the Liverpool Self-Efficacy Scale (Airlie, Baker, Smith & Young, 2001), which is a measure designed specifically for people with MS consisting of subscales relating to 'personal agency' and 'control'.

Ehde et al. (2015) used a MS-specific self-efficacy measure (University of Washington Self-Efficacy Scale; Amtmann et al., 2012). The measure comes in a short (6-item) and a long (17-item) form, although the author did not specify which form they used. It assesses one's confidence in the ability to manage MS and keep it from interfering with important activities. It is highly correlated with the Chronic Disease Self-Efficacy Scale.

Miller et al. (2011) used the control subscale of the MS Self-Efficacy Scale (MSSE; Schwartz, Coulthard-Morris , Zeng, Retzlaff, 1996). MSSE is an 18-item measure of confidence in the ability to perform behaviours related to functional independence and psychological management of MS. It includes three subscales related to function, symptoms and control.

Lastly, Hemmati Maskakpak and Raiesi (2014) described using the "Multiple Sclerosis Self-Efficacy Scale (MSSE)". The authors did not provide any reference to the scale and described it as a 14-item measure assessing different domains of self-efficacy in MS related to independence, mood, personal control and social self-esteem. It is impossible to definitively conclude which measure the authors used, but this description closely corresponds to the 14-item MSSE by Rigby, Domenech, Thornton, Tedman and Young (2003).

4.4.3.2 Stroke-specific measures. Two studies (Jones et al., 2009, McKenna et al., 2013) used The Stroke Self-Efficacy Questionnaire (SSEQ; Jones, Reid & Partidge, 2008). This is a measure assessing one's confidence in their ability to perform functional tasks, such as walking, positioning self in bed, dressing and coping with frustration.

4.4.4. Task-specific measures.

Three studies with patients with Multiple Sclerosis used measures specific to tasks and interventions. Two studies measured exercise self-efficacy and one measured cognitive management self-efficacy.

Plow et al. (2014) used an additional measure of self-efficacy (Marcus, Selby, Niaura & Rossi, 1992; Marcus, Rakowski & Rossi, 1992) assessing one's confidence in the ability to perform exercise in face of barriers, such as bad weather. This measure was chosen specifically to target components covered by the intervention, which aimed to increase physical activity in women with MS.

Similarly, Suh et al. (2015) specifically matched The Exercise Self-efficacy Scale (EXSE; McAuley, 1993) to their intervention, which was aimed at increasing patients' physical activity.

Lastly, Shevil and Finlayson (2010) used the Cognitive Management Self-Efficacy Questionnaire (CMSEQ) to measure self-efficacy related to their intervention, which focused on management of cognitive symptoms of MS. CMSEQ is the only non-standardised measure reviewed, which was specifically developed for the purposes of their study.

4.5   The effects of the interventions on self-efficacy

Twelve studies reported significant improvements in self-efficacy as a result of the intervention. Six of the studies were RCTs, two studies used a quasi-experimental controlled design, three studies used pre-post designs and one study used a pre-post, single subject design case series. Eight other studies showed no significant changes in self-efficacy.

4.5.1   RCTs

Barlow et al.'s (2009) adapted Chronic Disease Self-Management Course for Multiple Sclerosis resulted in increased self-management self-efficacy in the intervention group. There were no statistically significant differences between the groups at baseline and the scores of the control group decreased over time, as opposed to the scores of the intervention group, which were significantly higher at 4-month follow-up (effect size 0.30, p = 0.009). This effect was maintained at 12-month follow-up and there were no further changes in self-management self-efficacy for either group at this time point. The intervention also showed trends in the increased direction for MS self-efficacy in the intervention group at 4 months (effect size 0.16, p=0.049). The study had a relatively high dropout rate at 12-month follow-up with 45% of participants dropping out from the intervention group and 35% of the control group. The authors compared people who stayed, to the people

who left the intervention, and found no differences between them at 4 months. However, non-respondents showed significantly lower self-efficacy at 12 months (means 46.8 and 40.8 respectively, $p = 0.003$). This may suggest that the participants who engaged in the full duration of the study were more motivated and able to make more use of the intervention, resulting in higher increase in self-efficacy.

Damush et al. (2011) found a significant increase in the scores on the self-efficacy measure of communicating with the physician following self-management programme based on CDSMC for veteran stroke survivors. There were significant differences in self-efficacy at baseline with the intervention group showing lower self-efficacy. In addition, the intervention group had slightly higher baseline levels of depression ($p<0.06$), which has previously been found to be related to lower self-efficacy levels (Robinson-Smith & Rizzi, 2003). Despite that, the intervention group showed an increase in self-efficacy scores across at all time points and there were significant differences between groups at 6-month follow-up, but not at 3 months. Conversely, the control group showed a decrease in self-efficacy from baseline at both measurement points.

Fraser et al. (2015) found positive effect of the PACES self-management programme on epilepsy self-efficacy scores at treatment completion in favour of the intervention group ($p<0.001$). This effect was maintained at 6-month follow-up. The control group did not show an increase in self-efficacy immediately following the intervention. However, at 6 months, the control group showed an increase in their self-efficacy scores resulting in no significant differences between the groups at this time point. The limitations of this study included lack of blinding of the researchers during outcome measurement and when conducting baseline assessments following randomisation. Although the intervention appeared to be effective at increasing self-

efficacy immediately following its completion, the groups were equivalent in their ratings at follow-up. This indicates that other factors unrelated to the intervention may have been responsible for the increase in self-efficacy.

McKenna et al. (2013) recruited 25 participants with stroke in their pilot study comparing the effects of the Bridges stroke self-management programme (SSMP) to outcomes in a control group. They measured self-efficacy using general and stroke-specific measures. There were no statistically significant differences between groups at baseline for either measure. Both Bridges SSMP and control participants showed significant increase in their stroke specific self-efficacy scores at 6 weeks, with Bridges SSMP demonstrating higher increases, CI (0.5, 1.69) than the control group, CI (0.8, 0.99). There were no significant changes in general self-efficacy for either group at this stage, but both showed some increase in scores. At 3-month follow-up, there were no statistically significant changes, but both groups showed a slight decline in stroke specific self-efficacy scores and the control group showed some improvement in general self-efficacy scores. The authors highlighted that caution needs to be exercised when interpreting the results due to the small sample size limiting the power to compare the groups and difficulty ensuring that they were balanced in their characteristics. One of the possible explanations to the mixed findings could be that the control group comprised higher functioning individuals at a later recovery stage, which may have been related to the further increase in general self-efficacy scores at 3 months.

Ehde et al. (2015) randomised 163 people with MS to either individual telephone based self-management intervention or individual telephone-based education intervention. There were no baseline differences in self-efficacy between the groups. Both control and intervention groups showed a significant increase in

self-efficacy over time. The intervention group showed on average an increase of 6.6 points between baseline and 12-month follow-up and the control group showed an increase of 4.7 points. There were no significant differences between the groups at any time point, although there were trends towards significant differences in self-efficacy between the groups at the 12-month follow-up, in favour of the intervention group. Since both groups improved, it is difficult to ascertain whether specific self-management procedures or variables common across the groups, such as therapeutic relationship, accounted for the increase in self-efficacy. In addition, the intervention did not include any explicit strategies aimed at enhancing self-efficacy but rather utilised cognitive-behavioural and positive psychology strategies. The study exhibited little risk of bias due to blind randomisation and allocation to treatment of both participants and facilitators. The authors also described thorough fidelity control with over 98% adherence of the therapists to the protocol. However, as the study was targeted at individuals with moderate depressive symptoms, the findings may not be generalisable to a wider MS population. The power of the study was potentially limited due to the large number of outcome measures collected.

DiIorio, Bamps, Walker and Escoffery (2011) compared an online self-management intervention (WebEase) based on Social Cognitive Theory and a Transtheoretical Model of Behavioural Change for people with epilepsy to a waitlist control. Given that around 25% of the intervention group and 40% of control group dropped out of the study by the 12-week follow-up, the authors compared the data from participants who completed at least one module of the intervention ("completers" group) to participants who did not complete any modules ("non-completers" group). They found that "completers" showed an increase in self-efficacy, whereas "non-completers), showed a decrease in self-efficacy over time,

with significantly lower scores post-intervention (p=0.013). There were no significant differences in self-efficacy between the two groups at baseline. One of the drawbacks of the study was participant self-selection, potentially limiting the sample to more motivated individuals, as well as the sample being limited to those who have access to and can use the Internet.

4.5.2 Quasi-experimental designs

Hemmati Maslakpak and Raiesi (2014) used a quasi-experimental controlled design and found a positive effect of self-management intervention on the self-efficacy of patients with relapsing remitting MS. There were no differences in self-efficacy scores at baseline and the study resulted in a significant difference between control and intervention groups following the intervention (p<0.001). The intervention group showed an increase in self-efficacy scores over time, whereas the participants in the control group showed a decrease in their scores, despite the fact that the intervention did not explicitly focus on self-efficacy enhancing strategies or theories of behaviour change. Due to the design of the study, it remains possible that the two groups differed in key characteristics, thus limiting the power of the study to draw definitive conclusions regarding the effectiveness of the intervention.

Feicke and colleagues (2014) used a non-randomised, quasi-experimental design to compare the effects of a self-management intervention based on principles of Chronic Disease Self-Management Course and self-efficacy in MS to the control group. They found no baseline differences in self-efficacy between the intervention and control groups. However, the control group was on average significantly younger at the time of diagnosis and suffered from more severe symptoms. The scores of the intervention group slightly decreased post-intervention and the scores of the control group increased, resulting in significant differences between the

groups at this time point, in favour of the control group. However, this outcome was reversed at 6 months of follow-up, with scores in the intervention group being significantly higher than in the control group. Self-efficacy was measured using a subscale of a larger measure of self-management. The total score of the overall self-management ability increased over time in the intervention group and decreased in the control group (p<0.001; effect size 0.19). It is possible that other factors, such as age and unpredictable course of illness, affected the ratings of self-efficacy, suggesting that the mechanism of change of self-efficacy as a result of the intervention might have been more complex. Lack of randomisation was the main limitation of this study.

4.5.3   Pre-post design

Anderson et al. (2013) implemented a videoconferencing self-management intervention for veterans with stroke. The intervention was initially piloted in a first phase of the study, revised, and then implemented in the second phase. The authors found positive effects of the intervention in phase one with significant increases in self-efficacy between baseline and 12 weeks (p=0.004). This effect was not maintained at the 18-week follow-up. There were no significant changes in the second phase of the study and self-efficacy remained stable over the course of the intervention.

A feasibility study conducted prior to the WebEase intervention mentioned in section 4.5.1, also found a significant increase in self-efficacy scores (p<0.001; DiIorio et al., 2009a) among individuals with epilepsy. This effect was present even though over a half of the sample did not complete all three modules of the intervention. Similarly, Shevil and Finlayson (2010) found a significant increase in

self-efficacy (p<0.001) immediately following the intervention for self-management of cognitive symptoms in MS. The result was maintained at the 6-week follow-up.

All pre-post studies are subject to bias due to a lack of control and a lack of possibility to ascertain whether any increase in self-efficacy was an effect of the interventions or whether it occurred as a result of other factors.

4.5.4   Single Subject Design

Jones et al. (2009) administered a self-management workbook to ten patients with stroke and visually inspected the data for the effects of the intervention on various outcomes. They found that majority of participants showed increased self-efficacy over the 14-week study period, measured by Stroke Self-Efficacy Questionnaire. However, the authors noted that some participants showed a steady increase in self-efficacy before the introduction of the intervention, which suggests that these participants may have shown the increase in self-efficacy regardless of the intervention. The week-by-week measurement adopted in the study allowed for recording of changes in scores over time and showed that some participants experienced a decrease in scores at some weeks of the intervention, reflecting a degree of instability of self-efficacy across the measurement points. The authors also noted interesting findings with regards to the relationship between self-efficacy beliefs and outcome, showing that one participant demonstrated at the same time the greatest change in self-efficacy score but also one of the lowest functional outcome scores.

4.6   Lack of significant effects on self-efficacy

4.6.1   RCTs

DiIorio et al. (2009b) found trends in the positive direction, with the treatment group reporting higher self-efficacy scores than the control group following a telephone-based pilot self-management program for people with epilepsy (p=0.097). There were no differences between the groups at baseline (although the authors did not report the exact baseline self-efficacy figures) and the programme showed good acceptance by the participants with 95% completion rate of the planned motivational interviewing sessions and courtesy calls. Although the intervention was based on the principles of self-efficacy, the small sample size of 22 may have limited the power of the study to detect the effects of the intervention. One of the strengths of the study was the quality control of the provided intervention.

Pramuka et al. (2007) found no significant differences between the treatment and control groups in terms of self-efficacy following the psychosocial intervention, which aimed to increase self-efficacy in people with epilepsy. The authors concluded that they found trends in the positive direction. There were no significant differences in self-efficacy at baseline and the treatment group showed on average 9.5-point higher scores in epilepsy self-efficacy than the control group at the follow-up. This was a somewhat surprising finding given that the intervention involved explicit self-efficacy enhancing strategies. The small sample size may have limited the power of the study to detect change. The authors also found a significant, positive correlation between self-efficacy and the locus of control, overall psychosocial functioning and overall quality of life, and a significant, negative correlation between self-efficacy and measures of depression.

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Kendall et al. (2007) failed to find support for their hypothesis that a Chronic Disease Self-Management Course would positively impact on self-efficacy among stroke patients. Participants in the control group showed consistently significantly lower levels of self-efficacy across all time-points, including at baseline. The authors also ran a covariate analysis and found a significant positive main effect of self-efficacy on stroke-specific quality of life, but not on other outcomes. The study questions the centrality of self-efficacy as a determinant of self-management related behaviour change.

Suh et al. (2015) conducted a pilot study of a newsletter and phone-based intervention aimed at increasing physical activity in physically inactive people with MS exhibiting medium levels of self-efficacy. The authors found no significant increase in self-efficacy as a result of the intervention. Self-efficacy in the control group slightly decreased over time and did not change in the treatment group, suggesting it was maintained throughout the course of treatment. The authors noted that this may have been a result of the realistic ratings of efficacy in people with medium levels of self-efficacy. On the other hand, the lack of significant findings may have also been caused by the fact that the study was not sufficiently powered to detect changes in self-efficacy levels.

Plow and colleagues (2014) found no significant changes in self-management self-efficacy and physical activity self-efficacy following their pamphlet-based intervention aimed at increasing physical activity in people with MS. In fact, both groups reported slightly lower levels of self-efficacy following the intervention, although these findings did not reach the level of significance. The authors concluded that one possible explanation for this was that inactive people with MS may initially overestimate their self-efficacy beliefs, which may result in the lack of

improvement or decrease in self-efficacy levels once they test their ability to engage in physical exercise in practice. These findings were consistent with the Transtheoretical Model of Stages of Change, on which the intervention was partially based.

Tielemans et al. (2015) compared self-management intervention aimed at increasing proactive coping strategies for patients with stroke, to an education intervention, in order to control for other non-specific factors such as group dynamics. They found no significant changes in self-efficacy as a result of the intervention and found that patients who were lost to follow-up had significantly lower levels of self-efficacy (p<0.001).

Miller et al. (2011) found no significant changes in self-efficacy following online self-management intervention for people with relapsing-remitting MS. A particular highlight of the study was its high power, estimated at between 0.85 to 0.93, with a sample size of 224. The intervention was not based on theories of behaviour change and included a variety of self-management strategies without explicit self-efficacy enhancing ones, which may have accounted for the lack of increase in self-efficacy as a result of the intervention. The study compared two similar interventions (original and enhanced version), and this may have diminished the possibility of detecting subtle differences in self-efficacy.

4.6.2   Pre-post design

Muenchberger et al. (2011) found no effect of the community-based self-management intervention on the self-efficacy of people with acquired brain injury. The study was prone to a high dropout rate of around 50%. In addition, it did not

include any explicit individualised self-efficacy enhancing strategies and was not based on a specific theoretical framework.

5. Discussion

The construct of self-efficacy beliefs is a core component of many self-management interventions (Lorig and Holman, 2003) and some researchers believe that self-efficacy is one of the strongest predictors of behavioural change (Koban and DiIorio, 2003). This review focused on examining the effects of self-management programmes on self-efficacy of people with acquired neurological conditions. Due to the heterogeneity of outcome measures and interventions used across the studies, it was not possible to conduct a meta-analysis of the effects.

5.1   The effect of self-management interventions on self-efficacy

Overall, the review appears to partially support the effectiveness of self-management programmes in increasing levels of self-efficacy in patients with neurological conditions. Twelve out of 20 reviewed studies found some support in the effectiveness of self-management programmes in increasing self-efficacy. The successful studies utilised a range of patient populations including people with MS (N=5), stroke (N=4) and epilepsy (N=3). Six studies were RCTs, three of which involved samples of over 100 participants and two studies were feasibility/pilot RCTs. Two quasi-experimental studies, three pre-post and one pre-post single-subject design also found favourable effects of the intervention on self-efficacy levels. All but one of these studies (Ehde et al., 2015) involved some incorporation of social cognitive theory or self-efficacy enhancing strategies in their programmes.

Eight studies found no significant effects of interventions on the levels of self-efficacy. There was a range of patient populations among these studies including

MS (N=3), stroke (N=2), epilepsy (N=2) and TBI (N=1). Seven of these studies were RCTs, three of which had a sample of over 100 participants and four were pilot studies. One pre-post study did not find any significant change in self-efficacy over time.

One difficulty in comparing the effects of the studies was the heterogeneity of the outcome measures utilised among the studies. There were 14 different measures of self-efficacy administered across the 20 reviewed studies. One strength of the reviewed studies is that the majority used, individually or in combination, measures of chronic disease self-efficacy, disease-specific measures or task-specific measures. This is particularly important, given that self-efficacy may often be domain-specific (Marks, Allegrante and Corig, 2005). On the other hand, Feicke et al. (2014) used a subscale of a broader self-management questionnaire and Shevil and Finlayson (2010) used a non-standardised measure of cognitive management self-efficacy specifically developed for the purposes of their study. Given the relative lack of standardised measures in these studies, it is difficult to draw firm conclusions about the construct validity of these measures and thus, the meaning of the results. In addition, the study by McKenna et al. (2013) highlighted differences in the measurement of self-efficacy depending on the measure used. Their control group showed a decline in scores on stroke specific self-efficacy questionnaire at the same time as showing improvement on the general self-efficacy scale. Although their trends did not reach statistical significance, it indicates possible differences in the measurement of the same construct by different instruments.

Another factor that limits comparisons between the studies was the variety of self-management interventions employed across the reviewed studies. There were 19 different programmes implemented across 20 studies. They varied in terms of their

duration (most were delivered over 4-8 weeks), means of delivery, how they were facilitated and theoretical underpinnings. Eleven programmes explicitly cited Social Cognitive Theory and/or self-efficacy (Bandura, 2001) as a theoretical basis of the intervention. Other theories included the Transtheoretical Model of Behaviour Change (Prochaska & DiClemente, 1982), Motivational Interviewing (Miller & Rollnick, 2002) and cognitive-behavioural and positive psychology strategies. Interestingly, all of the studies that found increase in self-efficacy following the intervention either based their interventions on theories of behaviour change or utilised cognitive-behavioural or self-efficacy enhancing strategies. However, six out of eight studies that found no effects on self-efficacy, also described explicit theoretical basis in self-efficacy. Two remaining studies did not base their interventions on theories and did not make explicit reference to self-efficacy enhancing strategies. These findings are therefore only partially in support of the claim that self-management interventions should have a theoretical basis or focus on self-efficacy enhancing strategies (Marks, Allegrante & Corig, 2005).

5.2   Other factors affecting self-efficacy following interventions

Some self-management interventions failed to increase participants' self-efficacy, although this was not always associated with poorer outcome (Plow et al., 2014; Suh et al., 2015). Some of the reasons considered by these authors include the duration of the intervention, follow-up measurement time points, and individual differences in self-efficacy and patient readiness for change.

For instance, a relatively short duration of most self-management programmes may not allow opportunities for observing changes in self-efficacy, which may require more time, particularly for patients who are not ready to change their behaviours (Pramuka et al., 2007). According to Social Cognitive Theory, self-

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efficacy is influenced by the repetition and rehearsal of strategies, and some interventions may not allow enough time to affect individuals' beliefs. On the other hand, Jones et al. (2009) demonstrated fluidity of self-efficacy ratings and how they could markedly change from one week to another.

Some authors found that factors such as gender could be related to different levels of self-efficacy. For example, Fraser and Polito (2007) reported that women with Multiple Sclerosis exhibited higher average ratings of self-efficacy than men. Moreover, women with relapsing-remitting MS tend to demonstrate higher confidence in managing their disease than women with progressive types of MS. This suggests that self-efficacy may be subject to individual differences and studies focusing on self-efficacy enhancing interventions should further investigate how they could be adapted for individual needs.

Finally, it appears that self-efficacy ratings may be affected by individuals' stage of readiness for change (Prochaska & DiClemente, 1982), such that some self-management interventions may be less efficacious for people who are in the "pre-contemplation" stage (Pramuka et al., 2007). Baseline levels of self-efficacy may indicate how much scope there is for improvement. For instance, individuals with high baseline self-efficacy may overestimate their abilities resulting in a decrease in scores over time and individuals with medium levels of efficacy may make more realistic predictions of their ability, therefore showing stable levels of self-efficacy over time (Suh et al., 2015).

5.3   Limitations of this review

The review was limited to articles published in English language only. As some of the studies were conducted outside of English-speaking countries, it may

suggest that the use of self-management programmes is increasing elsewhere in Europe and other parts of the world. Reviewing literature in other languages would provide useful insights into similarities and differences in the effects of self-management programmes conducted in different countries and languages.

In addition, although this review aimed to include a broad sample of various neurological conditions it may have failed to detect differences between the effects of the interventions on self-efficacy depending on the disorder. For instance, patients with stroke may experience a different development of the condition than patients with MS, who suffered from it over the years, or from patients with epilepsy, who experiences it from childhood or adolescence. The review did not discriminate between these disease-specific differences.

5.4   Clinical implications and future recommendations

There is growing evidence supporting the inclusion of self-efficacy enhancing strategies in the contents of rehabilitation interventions. However, given the multidimensionality of the construct, it is important that interventions are adapted to individual needs and incorporate factors such as gender, stage of readiness for change, cultural background and cognitive and language ability. Some authors believe that there is a danger in providing interventions that instruct people what to do without taking these factors into account (Jones et al., 2013) and the beliefs and values of the wider organisational and professional context should be included into the development of future interventions (Kennedy et al., 2007).

Importantly, the majority of the studies in this review excluded patients with moderate to severe cognitive and communication problems, as well as psychological difficulties, which are highly common in this patient population (Jones et al., 2013).

This excludes a large number of patients with neurological disorders and questions the clinical applicability of the interventions to this complex population.

The concept of self-efficacy and its role in self-management programmes remains to be satisfactorily delineated. Future studies should focus on exploring the role of the construct both as the outcome and as the mediator of change. This will allow for a better understanding of the mechanisms underlying any improvement and also assist in the development of appropriate strategies to ensure the effectiveness of the programmes, with the aim of helping people manage their own neurological conditions.

References

Ahmad, N., Ellins, J., Krelle, H., & Lawrie, M. (2014). *Person-centred care: from ideas to action. The Health Foundation*.

Airlie, J., Baker, G., Smith, J., Young, C. (2001). Measuring the impact of Multiple Sclerosis on psychosocial functioning: the development of a new self-efficacy scale. *Clinical Rehabilitation, 15,* 259–65.

Amtmann, D., Bamer, A. M., Cook, K. F., Askew, R. L., Noonan, V. K. & Brockway, J. A. (2012). University of Washington Self-Efficacy Scale: a new self-efficacy scale for people with disabilities. *Archives of Physical Medicine and Rehabilitation, 93*, 1757-65

Anderson, J., Godwin, K. M., Petersen, N. J., Willson, P., & Kent, T. A. (2013). A pilot test of videoconferencing to improve access to a stroke risk-reduction programme for Veterans. *Journal of Tele, 19*, 153–159.

Bandura, A. (2001). Social cognitive theory: An agentic perspective. *Annual Review of Psychology, 52, 1–26.*

Barlow, J., Wright, C., Sheasby, J., Turner, A., & Hainsworth, J. (2002). Self-management approaches for people with chronic conditions: A review. *Patient Education and Counseling*, *48*(2), 177–187.

Barlow, J., Turner, A., Edwards, R., & Gilchrist, M. (2009). A randomised controlled trial of lay-led self-management for people with Multiple Sclerosis. *Patient Education and Counseling*, *77*(1), 81–89.

Bonetti, D. & Johnston, M. (2008). Perceived control predicting the recovery of individual-specific walking behaviours following stroke: Testing psychological models and constructs. *British Journal of Health Psychology, 13,* 463-478.

Caller, T. A, Secore, K. L., Ferguson, R. J., Roth, R. M., Alexandre, F. P., Henegan, P. L., Harrington, J. J., Jobst, B. C. (2015). Design and feasibility of a memory intervention with focus on self-management for cognitive impairment in epilepsy. *Epilepsy & Behavior*, *44*, 192–194.

Damush, T. M., Ofner, S., Yu, Z., Plue, L., Nicholas, G., & Williams, L. S. (2011). Implementation of a stroke self-management program. *Translational Behavioral Medicine*, *1*(4), 561–572.

Department of Health (2001). *The expert patient: a new approach to chronic disease management for the 21st century*. UK: London.

Department of Health (March, 2010). *The National Service Framework for Long-term Conditions*. England. Retrieved from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/198114/National_Service_Framework_for_Long_Term_Conditions.pdf

de Silva, D. (2011). *Evidence: Helping people help themselves*. *Health Foundation*. UK: London.

DiIorio, C., Faherty, B. & Manteuffel, B. (1992). The development and testing of an
instrument to measure self-efficacy in persons with epilepsy. *Journal of
Neuroscience Nursing, 24,* 9–13.

DiIorio, C. & Yeager, K. (2003). The Epilepsy Self-Efficacy Scale. In: Strickland,
O. L., DiIorio, C. (eds). *Measurement of Nursing Outcomes: Self Care and
Coping, 2nd edn*. New York: Springer Publishing Company.

DiIorio, C., Escoffery, C., McCarty, F., Yeager, K. A., Henry, T. R., Koganti, A.,
Reisinger, E. L. & Wexler, B. (2009a). Evaluation of WebEase: an epilepsy
self-management Web site. *Health Education Research*, *24*(2), 185–197.

DiIorio, C., Reisinger, E. L., Yeager, K. A., & McCarty, F. (2009b). A telephone-
based self-management program for people with epilepsy. *Epilepsy & Behavior*,
14(1), 232–236.

DiIorio, C., Bamps, Y., Walker, E. R., & Escoffery, C. (2011). Results of a research
study evaluating WebEase, an online epilepsy self-management program.
Epilepsy & Behavior, *22*, 469–474.

Ehde, D. M., Elzea, J. L., Verrall, A. M., Gibbons, L. E., Smith, A. E., & Amtmann,
D. (2015). Efficacy of a Telephone-Delivered Self-Management Intervention
for Persons With Multiple Sclerosis: A Randomized Controlled Trial With a
One-Year Follow-Up. *Archives of Physical Medicine and Rehabilitation*,
96(11), 1945–1958.

Feicke, J., Spörhase, U., Köhler, J., Busch, C., & Wirtz, M. (2014). A multicenter,
prospective, quasi-experimental evaluation study of a patient education program
to foster Multiple Sclerosis self-management competencies. *Patient Education
and Counseling*, *97*(3), 361–369.

Fraser, C., & Polito, S. (2007). A comparative study of self-efficacy in men and

women with Multiple Sclerosis. *The Journal of Neuroscience Nursing :*

Journal of the American Association of Neuroscience Nurses, *39*(2), 102–106.

Fraser, R. T., Johnson, E. K., Lashley, S., Barber, J., Chaytor, N., Miller, J. W.,

Ciechanowski, P., Temkin, N. & Caylor, L. (2015). PACES in epilepsy: Results

of a self-management randomized controlled trial. *Epilepsia*, *56*(8), 1264–1274.

Hellstrom, K., Lindmark, B., Wahlberg, B. & Fugl-Meyer A. (2003) Self- efficacy in

relation to impairments and activities of daily living in elderly patients with

stroke: A prospective investigation. *Journal of Rehabilitation Medicine, 35*, 202

– 207.

Hemmati Maslakpak, M., & Raiesi, Z. (2014). Effect of a self-management and

follow-up program on self-efficacy in patients with Multiple Sclerosis: a

randomized clinical trial. *Nurs Midwifery Stud*, *3*(4), e25661.

Jack, M. (2007). FERUS Fragebogen zur Erfassung von Ressourcen und

Selbstmanagementfahigkeiten. FERUS—Questionnaire for measuring resources

and self- management ability Manual. Gottingen u.a: Hogrefe. (cited in Feicke

et al., 2014).

Joice, S. (2012). Self-management following stroke. *Nursing Standard (Royal*

College of Nursing (Great Britain) : 1987), *26*(22), 39–46.

Jones, F. (2006). Strategies to enhance chronic disease self-management: how can

we apply this to stroke? *Disability and Rehabilitation*, *28*(13-14), 841–7.

Jones, F., Reid, F. & Partridge, C. (2008). The Stroke Self-Efficacy Questionnaire

(SSEQ): measuring individual confidence in functional performance after

stroke. *Journal of Nursing and Healthcare of Chronic Illness, 17,* 244–52.

Jones, F., Mandy, A., & Partridge, C. (2009). Changing self-efficacy in individuals following a first time stroke: preliminary study of a novel self-management intervention. *Clinical Rehabilitation*, *23*(6), 522–33.

Jones, F., & Riazi, A. (2011). Self-efficacy and self-management after stroke: a systematic review. *Disability and Rehabilitation*, *33*(10), 797–810.

Jones, F., Riazi, A., & Norris, M. (2013). Self-management after stroke: Time for some more questions? *Perspectives in Rehabilitation*, *35*(3), 257–264.

Jones, T. M., Dean, C. M., Hush, J. M., Dear, B. F., & Titov, N. (2015). A systematic review of the efficacy of self-management programs for increasing physical activity in community-dwelling adults with acquired brain injury (ABI). *Systematic Reviews*, *4*(1), 51.

Kendall, E., Catalano, T., Kuipers, P., Posner, N., Buys, N., & Charker, J. (2007). Recovery following stroke: the role of self-management education. *Social Science & Medicine (1982)*, *64*(3), 735–46.

Kennedy A, Rogers A, Bower P. (2007). Support for self care for patients with chronic disease. *British Medical Journal, 335*, 968–970.

Kobau, R., & DiIorio, C. (2003). Epilepsy self-management: a comparison of self-efficacy and outcome expectancy for medication adherence and lifestyle behaviors among people with epilepsy. *Epilepsy & Behavior*, *4*(3), 217–225.

LeBrasseur, N., Sayers, S., Oullette, M. & Fielding R. (2006). Muscle impairments and behavioural factors mediate functional limitations and disability following stroke. *Physical Therapy, 86,* 1342–50.

Lennon, S., McKenna, S., & Jones, F. (2013). Self-management programmes for

    people post stroke: A systematic review. *Clinical Rehabilitation*, *27(10)*, 867 –

    878.

Lorig, K., Chastain, R. L., Ung, E., Shoor, S. & Holman, H.R. (1989). Development

    and evaluation of a scale to measure perceived self-efficacy in people with

    arthritis. *Arthritis & Rheumatism, 32,* 37–45.

Lorig, K., Stewart, A., Ritter, P., Gonzalez, V., Laurent, D., Lynch, J. (1996)

    Outcome Measures for Health Education and Other Health Care Interventions.

    Thousand Oaks, CA: Sage Publications.

Lorig, K. R., Sobel, D. S., Stewart, A. L., Brown, B. W., Bandura, A., Ritter, P.,

    Gonzalez, V. M., Laurent, D. & Holman, H. R. (1999). Evidence suggesting

    that a chronic disease self-management program can improve health status

    while reducing hospitalization: a randomized trial. *Medical Care*, *37*(1), 5–14.

Lorig, K. R., Sobel, D. S., Ritter, P. L., Laurent, D., & Hobbs, M. (2001). Effect of a

    self-management program on patients with chronic disease. *Effective Clinical*

    Practice : ECP, *4*(6), 256–262.

Lorig, K. R., & Holman, H. (2003). Self-management education: history, definition,

    outcomes, and mechanisms. *Annals of Behavioral Medicine : A Publication of*

    the Society of Behavioral Medicine, *26*(1), 1–7.

Marcus, B. H., Rakowski, W. & Rossi, J. S. (1992). Assessing motivational

    readiness and decision making for exercise. *Health Psychology, 11,* 257–61.

Marcus, B. H., Selby, V. C., Niaura, R. S. & Rossi, J. S. (1992). Self-efficacy and

    the stages of exercise behavior change. *Research Quarterly for Exercise and*

    Sport, 63, 60–6.

Marks, R., Allegrante, J. P., & Lorig, K. (2005). A Review and Synthesis of

    Research Evidence for Self-Efficacy-Enhancing Interventions for Reducing

    Chronic Disability: Implications for Health Education Practice (Part II). *Health*

    Promotion Practice, *6*(2), 148–156.

McAuley, E. (1993). Self-efficacy and the maintenance of exercise participation in

    older adults. *Journal of Behavioral Medicine*, *16*(1), 103–113.

McKenna, S., Jones, F., Glenfield, P., & Lennon, S. (2013). Bridges self-

    management program for people with stroke in the community: A feasibility

    randomized controlled trial. *International Journal of Stroke : Official Journal of*

    the International Stroke Society, (10), 1–8.

Miller L. & Rollnick S. (2002). *Motivational interviewing*. New York: Guilford

    Press.

Miller, D. M., Moore, S. M., Fox, R. J., Atreja, A., Fu, A. Z., Lee, J.-C., Saupe, W.,

    Stadtler, M., Chakraborty, S., Harris, C. M. & Rudick, R. A. (2011). Web-

    Based Self-Management for Patients with Multiple Sclerosis: A Practical,

    Randomized Trial. *Telemedicine and E-Health*, *17*(1), 5–13.

Muenchberger, H., Kendall, E., Kennedy, A., & Charker, J. (2011). Living with

    brain injury in the community: Outcomes from a community-based self-

    management support (CB-SMS) programme in Australia. *Brain Injury*, *25* (1),

    23-34.

Nolte, S., & Osborne, R. H. (2013). A systematic review of outcomes of chronic

    disease self-management interventions. *Quality of Life Research*, *22*(7), 1805–

    1816.

Phillips, J. (2012). The need for an integrated approach to supporting patients who should self manage. *Selfcare*, *3*(March), 33–41.

Plow, M., Bethoux, F., Kimloan, M., & Marcus, B. (2014). A formative evaluation of customized pamphlets to promote physical activity and symptom self-management in women with Multiple Sclerosis. *Health Education Research*, *29*(5), 883–896.

Pramuka, M., Hendrickson, R., Zinski, A., & Van Cott, A. C. (2007). A psychosocial self-management program for epilepsy: A randomized pilot study in adults. *Epilepsy & Behavior*, *11*(4), 533–545.

Prochaska J. & DiClemente C., (1982). Transtheoretical therapy: toward a more integrative model of change. *Psychotherapy: Theory, Research and Practice, 19,* 276–88.

Rae-Grant, A. D., Turner, A. P., Sloan, A., Miller, D., Hunziker, J., & Haselkorn, J. K. (2011). Self-management in neurological disorders: Systematic review of the literature and potential interventions in Multiple Sclerosis care. *The Journal of Rehabilitation Research and Development*, *48*(9), 1087.

Rigby, S. A, Domenech, C., Thornton, E. W., Tedman, S. & Young, C. A. (2003). Development and validation o f a self-efficacy measure for people with Multiple Sclerosis : the Multiple Sclerosis Self-efficacy Scale. *Multiple Sclerosis, 9*, 73–81.

Robinson-Smith, G., & Pizzi, E. R. (2003). Maximizing stroke recovery using patient self-care self- efficacy. *Rehabilitation Nursing, 28*(2), 48–51.

Scholz, U., Doña, B. G., Sud, S., & Schwarzer, R. (2002). Is general self-efficacy a universal construct? Psychometric findings from 25 countries. *European Journal of Psychological Assessment*, *18*(3), 242–251.

Schwarzer, R. & Jerusalem, M. (1995). Causal and control beliefs: the generalised self-efficacy scale. In Weinman, J., Wright, S., Johnston, M. eds. *Measures in health psychology: a user's portfolio. Windsor, NFER-Nelson, 35–37.*

Schwartz, C. E., Coulthard-Morris, L., Zeng, Q. & Retzlaff, P. (1996). Measuring self-efficacy in people with Multiple Sclerosis: A validation study. *Archives of Physical Medicine and Rehabilitation, 77,* 394–398.

Scobbie, L., Wyke, S., & Dixon, D. (2009). Identifying and applying psychological theory to setting and achieving rehabilitation goals. *Clinical Rehabilitation*, *23*(4), 321–33.

Shevil, E., & Finlayson, M. (2010). Pilot study of a cognitive intervention program for persons with Multiple Sclerosis. *Health Education Research*, *25*(1), 41–53.

Suh, Y., Motl, R. W., Olsen, C., & Joshi, I. (2015). Pilot trial of a social cognitive theory-based physical activity intervention delivered by nonsupervised technology in persons with Multiple Sclerosis. *Journal of Physical Activity & Health*, 12, 924 -930.

Tielemans, N. S., Visser-Meily, J. M. A., Schepers, V. P. M., Passier, P. E., van de Port, I. G. L., Vloothuis, J. D. M., Struyf, P. A. A. & van Heugten, C. M. (2015). Effectiveness of the Restore4Stroke Self-Management Intervention " Plan Ahead !": a Randomized Controlled Trial in Stroke Patients and Partners, *Journal of Rehabilitation Medicine, 47*, 901–909.

Warner, G., Packer, T., Villeneuve, M., Audulv, A., & Versnel, J. (2015). A

    systematic review of the effectiveness of stroke self-management programs for

    improving function and participation outcomes: self-management programs for

    stroke survivors. *Disability and Rehabilitation*, *37*(23), 2141–2163.

Part 2: Empirical Paper

Goal setting in neurorehabilitation: development of a

patient-centred tool with theoretical underpinnings

Abstract

Aims: This study aimed to synthesise theories of goal setting, behaviour change and identity reconstruction and explore goal setting perspectives of patients, staff members and carers, in order to develop a goal setting tool for an inpatient neurological rehabilitation service.

Methods: The study followed guidelines produced by the UK Medical Research Council for designing complex interventions. Theories relevant to rehabilitation were extracted from existing reviews of literature. Perspectives of patients, staff members and carers with respect to goal setting were explored by conducting ten focus groups. Eighteen patients, 5 carers and 14 staff members took part in the study. Qualitative data were analysed using thematic analysis.

Results: Social Cognitive Theory, Goal Setting Theory, Theories of Self-Regulation and Theories of Loss and Identity Reintegration were found to usefully inform the development of the goal setting tool. Nine overall themes were identified in the analysis of data from the focus groups. The need for education about goal setting was evident across the groups. The importance of identity and linking activities with meaningful goals were highlighted by evidence gathered from patients. Staff highlighted challenges in setting unrealistic but meaningful goals and carers emphasised goal continuity between inpatient stay and community. Participants expressed satisfaction with the goal-setting tool, which emanated from the study.

Conclusions: A theoretically-based, patient-centred goal setting tool was successfully developed. The tool needs to be formally evaluated to substantiate its clinical utility. This study adds to the growing body of research on theoretically-based patient-centred goal setting tools.

Introduction

Neurological rehabilitation is an active, multidisciplinary process aimed at maximising patients' participation in a range of settings and minimising distress to patients and families that results from the disability (Wade & de Jong, 2000). Goal setting lies at the core of neurorehabilitation practice (Playford, Siegert, Levack & Freeman, 2009) and is defined as "a process of discussion and negotiation in which the patient and staff determine the key priorities for that individual and agree the performance level to be attained by the patient for defined activities within a specified time" (Playford, 2015, p.90). Current developments in this area have focused on increasing patient participation in the process, as well as the need to construct more systematic, theoretically-grounded approaches to goal setting (Siegert and Levack, 2014b).

Since the endorsement of the International Classification of Functioning, Disability and Health (ICF) by the World Health Organisation (WHO, 2001), rehabilitation has increasingly moved away from a culture of medical paternalism (McClain, 2005) towards adopting a more bio-psycho-social model (Leplege et al., 2007). The ICF provides a framework for rehabilitation by addressing wider aspects of health and disability, such as body functions, body structures and activities with the aim of increasing participation in social activities. It also emphasises personal variables, such as emotions, hopes and expectations in the process of rehabilitation.

Although historically members of the multidisciplinary teams have largely set goals for patients (McClain, 2005), patient participation in goal setting is now considered to be a standard aspect of care for people with long term conditions (Department of Health, 2010). Some of the main components of patient-centred practice in neurorehabilitation include education about the process and allowing the

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patient to identify and prioritise meaningful goals. Patient-centred practice also emphasises the involvement of the patient's family in the process of goal setting (Leach, Cornwell, Fleming & Haines, 2010; Lloyd, Roberts & Freeman, 2014).

There is a general consensus that patient participation in setting rehabilitation goals is important (Rosewilliam, Roskell & Pandyan, 2011). Nevertheless, despite existing recommendations on patient-centred care, there is still a lack of its systematic application in practice (Prescott, Fleming & Doig, 2015). Educating patients about goal setting, involving families and carers in the process, establishing clear links between therapeutic interventions and goals, and allowing for flexibility and modification of goals with changing needs of the patients, are still aspects of the process routinely under-represented in practice (Prescott et al., 2015). In addition, although an increasing number of studies reports engaging patients in goal setting (Prescott et al., 2015), it does not ensure that the goals established in the process are patient-centred. Research suggests that therapists still tend to control the process of goal setting by employing certain strategies, such as privileging goals related to physical functioning, using short time-frames for goals and avoiding discussions of goals that appear to be unachievable or unrealistic (Barnard, Cruice & Playford, 2010; Levack, Dean, Siegert & McPherson, 2011). Clinicians recognise the process of goal setting as a complex activity that requires finding a balance in the management of competing demands between meeting patients' needs and professional accountability (Levack et al., 2006; Lloyd et al., 2014).

Since patient perspectives are under-utilised in the process of development of goal setting interventions (Prescott et al., 2015), existing approaches often provide a framework for professionals rather than for patients, despite their relative patient-centredness (e.g. McPherson, Kayes & Kersten, 2015). Thus, there is an increasing

need to involve patients not only in the goal setting process, but also in the development of interventions, in order to maximise opportunities for providing a truly patient-centred service.

In addition to considering patient-centredness of interventions, researchers and clinicians have emphasised the need to establish a theoretical basis to goal setting (Playford et al., 2009; Siegert & Taylor, 2004). Although health providers tend to draw on psychological theories to inform current practice, pragmatic and empirical research currently dominates neurorehabilitation evidence-base (Siegert, O'Connel & Levack, 2015). There are multiple, mutually compatible theories that could be applied to goal setting and mapping theoretical concepts to aspects of interventions has been recommended (Playford et al., 2009). However, despite some encouraging research in this area (Scobbie, Dixon and Wyke, 2011; Ylvisaker, McPherson, Kayes, Pellet, 2008), approaches with strong theoretical underpinnings are still relatively rare (Siegert et al., 2015).

The current study seeks to address the gap between theory and practice of neurorehabilitation goal setting and improve patient-centredness of the process by developing a theoretically-grounded goal setting tool for patients and families in an inpatient neurorehabilition service.

The present study addresses the following research questions:

- Which theories have been considered in rehabilitation literature that could inform the development of the goal setting tool?
- What are the goal setting perspectives of patients undergoing inpatient neurological rehabilitation, their carers and therapists?

- How can these perspectives, in combination with theories, inform the construction of a patient-centred goal setting tool?

Method

This study was conducted jointly with Fouzia Siddique (2016). Appendix B provides a brief outline of each of our contributions to the joint study.

According to Levack, Dean, McPherson and Siegert (2015), goal setting should be treated as a complex intervention. Interventions are defined as complex when they include multiple interacting components of different levels of complexity (Craig, Dieppe, Macintyre & Michie, 2008). With that in mind, research in the area of rehabilitation goal setting should follow guidance for developing complex interventions, such as that published by the UK Medical Research Council (MRC; Craig et al., 2008). According to the MRC framework, development of interventions should start with the identification of a theoretical framework that will support the intervention. In addition, theoretical understanding should be supplemented by incorporating stakeholders' views in the design, as well as situating interventions in a clinical context relevant to the target population. As per the MRC protocol, there were two main stages to the study.

The identification and synthesis of theoretical concepts

The aim of the first stage was to synthesise theories relevant to the development of a goal setting tool. Although the MRC recommends that a systematic review of literature is conducted at this stage, it is also suggests that the use of recent high quality reviews may be appropriate to achieve this aim. It has been highlighted that producing a unified theory or set of theories relevant to any goal setting

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intervention is unlikely, but explicit linking of theories and practice is warranted in goal setting research (Scobbie & Dixon, 2015).

In order to identify theoretical concepts relevant to goal setting in neurological rehabilitation, recent comprehensive reviews of literature on theoretical concepts in neurorehabilitation were accessed. These included: a recently published book on rehabilitation goal setting (Siegert & Levack, 2015a) with a chapter devoted to theoretical foundation and psychology of setting goals in neurological rehabilitation (Siegert, O'Connell & Levack, 2015); a previous systematic review of theories in neurorehabilitation goal setting (Scobbie, Wyke & Dixon, 2009), which identified key constructs relevant across various theories of behaviour change; Siegert, McPherson and Taylor's (2004) consideration of theories of self-regulation as a useful theoretical framework for goal setting; and Siegert and Taylor's (2004) review of theoretical aspects of goal-setting and motivation in rehabilitation. In addition, following discussions within the research group and through the iterative and parallel process of the theoretical synthesis and focus group data collection, theories related to reconstruction of identity and loss were also considered in the creation of the tool. These mainly drew from the work of Ylvisaker, McPherson, Kayes and Pellett (2008). Some of the relevant papers were also identified through preliminary searches of Fouzia Siddique's (2016) systematic literature review. Following the collection of relevant literature, all theories were listed in a table, together with the important aspects and core mechanisms of each theory. Ideas on how these could be applied to the tool were discussed within the research team.

Exploring participants' perspectives

The aim of the second stage was to explore the goal-setting perspectives of patients, carers and staff members in order to inform the design of the tool. A focus group, rather than a series of individual interviews, was chosen as a primary method of data collection, in order to allow for exploration of the perspectives representative of participant groups (Massey, 2011). Focus groups are particularly useful in exploratory studies, such as those aiming to research novel topics or to evaluate new health programmes (Dawson, Manderson & Tallo, 1993). Given the direct involvement of stakeholders in the development of the tool, the use of focus groups also served to empower patients and potentially model involvement in their own healthcare (Rabiee, 2004; Wilkinson, 1998). It has been argued that focus groups may be prone to social conformity and thus, reduce the opportunity to explore unique personal experiences of participants (Dawson et al., 1993). However, as the study focused on exploring collective ideas of the participants in order to allow for the flexibility of the tool, a focus group was deemed the most appropriate method for this study.

In order to analyse the data, thematic analysis (Braun & Clarke, 2006) was chosen over other approaches to qualitative analysis, such as Interpretative Phenomenological Analysis (Biggerstaff & Thompson, 2008) or Grounded Theory (Corbin & Strauss, 2008). It was deemed the most suitable method for the current study due to its flexibility and lack of reliance on specific theoretical and epistemological frameworks, as well as its explorative, discovery-oriented nature (Barker, Pistrang & Elliott, 2002). Braun and Clarke (2006) defined thematic analysis as a method for "identifying, analysing, and reporting patterns (themes)

within data". It is particularly useful when searching for themes across, as opposed to themes within data sets, such as in individual interviews (Braun & Clarke, 2006).

Ethical Approval

This study received full ethical approval from the NHS London Queen Square Research Ethics Committee (See Appendix C).

Setting

The study was based in The Neurological Rehabilitation Unit (NRU) in a metropolitan teaching hospital in London, UK. This is an 18-bed, National Health Service (NHS) unit, which specialises in the treatment and rehabilitation of neurological conditions such as stroke, multiple sclerosis and non-traumatic spinal cord lesions. It offers short (two weeks to four months), individually tailored rehabilitation, which conforms to the standards set by the British Society of Rehabilitation Medicine (Turner-Stokes et al., 2000). The multidisciplinary team comprises a consultant neurologist, physiotherapist, occupational therapist, speech therapist, clinical psychologist and rehabilitation specialist nurse. Each patient has a designated keyworker who is responsible for supporting them during their stay.

The established goal setting approach, that had been in use prior to the study, involved the patient being met by the treating team on admission, and working with the team for a week. At the end of the first week, the team then set goals in the light of discussions with the patient. The patient may or may not have attended the goal setting meeting depending on their preference. On Monday of the following week, the goals were reviewed by the team and if necessary, refined. The goals were then given to the patient in writing and the patient could further discuss them with the

team and agree or disagree with the plan. There was no formal framework to support patients' understanding or engagement in the goal setting process.

Participants

Participants for the study consisted of patients, their carers and unit staff. For the patient cohort in the study, inclusion criteria were: the patient was currently an inpatient in the unit; he/she had the ability to consent to the study; he/she had satisfactory cognitive and communication ability to take part in a focus group, this being on the basis of advice from clinical team members. Eligible patients were identified by the members of the clinical team and invited to take part in the study. They were also asked if their carers could be approached and invited to take part in the focus group. The only inclusion criterion for staff members was their willingness to take part in the study. The ability to communicate in English was essential in order to be invited for all participant groups.

All participants signed the informed consent form. They were offered time to read the study information sheet and ask questions (see Appendix D). Where a patient was unable to sign the form due to mobility restrictions, a witness (member of staff) was present during the procedure and countersigned the form.

The participants were 18 patients, 5 carers and 14 staff members. Eighteen patients in total took part in five focus groups. There were 9 women and 11 men aged 19 to 67, with a mean age of 45.67 years. Although more patients were approached, participation rate was not formally recorded. The most common reason for patients' lack of consent to participate was their lack of willingness to take part in research or group discussions. Some of the patients who agreed to take part were not able to join a focus group due to other commitments at the time or withdrawal of

consent due to no longer wanting to take part. The diagnoses included haemorrhagic stroke (n=7), ischaemic stroke (n=4), brain tumour (n=3), a disorder of brain and spinal cord due to side effects of treatment for cancer (n=2), cancer related spinal nerve damage (n=1) and multiple sclerosis (n=1). Patients belonged to various ethnic backgrounds: White (n=8), Black (n=5), Asian (n=4) and mixed race (n=1).

Nine carers agreed to take part in the study. Four carers could not participate due to other time commitments coinciding with the timing of the focus groups. Therefore, five carers took part in two focus groups in total, and they consisted of a daughter, a wife, a son, a husband, and a father. Although participation rate was not formally recorded, the most common reason for declining to take part in the study was the lack of time or the lack of willingness to take part in research.

Twenty staff members were approached to take part and all agreed. Six staff members could not participate due to absence on the day of the focus group or due to having other commitments at the time. Fourteen staff members took part in three focus groups in total. There were 10 women and 4 men. Their roles were: physiotherapist (n=5), occupational therapist (n=4), clinical psychologist (n=1), nurse (n=1), social worker (n=1), speech and language therapist (n=1) and rehabilitation assistant (n=1). No further demographic data were collected from carers and staff members.

Procedure

Ten focus groups in total were conducted by the author of this thesis (Agata Aleksandrowicz) and by the second researcher (Fouzia Siddique). Seven initial focus groups (4 patient groups, 1 carer group and 2 staff groups) were conducted to explore the experiences of current goal setting and ideas for possible improvements.

Following this, a draft goal setting tool was constructed, as informed by theories and by participants' contributions. A final set of three focus groups (1 patient group, 1 carer group and 1 staff group) was conducted to gather feedback on the draft tool, following which improvements were made and the final version of the tool was constructed. Participants could take part in each focus group only once in the first set of focus groups. However, due to the close proximity of the focus groups in time, all six patients who took part in the feedback group had also previously taken part in the initial set of focus groups. Different carers took part in each focus group at both stages. Eight staff members who took part in the feedback focus group had also taken part in one of the initial focus groups. Focus groups lasted from 30 minutes to 95 minutes (45 minutes on average). All of the focus groups were held at the neurorehabilitation unit. Figure 1 depicts the process of the development of the tool.

Following data collection and the finalisation of the tool, the staff members received a one-hour-long training session delivered by the author (AA) and the second researcher (FS) via a PowerPoint presentation. The training session outlined the development of the tool and theories that informed it, with the aim of providing staff with background knowledge and the rationale behind the tool, as well as ideas on how it might be implemented in practice.
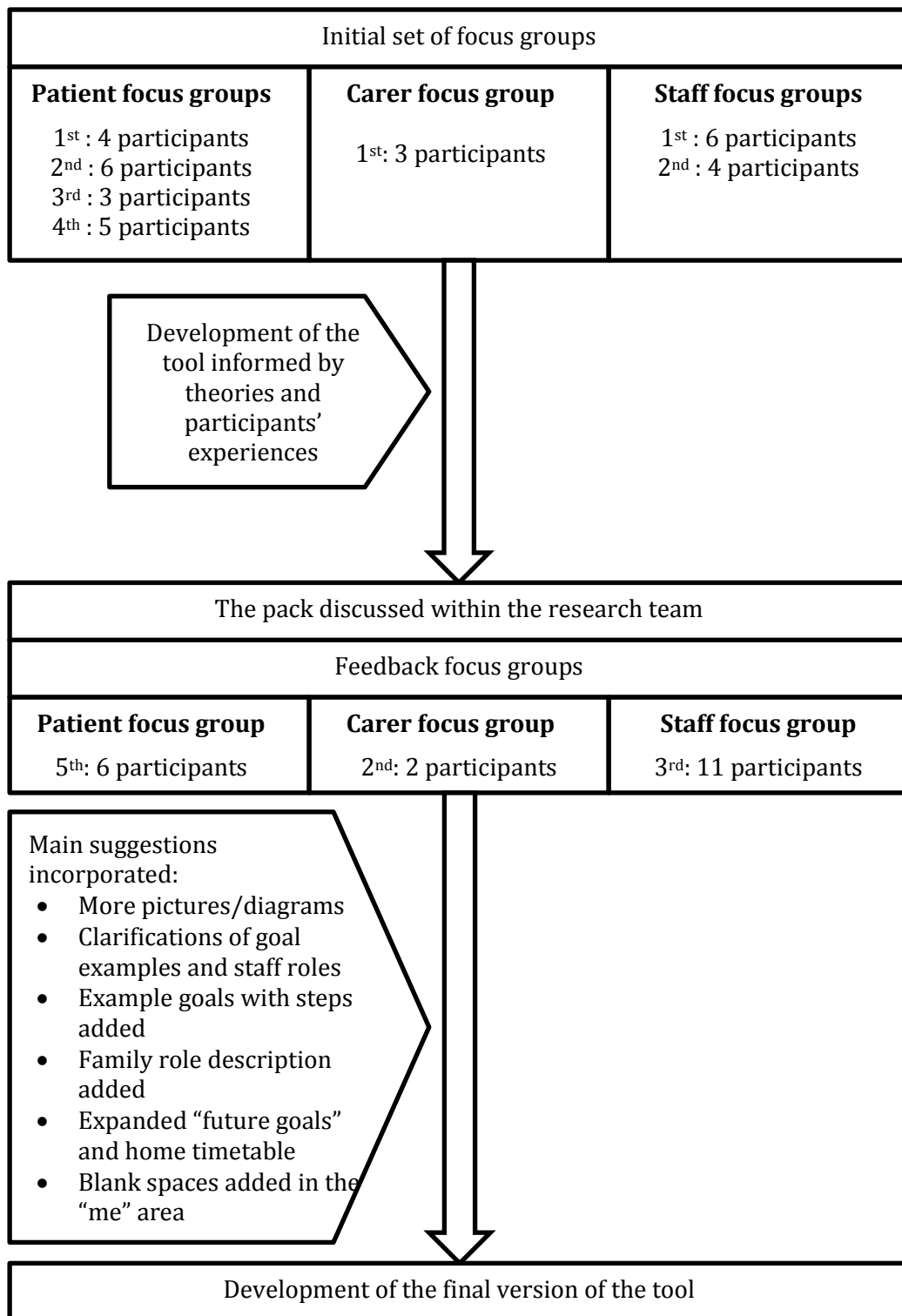
Initial set of focus groups		
Patient focus groups	**Carer focus group**	**Staff focus groups**
1st : 4 participants 2nd : 6 participants 3rd : 3 participants 4th : 5 participants	1st: 3 participants	1st : 6 participants 2nd : 4 participants

Development of the tool informed by theories and participants' experiences

The pack discussed within the research team		
Feedback focus groups		
Patient focus group	**Carer focus group**	**Staff focus group**
5th: 6 participants	2nd: 2 participants	3rd: 11 participants

Main suggestions incorporated:
- More pictures/diagrams
- Clarifications of goal examples and staff roles
- Example goals with steps added
- Family role description added
- Expanded "future goals" and home timetable
- Blank spaces added in the "me" area

Development of the final version of the tool

Figure 1. Flowchart to illustrate the process of the development of the goal setting tool.

The interview schedule

The interview schedule for the focus groups was developed by the author (AA) and the second researcher (FS), and later finalised through discussion within the research team (See Appendix E). Three main areas that were considered to be key for exploration were: current experiences and views of goal setting on the ward, patient/carer involvement in the process, and ways of improving the process or suggestions for the tool. Parts of the schedule were informed by the schedule used in a previous study conducted in the unit (Holliday, Ballinger & Playford, 2007). We used the interview schedule as a guide, rather than a structured interview, and allowed participants to expand on topics discussed, thus providing an opportunity for the emergence of issues relevant to them (Dawson et al., 1993).

Analysis

The content of the focus group discussions was audio-recorded and transcribed verbatim. One recording was transcribed by the author and nine were transcribed by volunteer research assistants. All transcripts were checked by the researcher for accuracy and missing utterances. This also allowed for the immersion of the researcher in the data, the first stage of thematic analysis (Braun & Clarke, 2006).

The whole process roughly followed the stages of focus group analysis described by Rabiee (2004): (1) Immersion in the data through listening to recordings and reading transcripts; (2) Writing memos in the margins of the transcripts – coding; (3) Indexing – organising the data between and within the transcripts; (4) Charting – moving quotes around and re-arranging according to the

emerging themes; (5) Mapping and interpretation – analysing the relationships between the themes and expressing this as a coherent narrative.

Data were coded line-by-line and rechecked through a continuous iterative process to allow for the construction of themes and patterns summarising key concepts raised by the participants. The author (AA) and the second researcher (FS) coded the data independently. Agreements and disagreements were compared and the initial set of themes was discussed within the research team. Codings of the data were largely consistent between the two researchers. A table of codes was constructed for each participant group (patients, carers and staff members) and for each stage (initial focus groups and feedback focus groups) separately. The codes were combined into groups of similar and corresponding topics to form themes using "copying and pasting" method in the Word document table (Stewart, Shamdasani & Rook, 2006). Finally, given that the themes were largely similar between initial and feedback focus groups, the themes were combined. Following this, a final set of separate themes for each groups (patients, carers and staff members) was derived (See Appendix F for an example of the analysis process).

Credibility checks

In order to ensure rigour, two researchers independently coded all transcripts. The supervisor (DP), experienced in qualitative research, read the codings and initial themes, which were then discussed within the team (AA, FS, DP). In addition, preliminary ideas of themes were discussed with four research assistants and the second researcher (FS) following their completed transcriptions. A list of final themes was discussed and refined within the research team in order to reach a consensus. Field notes were collected during and following each focus groups to increase reflexivity during the analysis of the data.

<center>**Results**</center>

Theoretical concepts

Multiple psychological theories have been considered with reference to rehabilitation goal setting. Among the most commonly cited theories in the rehabilitation literature were:

- Self-efficacy and Social Cognitive Theory (Bandura, 1978; 2001)

- Goal Setting Theory (GST; Locke & Latham, 2002)

- Self-Regulation Theory (Carver & Scheier, 1998)

- Emmons' (2003) theories about subjective goals

- Deci and Ryan's (2000) Self-Determination model

- Karniol and Ross' (1996) temporal influences on goal setting

The results of this study also included theories of identity reconstruction (Self-Discrepancy Theory; Higgins, 1987; Cognitive Developmental Model of Social Identity Reconstruction; Amiot, de la Sablonnière, Terry & Smith, 2007) and models of loss (Stage model of bereavement; Kübler-Ross, 1969; Acceptance of Loss Theory; Wright, 1960; 1983), which have recently received growing attention in our understanding of adjustment to disability and the role they may play in setting rehabilitation goals.

Social Cognitive Theory. One of the most frequently cited theories of behaviour change is Social Cognitive Theory (Bandura, 2001; Scobbie, Wyke & Dixon, 2009), with self-efficacy as a key component. Self-efficacy is about the belief in one's ability to achieve goals and complete tasks, as well as confidence in one's ability to cope with challenges (Bandura, 2001). There are four main sources of information that contribute to one's self-efficacy (Bandura, 1982):

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- enactive attainments or mastery experiences

- vicarious experiences

- verbal persuasion

- and physiological feedback

More specifically, according to Social Cognitive theory, an individual will have high self-efficacy when he or she experiences repeated success at task completion, observes others succeed, receives verbal encouragement and is able to interpret physiological reactions as normal and not related to one's ability (e.g. interpreting sweaty palms as a normal sign of anxiety rather than a sign of poor ability).

Self-efficacy is believed to be an important construct in health behaviours and forms the theoretical basis of chronic disease self-management programmes (Jones, Mandy, & Partridge, 2009). Some evidence suggests that interventions which enhance self-efficacy can improve functional outcomes and quality of life (McKenna, Jones, Glenfield & Lennon, 2013). Self-efficacy is thought to influence health outcomes by increasing motivation to pursue goals and adherence to treatment (Scobbie et al., 2009). It also appears to play an important part in other theories of behaviour change, such as Goal Setting Theory and Health Action Process Approach (Schwarzer, 1992, cited in Scobbie et al., 2011), which emphasises action planning (setting specific plans for goal achievement) and coping planning (planning how to overcome potential barriers in the goal pursuit) as important aspects of goal setting process.

Goal Setting Theory. Goal Setting Theory has found some applications in rehabilitation despite having been developed in the context of organisational psychology (Gauggel & Billino, 2002). The main principle of GST assumes that

setting specific, difficult goals is associated with better performance on a task. Although this is somewhat in conflict with a commonly held view that rehabilitation goals need to be achievable (Playford et al., 2009), Levack et al. (2006) reported studies that supported this idea. Gyurcsik, Estabrooks and Frahm-Templar (2003) suggested that the relationship between goal difficulty and achievement might be more complex and proposed self-efficacy to be a moderator of this effect. They argued that people with low self-efficacy might benefit more from setting easier goals, whereas setting difficult goals may result in better performance for people with high self-efficacy. Locke and Latham also emphasized the importance of feedback and personal relevance of goals and minimised the impact of involvement in decision-making.

Self-Regulation Theories. In contrast to GST, Self-Regulation Theory has been more widely applied in the context of rehabilitation goal setting (Hart & Evans, 2006; Siegert et al., 2004). There are multiple definitions of self-regulation, as well as various approaches to it (Siegert et al., 2004). De Ridder and de Wit (2006) see human beings as active agents in goal pursuits and describe self-regulation as the ability to resist own impulses and adapt behaviour in order to attain certain life goals. Several different approaches to self-regulation have been outlined below.

Carver and Scheier (1998). One of the most common approaches to self-regulation is that of Carver and Scheier (1998). They proposed that goal-oriented behaviour functions as a negative feedback loop, based on evaluation of the discrepancy between current and desired state and attempts to decrease this discrepancy. Carver and Scheier argued that goals should be organized hierarchically with sequences (routine behaviours) at the bottom and a system concept (idealised self) at the top, because people tend to pursue multiple goals at any given time. The

main implication of this approach is that the more linked the sequences are to the system concept, the more motivated the person is to pursue his or her goals. For instance, according to their theory, a patient would be more motivated to engage in upper limb physiotherapy practice if it linked to a higher order goal of being able to use a computer keyboard, which is necessary to fulfil the patient's role as a computer programmer.

Emmons (2003) and related approaches. The concept of higher order values is closely linked to the approach of Emmons (2003), who emphasised the role of emotions and meaning in human goal-driven behaviours. According to Emmons, incorporating the patient's perspective is key to successful goal setting in rehabilitation. This is in line with the suggestion of Rosewilliam et al. (2011) that exploration of higher order values to determine goals could be a beneficial approach to goal setting. Karniol and Ross (1996) proposed similar ideas and highlighted the need to acknowledge the effects of past experiences in the pursuit of goals. They argued that goals need to be linked to past memories of self in order for them to be meaningful.

Deci and Ryan (2000). Deci and Ryan's (2000) Self-Determination Model proposes that goal-driven behaviours are motivated by the need to fulfil three fundamental needs: autonomy (need to act accordingly with self), relatedness (need to establish significant relationships) and competence (need to gain mastery over one's actions and environment). One of the applications of this model in rehabilitation settings would be to consider competence goals as related to functioning and activities of daily living; to consider relatedness goals as those that pertain to meeting one's social needs; and autonomy goals as those related to the possibility to pursue valued activities (Siegert & Taylor, 2004). Deci and Ryan also

emphasised the role of intrinsically motivated goals in the process of goal pursuit and argued that goals originating from the patient's expectations, as opposed to the clinician's expectations, are more powerful and result in higher perceived competency and self-determination (Siegert & Taylor, 2004).

Metaphoric Identity Mapping (Ylvisaker, et al., 2008) is an approach largely based on theories of self-regulation. It has been applied in neurological rehabilitation practice with patients with traumatic brain injury and was found to be particularly helpful for setting meaningful goals in a collaborative way. It also found utility in increasing insight and awareness and thus, facilitating identity reconstruction following brain injury.

Theories of identity reconstruction. Theories and models of identity change and reconstruction have gained more prominence within the field of rehabilitation in recent years, particularly in the area of traumatic brain injury and other sudden-onset disorders such as stroke (Cloute, Mitchell & Yates, 2008). Most developmental models assume that disability causes a state of "psychological disequilibrium" which requires re-integration of identity in order to adapt to disability and achieve successful adjustment (Cantor et al., 2005).

Self- Discrepancy Theory (SDT; Higgins, 1987). Cantor et al. (2005) applied Self-Discrepancy Theory in order to better understand emotional difficulties associated with identity change as a result of a brain injury. SDT assumes that the discrepancy between "actual-self" (perception of oneself and attributes that one possesses) and "ought-self" and "ideal-self" gives rise to anxiety and depression. Cantor et al. (2005) adapted the theory to help explain changes in identity following disability and found that large discrepancies between "pre-injury self" and "post-injury self" were associated with anxiety and depression. Gracey et al. (2008)

conducted a group discussion with individuals with brain injury to conceptualise construction of self following the brain jury. They concluded that engaging in personally meaningful activities may reinforce the idea of "who I am" and potentially help reduce self-discrepancies. These concepts are similar to the self-regulation theory of Carver and Scheier (1998).

Cognitive Developmental Model of Social Identity Integration (CDMSII; Amiot et al., 2007). Gendreau and de la Sablonnière (2013) applied the Cognitive Developmental Model of Social Identity Integration to patients with traumatic brain injury and spinal cord injuries to understand the process of adjustment to disability. The model describes three stages of identity reconstruction: categorisation, compartmentalisation and integration. During the stage of categorisation, pre- and post-injury self representations are seen as conflicting by the individual. During the stage of compartmentalisation, the individual is able to recognise different roles and aspects of identity as similar in both pre- and post-injury selves; however, these are largely context-specific. Finally, during the integration stage, one is able to recognise mutual importance and similarities between pre- and post-injury self characteristics. Successful integration can also be related to a creation of superordinate categories of one's identity under which other aspects of self can be united.

Models of loss and grief. Theories and models of identity also emphasise the idea of loss, mourning or grieving the pre-injury identity (Gendreau & de la Sablonnière, 2013), which is connected with the initial stage of categorisation in the CDSMSII, during which an individual is distinctly aware of the loss of parts of self and previous abilities. Models of loss have been helpful in understanding the process of adjustment to disability (Cantor et al., 2005). One of the commonly cited theories of grief is the stage model of Kübler-Ross (1969) which assumes five common

stages of adjustment to loss from denial to acceptance. Acceptance of Loss Theory (Wright, 1960;1983) has also been used to explain changes in identity following the onset of disability. The theory states that in order to accept disability an individual needs to reorganise his or her value system to include characteristics of the person not related to the physical aspects, and try to find aspects of disability that fit with one's existing value system (Keany & Glueckauf, 1993). The theory also emphasises the importance of finding meaning in goals and activities as means to reaching the state of acceptance.

Theoretical summary

There were multiple aspects of theories listed above found to be relevant for neurological rehabilitation. It was evident across most theories that personal involvement in goal setting was considered an important aspect of goal pursuit. Although some theories differed in their mechanisms, setting specific, challenging, personally meaningful, intrinsically motivated goals linked to higher order values or idealised aspects of self, were considered important in increasing motivation for pursuing goals. Both theories of self-regulation and identity reconstruction considered goal-driven behaviours in terms of actions aiming to reduce discrepancies between the current self (or state) and the desired self (or state). Models of loss, identity reintegration and self-regulation emphasised the importance of allowing the person to grieve for their losses and allowing the time and space to consider multiple aspects of self when goal planning.

Qualitative findings

Context

The study took place in one of the most prestigious neurological rehabilitation centres in the country, which suggests that the existing quality of goal setting at the unit was already of a relatively high standard. The ward is regularly involved in conducting various research projects. However, given the funding cuts to the NHS services, it also suffered from staff shortages, which inevitably increased pressure at the work, as reflected by staff members and patients. Finally, although the external supervisor (Professor Diane Playford) did not take part in data collection, she was involved in her clinical role of the ward director throughout the majority of the duration of the project and had clinical contact with patients, staff and carers of the ward.

Themes

Following the analysis of the data, nine themes and six subthemes were identified across the three participant groups. They are described in Table 1.

Table 1.
Summary of themes and subthemes.

Participants	Theme	Subtheme
1. Patients	1.1 Not knowing what is expected	
	1.2 "You can't lose half your brain and come out exactly the same"	
	1.3 "It's a jigsaw"	1.3.1 Collaborative exercise
		1.3.2 Staff are the experts
	1.4 Goals should be meaningful and relevant to daily life.	
2. Staff	2.1 Patients are not prepared for goal setting	
	2.2 Aspirational goals	2.2.1 Linking rehabilitation to aspirational goals
		2.2.2 Allowing patients to set aspirational goals
3. Carers	3.1 "How do we prepare?"	
	3.2 Continuing the trajectory of rehabilitation	3.2.1 Not "defaulting" therapists' work
		3.2.2 Continuity of goals
	3.3 "Will we be criticised for putting far-fetched goals?"	

1. Patient themes

There were four patient themes identified through the data analysis. They related to a sense of isolation on the ward and lack of information about the goal setting process, changes in identity, role and ability following injury, collaboration

between patients and staff during goal setting, and the importance of setting meaningful and relevant goals.

Theme 1.1: Not knowing what is expected. Patients spoke about feelings of isolation and not knowing what to expect of rehabilitation when they first came to the ward. One person compared it to a "first day at school" and spoke about how "daunting" the experience was. Patients expressed feeling unprepared for setting goals and spoke about a lack of familiarity with this concept, given no previous experience of goal setting.

> *"I'm still a bit in the dark, because I'm not sure I entirely know what to expect (...). I don't feel that I'm either particularly prepared or necessarily sure that I will be prepared for it."* (Patient group 4)

One patient, who could not take part in the focus group but offered his impressions on the tool, spoke about not knowing what was expected of him during his goal setting session. He compared goal setting to a "business exercise" and thought that he was expected to come up with clear linear targets that needed to be ordered according to priority. Therefore, he found this idea overwhelming. Patients agreed that it would be useful to have a booklet that would introduce them to the concept of rehabilitation and outline the process and expectations.

> *"I was just looking around, in the day room, thinking, what's going to happen, (...) so I didn't know what to expect. Lots of people asking questions when they did the assessments. And if it was all self explanatory: a number of people are going to come, one's an OT and this is what we're going to do to help you, a self explained package, like an introduction booklet, it would be helpful. The whole process."* (Patient group 3)

Patients also felt that there was not enough time to allow for thinking about their goals prior to the initial goal setting meeting. Thinking of goals "on the spot" was sometimes associated with setting goals that were not meaningful.

"I wish we would have more time to think about our goals, because sometimes we just go into the meeting and it's just on the spot and it's hard to think about what you want to really do, and you just come up with random goals that you don't really really want to do (...) I wish we had a time to discuss prior to the meeting with them and then actually have the goal meeting." (Patient group 4)

Emotional preparation, or "the right mindset" was recognised as another aspect of preparation. Apart from practicalities and information, it was important for patients to be emotionally prepared for setting and pursuing goals.

"You have to have the right mindset, you know. You've got to be able to physically… you know, you want to be able to do it emotionally as well. You can't just give up and just switch on switch, and say 'right I'll just start doing this now'". (Patient group 1)

Theme 1.2: "You can't lose half your brain and come out exactly the same." Most patients spoke about the "devastating" change that their injury caused to their life and compared the process of rehabilitation to "a journey". Some people spoke about the difficulty believing that it actually happened and feeling as if they had started a new life, and as if the life they had before never existed.

"It's like you have a false impression, you think it doesn't exist but it does." (Patient group 2)

"It's almost like, I feel like a lot of the stuff I did in the past is almost like it didn't happen." (Patient group 1)

Some acknowledged the impact of the "massive change" and one person said "you can't lose half your brain and come out exactly the same". Others spoke about feelings of loss and feeling "strange" to not be able to do the things that they used to be able to do before the injury. Patients compared this experience to grief:

"Kind of like grieving for that chunk that I've lost. Becoming really aware of what I've lost." (Patient group 1)

They acknowledged the uncertainty of how they might progress in their rehabilitation and the importance of allowing themselves time to grieve their losses.

> *"In the end of the day you've lost a chunk of your life and you've got to see how far you get, but at the moment we also have lost chunk of our lives."* (Patient group 1)

Patients normalised their experiences by discussing how any life experience, such as going to university or getting married, may change a person, which made it understandable that they felt differently given the impact of their injuries. Some spoke about knowing that there were still parts of them that had not changed, but also that there were aspects of their identities that felt different and new:

> *"I'm still basically the same person but I'm not."* (Patient group 1)

It appeared that the injury possibly created a "split" into "two people" in one body: one that related to the "home me", and one that related to the "hospital me".

> *"For me it feels separate. Like two boxes, one box has 'outside', one box has 'in the hospital', until you take the lid off."* (Patient group 1)

> *"Yeah. Two people. Yeah you got 'hospital me' and the 'home me."* (Patient group 1)

They felt that staff did not ask about patients' past enough, possibly because it was a "tricky question to ask":

> *"Well you know cause you're not as good as you should be, or you ought to be and you...ummm, you know, it's taking bad news."* (Patient group 1)

However, they also expressed the view that it would be helpful to find ways of connecting the two "identities" of "home me" and "hospital me". Allowing space to speak about the past was seen as important as long as the staff exhibited a non-judgmental attitude. One patient expressed feeling frustrated at staff telling him what

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he could and could not do during goal setting, despite not finding out what he had done before:

> *"You don't know what I used to do before, so why are you telling me I can't do this."* (Patient group 2)

Theme 1.3: "It's a jigsaw". This theme considers the collaborative nature of goal setting as seen by patients. It is divided into two subthemes: one, which relates to patient-centred goal setting and another, which relates to the expectation of staff to assist patients in setting some goals.

Subtheme 1.3.1 Collaborative exercise. Patients shared overall agreement that goal setting process was a collaborative exercise. One patient likened the process to "a jigsaw":

> *"So this is where I think it's a jigsaw, I think maybe the psychologist gets you talking, when they have their meetings she'll say to the physio 'he likes doing this, he likes doing that', so they're all then having a meeting, through talking they're getting the information on what they think you need and they collaborate, put it all together and they do it."* (Patient group 3)

Patients felt that their opinions were taken into consideration and did not feel that the goals were imposed on them:

> *"They don't ever shut your opinions up because it's all about you in the goal meeting. You're always… cause you're in the middle and they're all around you so they will always talk to you and what you want and they don't ignore what you want."* (Patient group 4)

Subtheme 1.3.2 Staff are the experts. Although some patients found it difficult to think of goals for themselves, others had ideas on what they would like to work on throughout their stay but relied on the expertise of staff to assess whether this was realistic:

> *"I'd assume it will be mainly the physios and the OTs who will be the best judges of whether or not what we're looking at is realistic, and the best*

person to suggest if we're floundering in the dark, and what might be the goals we should be looking for." (Patient group 4)

Patients also recognised their own role in the goal pursuit and rehabilitation:

"The physiotherapist, they say in their goal, we can take you so far but there's a limit to how far we can go, you've got to go the whole way." (Patient group 1)

Another important aspect of the collaborative process was adjustment to the limitations which occurred as a result of the injury. One patient expected that staff would be able to help him in that process:

"I'm not going to be able to ride again, which would be ideally my first goal, I would love to be able to do it again, but I know I'm not going to be able to do it, I know why I'm not going to be able to do it and it's a question of can I get any help in leading me to accept that I'm not going to be able to do it, or indeed finding any alternative thing that might be reasonably satisfying." (Patient group 4)

Theme 1.4 Goals should be meaningful and relevant to daily life. There was an overall agreement that goals should be meaningful and relevant to daily life. One patient spoke about her goals being related to the activities that she enjoyed, such as spending time with family and helping around the house. Another patient said:

"The idea of setting goals at all is to try and bring us back as nearly as possible to the life that we used to be able to enjoy, or at least those parts that we did enjoy." (Patient group 4)

Some patients also agreed that goals should extend beyond the hospital stay of the rehabilitation:

"Because the idea isn't just to achieve something and not do it again. The idea is to achieve it and then use it as part of your everyday life." (Patient group 2)

Although a few patients spoke about their only goal being health and physical recovery, other patients felt that goal setting should address broader issues:

"I want to learn how the little things that are not part of the physical process, how they're gonna work. I also want to learn about how to talk with normal people and how to joke with people, you know I don't joke in here. How do you go to a coffee shop, yeah, things like that. And I'd like to know how it works. You know, how those people look and, you know, how you can get away with going into a pub or something and people not saying that you are … must have just come out or something." (Patient group 1)

Patients mostly felt that their goals were relevant and meaningful. However, two patients felt that this was not the case. One woman with hemiplegia following stroke spoke about her goals:

"Not relevant. I'll just give an example of yesterday, they sent me to put the washing in the washing machine, mind this hand doesn't work. She [the nurse] was holding my hand, holding my, clothes putting it in the washing machine. I wouldn't call that as a goal." (Patient group 4)

When asked what she would call a goal, she answered:

"I would be expecting to be doing it myself, not somebody doing it for me. Then I might as well tell my husband to do it at home because the amount of time I've spent, or he's spending up with me to just do that…to me it's not practical really. He might as well just do it himself and get on with it." (Patient group 4)

Although this patient's goals were aimed at her independence, she did not feel they were relevant to her. She lived with her family and received good support from them with practical tasks. Another patient felt that his goals were not relevant to him as he did not come to the ward to learn how to use the computer and could not see how, and if, it linked to his goals. Some patients struggled to see the links between specific exercises and goals. This woman commented:

"I've asked some of the physios to relate to what we are doing to my goal because I haven't really, it hasn't really been obvious." (Patient group 2)

Patients described some of their meaningful goals as potentially "unrealistic" or "overambitious". Some said they would find it upsetting to hear from staff that a goal was unrealistic or overambitious and they expressed a preference to set realistic but at the same time challenging goals. One patient spoke about her goal which may have been seen as unrealistic and described it as "ridiculous":

"My overarching goal was ridiculous, one I deliberately chose it, for very good reasons, but it was to ride a horse." (Patient group 2)

She felt that the goal of riding a horse helped her keep her motivation, at the same time addressing different areas of her physical difficulties. Another patient also spoke about his meaningful goal and thought that others would see it as "rubbish":

"One of my goals was to be able to play Monopoly with my son, and I achieved that goal set it off... and If you look at it, you say 'why Monopoly?'. It's another way of, like, being able to manage finance and things like that. So its like wrapped. One thing wrapped in everything. You have to buy the cards. You know these cards you buy, so it's like organisation in a way. So the day I finished playing the game I said that's gone and that helped. But anybody that saw that would say this is rubbish." (Patient group 2)

Patients recognised the importance of goals being meaningful to them and some found that the more meaningful the goals were and the more areas of rehabilitation they mapped onto, then the more motivated [they] felt. There was also some agreement that the goals were often not "challenging enough" and some patients found themselves bored when they managed to achieve their short-term targets before their review dates.

1. Staff themes

Two themes were identified following the analysis of the data from staff focus groups. They related to lack of preparation for goal setting for patients and the discussion about aspirational goals.

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Theme 2.1: Patients are not prepared for goal setting. Initially, there was a general agreement between staff that patients did not know what they wanted to work on when they first came to the ward and therefore they needed a lot of prompting and guidance by staff.

> *"A lot of patients don't know what they want to work on next. They need ideas."* (Staff group 2)

On the other hand, one staff member expressed a contrasting opinion:

> *"I think everyone who comes in here has got an idea of what they want to work on, before they arrive. However unrealistic or realistic that may be, but I think they do."* (Staff group 3)

Staff members wondered whether this may be caused by insufficient preparation of patients for goal setting and lack of education about the purposes of goals. They felt that introducing the tool would potentially provide patients and families with written information that could inform them about the process and expectations of goal setting.

> *"Sometimes I wonder whether it becomes a surprise to the patients around goal setting. It's explained within the goal set, but do we need to do more preparation without sort of… they arrive with more ideas and goals and aims as well."* (Staff group 1)

Staff also spoke about the language that they used in goal setting and felt that using different wording could help patients engage in the process better:

> *"I think sometimes the word goal isn't helpful for them I think. I think sometimes with the mood and adjustment issues if they're quite early on, it doesn't apply to patients. I think they find it quite challenging for most to try and set something and worry about getting there. Sometimes I sort of say "priorities", what are your priorities at the moment and it seems they tend to engage a bit more."* (Staff group 2)

There was an agreement that goals should be stated in patients' own words. Participants also acknowledged that although patients do not have enough

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preparation and information on goal setting, they would not state goals in the same

way as professionals:

> *"It's difficult to get a goal which is, you know, SMART [Specific, Measurable, Achievable, Relevant and Timely] goal planning and things like that. So, it's really specific and you gotta say 'yes I've achieved it'. But equally, patients are never going to set the goal that's structured in that sort of way."* (Staff group 1)

It appeared that having more preparation would help patients think of

meaningful goals, as opposed to staff framing the goals in a way that fitted with

professional jargon:

> *"I think our goals are quite depersonalised and actually what they really want to say is 'I want to go to the corner of my street and be able to do that' and we're not usually that specific. And that's not meaningful."* (Staff group 3)

Theme 2.2: Aspirational goals. A significant amount of time was spent on

discussing aspirational goals, which were broadly understood as the goals that may

not be achievable whilst at the ward, the goals that may not necessarily be realistic,

but also the goals that appear to be important to patients and congruent with their

values. This theme was divided to two subthemes.

Subtheme 2.2.1 Linking exercises to aspirational goals. Staff spoke about

feeling as if they did not talk about aspirational goals enough in their work with

patients and sometimes "forgot about it". They also spoke about the International

Classification of Functioning, Disability and Health (ICF) as a supporting framework

for expanding thinking of goals to participation and activities, which are often

domains in which goals are limited. One person commented on how the tool may

open discussions about goals in the area of participation, taking the patient's culture

and identity into account:

"(…) and we never link goals to that, but actually that's where those identity and life goals would most often fit. So if there's an issue around, kind of, more than just a participation restriction, bit more of an environmental, or you know, something cultural…" (Staff group 3)

One participant commented that staff did not clearly document aspirational goals, to which a member of staff responded:

"No… it's not that we don't do it, it's just that we maybe don't consistently do it. It's easier to write a wash-dress or work or a communication goal than…" (Staff group 3)

It appeared that staff found it easier to record goals that fell within the remit of their professional abilities than goals that related to patient aspirations. Staff also spoke about difficulties in documenting aspirational goals in the system that they used; however they acknowledged the importance of setting aspirational goals and linking these to therapy activities and exercises:

"So it will be quite nice to then, to be able to, like, 'What I did in today's session and how that helps me to work towards my goals'. Because a lot of the times it's really abstract, isn't it? Certainly in physio, you might be doing something, like, really minute and abstract on their shoulder or something. And they're like 'Oh, how is this actually fitting in with being able to', I don't know, 'my work as a cashier?'" (Staff group 1)

Although there was agreement that aspirational goals could be motivating, staff also agreed that some goals need to be achievable, as not achieving any goals could decrease motivation and lead to goal disengagment.

"So I think, my experience, again, they know that whilst they are here, they need to do something to improve their mobility and they will focus on it. And then if they think they are not achieving that, they are not going to be happy, they are going to be angry, they are not satisfied. If they are doing well, actually they are going to carry on with their goals." (Staff group 1)

"It can be quite demotivating isn't it as well? When you don't reach the goal." (Staff group 1)

Subtheme 2.2.2 Allowing patients to set aspirational goals. Staff spoke

about ways in which they managed goals that patients strongly identified with, but

which appeared unachievable to staff. One staff member commented that, at times,

staff made decisions regarding goal achievability "on [patients'] behalf", rather than

allowing patients to find out how realistic the goal was through their rehabilitation:

> *"And we always have that tousle don't we, of, 'do we put that in?'. And we*
> *end up saying, 'let's put it under an exploring headline', you know, because*
> *we know that it's unlikely to work. That's one way of dealing with it, but if*
> *patients actually absolutely identify what they want, I think it makes it easier,*
> *this way, to address it as it goes along, and then review it, because they've*
> *actually bought into the fact that it's not working."* (Staff group 3)

Participants also agreed that goal setting was particularly challenging for

patients with cognitive and language difficulties, where it required staff to help

patients raise awareness of their limitations due to lack of insight into their

difficulties, which sometimes resulted in patients setting over-ambitious goals.

> *"The most common goal our client, patient say is that they want to walk (…)*
> *they might not have insight into that, they may have some memory difficulties*
> *or difficulties in concentration, or all of these kind of planning issues, and...*
> *so… it's kind of trying then to bring in awareness to that by just even… and*
> *so, it's not always generated from them, I find, especially some of the*
> *cognition goals particularly."* (Staff group 1)

It was suggested that allowing patients to put down their aspirational,

potentially overambitious and unachievable goals could relieve staff of responsibility

for controlling the goals and allowing patients to "own it":

> *"I think one of the good things about it, is that actually, it takes, it feels to me*
> *it takes the pressure off us, from saying to patients at the beginning 'you*
> *can't possibly have that in your long term goal cause you're not going to*
> *achieve it'. Whereas actually if they're owning it, and we're reviewing it,*
> *regularly… I don't, I think that's less of a issue for putting in unrealistic*
> *thing in a long term goal."* (Staff group 3)

This would allow patients to increase the awareness of their limitations and potentially increase motivation for pursing goals that were relevant to them.

> *"I mean, the other part of it is, do you let patients set goals that you know and think that it's realistic and give them, and also trying to help them come around to the idea that perhaps that was an ambitious goal. It's that fine balance isn't it, cause you don't want to be in there whacking it all "oh no that's not going to be realistic" because they need that motivation, they need to work towards something. So, should we be setting, perhaps, more over-ambitious goals then letting them see themselves, when they're not achieving them it's just more of a reality."* (Staff group 1)

However, other staff members expressed some worries about what might happen if a patient came up with all "unrealistic" goals and what consequences it might have in terms of professional responsibilities:

> *"The other thing that was slightly worrying as well is that, we, when it comes to extensions and things, everyone talks about goals being met and that kind of dictates you know, how you move forwards here. So, if we're setting really unrealistic goals, does that mean everyone is gonna be here then for six months with the hope?"* (Staff group 1)

Staff recognised advantages to allowing more space for aspirational goals during goal setting but at the same time they felt that they might be "putting themselves at risk", given that there were no professional recommendations or structures to support this way of setting goals. They felt that one way of managing this was to rely on their clinical expertise to find the "right balance" of allowing patients to state their aspirations but at the same time not give them "false hope":

> *"Also our interpretation of their want is obviously we have the benefit of having the clinical experience, so what might be more realistic than what they would want to do. Let's say, they want to walk, and then they have no movement in their legs, never have movement in their legs for six months or something. And then, it's trying to find find a middle ground, still working towards something like that, trying to work out what's achievable, as well. The time factor they got… it's difficult to try and find that balance in between."* (Staff group 1)

2. Carer themes

Three themes were identified following the analysis of carer focus groups. They related to carers' preparation for goal setting, hope for continuing patients' rehabilitation following discharge and the remits of the role of carers in the goal setting process.

Theme 3.1 Preparation for carers. Overall, carers spoke about feeling unprepared for being with patients in the "real world", outside of the hospital:

> *"Yeah I think I agree with you both as well and I think it's kind of obvious, they are spending their time here preparing for like the real world, we hear what they do but we don't have our 'how do we prepare?'"* (Carer group 1)

Carers felt that education for carers was "paramount" and necessary. They would have appreciated having a booklet or links to websites as they agreed they had to do a lot of research to better understand patients' difficulties.

> *"But it's that, you know, it's the main thing really, a lot of research. It is gonna be difficult, but maybe some education, some bedtime reading or something, or a guide to an e-book from your website to read or something, because I think this kind of education is paramount. I really think it is."* (Carer group 1)

> *"The more education you can give us or the more facts we have, and the opportunity to, short paragraphs, short information, whatever we can read (...)."* (Carer group 1)

Given patients' cognitive and language difficulties carers spoke about their "back up role" in helping their loved ones process information and help in their recovery:

> *"And also sometimes because someone's had a brain injury or they've had a stroke and they're not related to a lot of the information that they give, they're not processing it, it's helpful for us as carers to go in and process that for them to remind them that these are what you've got to do and these are thing things that have been approached and said, so we're sort of their back up, so to say."* (Carer group 2)

"We should be helping them perhaps to meet those additional goals." (Carer group 2)

Carers also spoke about not knowing the remits of their role in a patient's rehabilitation and the extent of their possible involvement.

"I am not very clear on what participation was sort of... permitted or expected from the family, obviously I appreciate that the first choice is the patient, so coming here I didn't really know what to, what kind of role I would play." (Carer group 2)

They mostly reported that they were not fully aware of what rehabilitation goals patients had and having a tool where this information would be kept together would be helpful:

"I've seen some of the goals but it's only, if I've got it from (patient's name), you know, if he's lost his copy then I wouldn't see it." (Carer group 2)

Theme 3.2: Continuing the trajectory of rehabilitation. Carers expressed concern about being able to keep the same "trajectory" of rehabilitation following the patient's discharge. This theme was divided into three subthemes.

Subtheme 3.2.1 Not "defaulting" therapists' work. Carers felt fortunate that they received care in the centre known for its excellence; however that was also associated with a worry of what would happen once the intensive rehabilitation finishes.

"We do have that bit of worry, but for us, I think, it is that kind of...afterwards planning. And I think now we're getting towards the end of it, we just wanna make sure that the trajectory that he's on will continue in terms of physio afterwards." (Carer group 1)

"(...) when it falls onto me to take care of her, its going to be really scary, I want to carry on the same speed as you guys have been carrying on here." (Carer group 1)

On one hand carers felt that good preparation and education would allow them for better care for the patient at home, but at the same time they were aware of staff's expertise and did not want to "interfere" in their work. One carer stated:

"You don't wanna end up defaulting anything that they put." (Carer group 1)

Subtheme 3.2.2 Continuity of goals. Carers also spoke about learning from staff on how to care for their loved ones and how this was associated with them setting small goals or targets for themselves.

"I need to learn from the physio what is the best options that I need to start learning about so I'm a little way ahead on how I need to carry on all the work that's done here and to improve on everything, so I've set myself a target." (Carer group 1)

They thought it would be helpful to have a "template" of patients' needs, particularly due to the fact the injuries affected many aspects of patients' daily lives, such as eating or toileting.

"I mean even something like you know, some kind of template, because I get obviously everyone's going to be different but actually a template to say right, so these are the kind of main tasks that (name) has and a space to write ok, it takes them this long to eat, it takes them this long to go to the bathroom, just so that it helps you to plan your day." (Carer group 1)

They acknowledged that some goals would extend over the period of rehabilitation, some simply because of being more aspirational, overarching goals and some because of not being realistic to be achieved on the ward:

"I think realistically he still wants it as a goal overall but not a goal here because it's unrealistic as a goal here." (Carer group 1)

One suggestion was to set goals on admission and on discharge, which carers felt would be particularly useful to them given that they would be "taking over" the care from the therapists:

"Goal setting on entry and goal setting on exit, this is more when you are now in need, and just make sure getting somebody in a routine (…)if someone is trying to getting back a normal routine and trying to get back to normal, this time will be exercise and all that, it probably needs to be outlined a little bit on the exit side of things." (Carer group 1)

It was important to emphasise that the rehabilitation did not stop in the hospital. Carers highlighted that it was crucial for them to help the patients in continuing their recovery to prevent re-admission to the hospital. They suggested that it was important that the tool helped to bridge the inpatient admission with the care in the community.

"They need to, I guess, know that as part of this pack that it's not going to end here, there is something at the end of it, not just necessarily a goal but it's what's going to happen to them after, the aftercare (…)" (Carer group 1)

Subtheme 3.2.2 "Will we be criticised for putting far-fetched goals?"

Following the presentation of the draft tools carers liked the idea of being more involved in the process of goal exploration with patients, but they also expressed some worry about potentially being criticised by staff for having "unrealistic" expectations:

"Then would we be, sort of, criticised as family members when we put some far-fetched goals and have greater expectations for our husbands or our fathers to want to do something, and they say 'oh your expectations are way out the window and we're not going to get there'. Are we then raising up the patient's hope in doing something by filling in these goal settings for them, do you understand?" (Carer group 2)

Overall, carers agreed that they would not know what goals to set for patients and believed that therapists' expertise was crucial in the process.

"Because obviously our expectations are higher but realistically we're not the experts, we don't know if it's going to take x number of weeks or months for something to happen (…)"(Carer group 2)

They worried that setting unrealistic goals could potentially hinder patients'

progress:

> *"You know, we're here to be focusing on getting them or helping them through this but obviously are we then hindering what they're trying to achieve here by putting these unrealistic goals down. Because we obviously want our fathers, our husbands to be able to walk and get back to where they were before whatever happened…"* (Carer group 2)

However, another carer responded to some of these concerns:

> *"We probably won't get criticised because obviously that's our aspirations for our loved ones, but, you know, it's just, to what extent and how far can we write something down?"* (Carer group 2)

Another carer also felt that some of the solutions to separating aspirations

from rehabilitation targets would be breaking these down into short-term goals:

> *"I guess it's the case of separating out aspirations that are the overall (inaudible) goals before… whether we don't necessarily know if they're possible or not, but that can (inaudible) be broken down into smaller goals."* (Carer group 2)

Summary of the results

The summative translation of theories and qualitative findings into sections

of the tool is summarised in Table 2 below. The tool can be found in Appendix G.

Table 2

Integration of theoretical concepts and qualitative findings in the goal setting tool.

Elements of the tool		Function	Links to theories	Links to qualitative findings
Section 1	"Therapy Team"	Introduction to the structure of the ward - education	n/a	Expressed need for education about goal setting and rehabilitation - staff, patients and carers
Section 2	"Why am I here"	Introduction to the process of goal setting as a collaborative process	Emmons (2003) and Deci and Ryan (2000)– participation in goal setting process	"It's a jigsaw" – collaboration between staff and patients – patients
	"Who am I?"	Expansion of a repertoire of roles, consideration of different aspects of identity	Acceptance of Loss Theory (Wright, 1960;1983) – expansion of roles not limited to those related to disability Self- Discrepancy Theory (Higgins, 1987) – finding similarities in aspects of pre-and post-injury self	"You can't lose half your brain and come out exactly the same"- changes in identity following injury - patients

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	Section	Question	Content	Theory	Themes
		"What's important to me?"	Consideration of relevant aspects of one's life Consideration of past and discrepancies between past and present	Deci and Ryan (2000) – emphasis on intrinsically motivated goals Cognitive Developmental Model of Social Identity Integration (Amiot et al., 2007) – consideration of different aspects of self in the process of identity integration Karniol and Ross (1996) – need to acknowledge the past Acceptance of Loss Theory (Wright, 1960;1983) – consideration of aspects of self pre- and post-injury	Goals should be meaningful and relevant to daily life -patients Consideration of aspirational goals – staff Grieving for lost parts of self-patients
	Section 2 Section 3	"What have I already got going for me?" Assessment timetable	Drawing attention to strengths and support, linking with aspects of identity pre-injury that may help during rehabilitation	Cognitive Developmental Model of Social Identity Integration (Amiot et al., 2007) – consideration of aspects of self that were important pre-injury and post-injury Self-efficacy (Bandura, 1982) – facilitation of mastery experiences	Feeling as if life before never existed – patients Suggestion to note progress during assessment week – staff
	Section 4	"Working towards your goals"	Education about goals, expansion of vocabulary used	n/a	Need for education about goal setting - patients, staff and carers Using different words to describe goals – staff Describing goals in a way that does not seem business like – patient

Section 5	"Types of goals"	Linking identity and life goals, activities of daily living and basic goals	International Classification of Functioning, Disability and Health (ICF; WHO, 2001) – the model linking with components of the ICF	Goals should be meaningful and relevant to daily life – patients and staff
			Deci and Ryan (2000) – goals fostering competence, autonomy and relatedness	Linking rehabilitation to aspirational goals - staff
			Self-regulation, Carver and Scheier (1998) – linking lower-order goals or activities with with higher-order values	
Section 6	"My goals"	Consideration of motivation and challenge	Goal setting theory (Locke & Latham, 2002) – setting challenging specific goals	Goals need to be challenging – patients and staff
		Examples of goals	Self-efficacy (Bandura, 1982) – facilitating mastery by stetting small achievable targets/steps	Some goals need to be achievable as not achieving can be demotivating – patients and staff
		space to write and plan own goals with/without therapy staff or with family member	Health Action Process Approach (Schwarzer, 1992) - identifying barriers and plans to overcome them (coping planning)	Aspirational, overarching goals – staff and patients
	"How will this goal help me?"	Linking with goal relevance, consideration of why this goal is important	Cognitive Developmental Model of Social Identity Integration (Amiot et al., 2007) – allowing space for superordinate categories	
			Self-regulation, Carver and Scheier (1998) – linking lower-order goals or activities with higher-order values	
			Acceptance of Loss Theory (Wright, 1960;1983) – finding meaning in goals	

Section 7	"Goal reviews"	Goals change over time, allowance for goal reconsideration and reflection, feedback from staff	Cognitive Developmental Model of Social Identity Integration (Amiot et al., 2007) – iterative process of revaluation of what is important Self-efficacy (Bandura, 1982) – receiving feedback from staff	Goals are not set in stone - staff Allowing patients to set aspirational goals and then review – staff
Section 8	"My future plan"	Continuity of goals between inpatient stay and community	Cognitive Developmental Model of Social Identity Integration (Amiot et al., 2007) – goals continue over life span, process of rehabilitation takes longer than the time of admission	Goals need to be part of daily life even after rehabilitation - patients Aspirational life goals, not necessarily part of treatment – staff Need to keep the trajectory of rehabilitation– carers
Section 9 Section 10	"My contact list" "Resources"	Information for patients and carers	n/a	Providing carers with reliable resources and facilitating contact with staff - carers

Discussion

Goal setting forms a key feature in the rehabilitation of most forms of brain injury and there is a clear need to establish more theoretically-based patient-centred approaches to facilitate clinical practice. This study developed a patient-centred goal setting tool following a synthesis of theories relevant to neurological rehabilitation, supplemented with the accounts of patients, carers and staff of an inpatient neurological rehabilitation unit.

A range of theoretical approaches was considered in the design and development of the tool. Previous studies that developed theoretically-based goal setting approaches (Scobbie et al., 2011) drew on self-efficacy and Social Cognitive Theory (Bandura, 1978; 2001), Goal Setting Theory (Locke & Latham, 2002) and Health Action Process Approach (Schwarzer, 1992). Ylvisaker et al. (2008) focused on theories of self-regulation (e.g. Carver & Scheier, 1998) and identity change in the development of Metaphoric Identity Mapping approach to goal setting. The current study used a wider range of self-regulation theories (Siegert et al., 2004) and included models of loss and identity reconstruction (Gendreau & de la Sablonnière, 2013). There are many overlaps between theories of self-regulation and models of identity reintegration; however, the latter have not been applied in the previous studies of theoretically-based approaches to goal setting.

This study highlighted the importance of establishing a theoretical basis of goal setting interventions and demonstrated the potential for mapping these onto aspects of interventions. Common themes across theories applied to the tool included an emphasis on the involvement of patients in the goal setting process, setting goals that are personally meaningful and intrinsically motivated, considering multiple

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aspects of an individual's personality with the aim of reducing any discrepancy between pre-injury and post-injury self, linking activities with higher-order goals, and setting small achievable targets to improve patients' self-efficacy and motivation. These concepts have increasingly been recognised as principles of effective goal setting in neurological rehabilitation (Prescott et al., 2015; See Appendix H for full list of principles). However, according to Prescott et al.'s (2015) review, these principles are still not routinely applied in practice. The authors found that only 33% of studies described the breaking down of goals into achievable targets, around 21% established clear links between therapy exercises and goals and only 8% described approaches that allowed patients to monitor their progress towards goals and allowed for flexibility and possible modification of goals. This suggests that there are still gaps between practical steps and theoretical concepts in this area and the tool developed in this study is an attempt at bridging this gap.

Theoretical accounts were complemented by exploring the perspectives, needs and expectations of patients, carers and staff with respect to goal setting. Nine themes were identified through thematic analysis of the data. Themes identified by patients included: "Not knowing what is expected", "You can't lose half your brain and come out exactly the same", "It's a jigsaw" and "Goals should be meaningful and relevant to daily life". Staff themes included: "Patients are not prepared for goal setting" and "Aspirational goals" and carer themes were identified as: "How do we prepare?", "Continuing the trajectory of rehabilitation" and "Will we be criticised for putting far-fetched goals?".

There was a strong sense across the three participant groups that there was a need for education and information provision for patients and families regarding the

concept and process of rehabilitation goal setting. Patient and family education has been recognised as a crucial component of patient-centred approach to goal setting (Leach, et al. 2010; Rosewilliam et al., 2011), despite rarely being incorporated into goal setting in practice (Prescott et al., 2015). Educating patients and families about the process is vital for fostering a bio-psycho-social model of care and patient involvement in the process. However, as the model of medical paternalism has prevailed in medical settings over the years, education on the process may require modelling of adopting a more active stance in the process of one's rehabilitation (McClain, 2005).

Patients agreed that goal setting is a collaborative exercise, as summarised under "It's a jigsaw" theme. Patients expressed different levels of their involvement in the process and most agreed that they relied on staff expertise in understanding the process and guiding rehabilitation. This corresponds to the model proposed by Lloyd et al. (2014) suggesting that patient-centredness of goal setting lies along a continuum from patient-directed to therapist-directed activity. A truly collaborative negotiation should acknowledge patients' needs, even if it means that the person does not wish to be involved in the process. There may also be differences in the expected level of involvement of patients depending on the stage of rehabilitation and type of condition (e.g. sudden-onset or progressive). For instance, Lloyd et al. (2014) reported that patients early in their rehabilitation might express less willingness to take active part in the rehabilitation than patients in the community (Doig, Fleming, Cornwell & Kuipers, 2003). On the other hand, it is possible that rather than a patient's lack of willingness, patient-centredness is limited by institutional and time constraints faced by staff, which has previously been found to

be a barrier to providing patient-centred care (Leach et al., 2010; Van De Weyer,
Ballinger & Playford, 2010).

Another important implication of the findings is lack of agreement and
understanding by both patients and staff about what types of goals are acceptable to
be set during neurological rehabilitation. This has previously been reported in a
conference report by Playford et al. (2009). Clinicians differ in their opinions on
whether goals should be achievable and realistic or ambitious. In the current study,
staff recognised the advantaged of allowing patients to set more "aspirational" (and
potentially unrealistic) goals as increasing motivation and awareness of one's
limitations. The work of Scobbie et al. (2013) resonates with this idea. They found
that although failing to achieve goals may result in frustration, the subsequent re-
adjustment of priorities might play an important self-regulatory function in
increasing awareness of one's limitations. On the other hand, patients in the current
and a previous study (Baird, Tempest & Warland, 2010) agreed that some goals need
to be achievable and staff should ensure that goals are realistic. Clinicians agree that
there is a fine balance between allowing patients to set unachievable goals, which
may potentially give "false hope", and setting goals that are achievable and
motivating (Brown et al., 2014; Lloyd et al., 2014).

Levack et al. (2006) argued, however, that goals could be both motivating
and unrealistic at the same time. In fact, they proposed that setting long-term
ambitious goals could help engage patients in clinically relevant activities. This was
reflected both in the patient and in staff discussions, during which participants
agreed that overarching goals could help patients link therapy activities with the
meaning of their goals. Patients expressed often not knowing how their therapy

activities linked with their exercises, which was also echoed by some staff members. Although staff members expressed that they found setting aspirational goals with patients helpful, they also expressed a worry about how this fits with institutional arrangements, such as length of stay. Difficulty in managing the competing demands of institutional pressures and patients' best interest by staff has previously been reported in the literature (Levack et al., 2006; Levack et al., 2011; Lloyd et al., 2014; Young, Manmathan & Ward, 2008). Levack (2009) argued that the best use of health resources and evidence base should guide clinicians' reasoning when setting goals, which may effectively mean that at times other goals need to be prioritised over patient-centredness for the benefit of the wider service.

Another important theme that emerged from this study related to changes of identity that were described during patient focus groups. This is in keeping with theoretical accounts of identity reconstruction, such as the Cognitive Developmental Model of Social Identity Integration (Amiot et al., 2007). Patients described feelings of separation between "home me" and "hospital me", and they expressed feeling as if their previous life had not happened. This corresponds with the initial stages of identity re-integration: categorisation and compartmentalisation described by Gendreau and de la Sablonnière (2013) and is somewhat in keeping with previous qualitative exploration of a "self-body split" described by stroke patients admitted to hospital (Ellis-Hill, Payne & Ward, 2000). During this stage people may often feel unable to see parts of their pre- and post-injury self as compatible, which in practice, may result in their wanting to be "back to normal", an idea also found in a previous thematic study with stroke patients (Lawler, Dowswell, Hearn, Forster &Young, 1999). In the current studies, clinicians have sometimes recognised this as lack of insight. However, approaching this topic from a theoretical perspective of identity

reconstruction could recognise it as a normal phase of adjustment to disability. Addressing identity from the outset of rehabilitation may help bridge the gap between acute and community services and benefit patients and families over the long term (Coetzer, 2008). Nevertheless, staff need support and training to develop different ways of setting goals, as well as institutional support in measuring outcomes that reflect patient experiences not only on a functional, but also on a psychological, self-regulatory level (Levack et al., 2014).

Lastly, the findings of the current study highlight the importance of involving family members and carers in the process of rehabilitation and goal setting. Carers spoke about being patient's "back up", as well as a link between hospital and community care, a finding echoed in the study of Doig et al. (2003). However, although the family's role in rehabilitation is recognised as important, it is still not fully incorporated into routine practice (Prescott et al., 2015). Carers in the current study expressed worries of being criticised by staff for setting unrealistic goals on behalf of patients. This is in line with the previous qualitative research exploring views of clinicians, who expressed feeling frustrated when carers set unrealistic goals for patients, which often resulted in their avoidance of the family (Levack, Siegert, Dean & McPherson, 2009). Therefore, setting clear expectations of the family involvement in the process of setting goals is crucial for fostering positive relations between patient, staff and family members.

Limitations of the current study

Although the current study incorporated stakeholders' views in the design of the tool, the set of data from carers only represented that of five participants. This was due to difficulties in the recruitment of carers to the study, on account of the

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limited time they spent on the ward, as well as difficulties organising mutually convenient times with the researchers, given their other commitments. Although no formal participation rates were recorded, there were many patients and carers approached at the ward who did not consent to taking part in the study, most often due to not wanting or feeling able to commit to taking part in research whilst they, or their loved ones, were undergoing intense neurological rehabilitation. This poses implications for the representativeness of the sample, as it is likely that only highly motivated individuals agreed to take part. It also meant that patients who agreed to take part were usually more likely to have had socialised with other patients and thus less likely to have had isolated themselves in their rooms. Some patients reflected on this during focus groups, commenting that those taking part were "the motivated ones".

In addition, the patient feedback focus group generated a limited amount of data, as patients did not have many comments to add to the draft tool presented to them. Although this could have reflected their satisfaction with the tool, organising another focus group would have helped to confirm whether this was the case and it would have increased the opportunity to reach data saturation.

In addition, the results could have been affected by producing socially desirable answers (Dawson et al., 1993), as the patients had observed the researchers (AA and FS) conducting the study over an extensive period of time. They made multiple comments on how much work we had put into the project and therefore, may have not wanted to criticise the tool despite us encouraging their feedback. Similarly, although the staff were informed that the external supervisor (Professor Diane Playford) would read anonymised transcripts, given that staff members were

employed at the clinical site and were junior to Professor Playford, the data from staff focus groups may have potentially been subject to a degree of bias.

Lastly, the study aimed to include a diverse range of patients with various neurological conditions, which hopefully allowed for increased flexibility of the tool. Nevertheless, the findings of the study are limited to the inpatient neurological rehabilitation context. The patients who took part in the study were relatively high functioning and although a few patients experienced communication and cognitive difficulties, staff members and carers expressed concerns about whether the tool could be utilised by patients with more serious cognitive, language and insight difficulties. This has previously been reported to be a general difficulty in neurorehabilitation research (Baird, et al., 2010; Lloyd et al., 2014). However, others have reported that patients with insight and cognitive difficulties can successfully engage in patient-centred goal setting (Doig et al., 2003).

Research implications

This study adds to the growing body of literature on existing goal setting tools with strong theoretical underpinnings (Scobbie et al., 2011; Ylvisaker et al., 2008). It used the MRC framework to guide the development of the intervention and employed a user-centred design, which resulted in its patient-centredness. Such an approach has been increasingly used in the development of self-management interventions (Kidd, Lawrence, Booth, Rowat & Russell, 2015; Mawson et al., 2013). However, it is still under-utilised in the development of goal setting interventions.

In accordance with MRC guidelines, this study should be seen as only reflecting the development phase of an intervention. Future research should focus on

testing the feasibility of the tool in neurorehabilitation settings and modelling outcomes relevant to the use of the tool. The theoretical basis of the intervention could be enriched by conducting a more systematic review of the literature and by extracting core constructs relevant across theories, as previously done using a causal modelling approach by Scobbie et al. (2009).

Clinical implications

This study highlighted areas of importance for patients, carers and staff members of neurological rehabilitation unit. Despite previous findings that patients and staff members differ in their views on goal setting (Brown et al., 2014), this study showed that there are also areas of agreement. Both staff and patients want to talk about patients' identity and their aspirational goals, but it appears that neither party has the means to do this in a structured way. Implementing goal setting tools, such as the one outlined in this study could allow for bridging this gap.

In addition, this study reinforces the idea that goal setting is a complex process, which should not be applied in a "cookbook" fashion (Siegert & Taylor, 2004). There is a clear need for developing interventions that will allow for flexibility within goal setting both for patients and staff members, as previously noted by Rosewilliam et al. (2011). This requires raising awareness of the complexity of the process for both staff and patients and changing the focus from pre-defined aspects of goals to setting goals that are meaningful to individual patients. The results of the study also highlight the importance of involving family and carers in the clinical practice of rehabilitation.

Giving staff time and opportunities for training in goal setting, both of which are scarce in the current NHS climate, is vital for practising patient-centred care

(Leach et al., 2010; Prescott et al., 2015). Although increasing patient-centredness of goal setting within neurological rehabilitation may require a philosophical shift (Prescott et al., 2015), forming an evidence base of theoretically-grounded, patient-centred tools is a positive step in this direction.

References

Amiot, C. E., de la Sablonniere, R., Terry, D. J. & Smith, J. R. (2007). Integration of social identities in the self: toward a cognitive-developmental model. *Personality and Social Psychology Review*, 11, 364–88.

Baird, T., Tempest, S., & Warland, A. (2010). Service users' perceptions and experiences of goal setting theory and practice in an inpatient neurorehabilitation unit. *The British Journal of Occupational Therapy*, *73*(8), 373–378.

Bandura, A. (1978). Self-efficacy: Toward a unifying theory of behavioral change. *Advances in Behaviour Research and Therapy*, 1, 139–161.

Bandura, A. (1982). Self-efficacy mechanism in human agency. *American Psychologist, 37*(2), 122–147.

Bandura, A. (2001). Social cognitive theory: An agentic perspective. *Annual Review of Psychology*, 52, 1–26.

Barker, C., Pistrang, N., & Elliott, R. (2002). *Research methods in clinical and counseling psycholog*y. Chichester, England: John Wiley & Sons.

Barnard, R. A, Cruice, M. N., & Playford, E. D. (2010). Strategies used in the pursuit of achievability during goal setting in rehabilitation. *Qualitative Health Research, 20*(2), 239–50.

Biggerstaff, D. L. & Thompson, A. R. (2008). Interpretative Phenomenological Analysis (Ipa): a Qualitative Methodology of Choice in Healthcare Research. *Qualitative Research in Psychology*, *5,* 173–183.

Braun, V. and Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*, (2),77-101.

Brown, M., Levack, W., McPherson, K. M., Dean, S. G., Reed, K., Weatherall, M., & Taylor, W. J. (2014). Survival, momentum, and things that make me "me": patients' perceptions of goal setting after stroke. *Disability and Rehabilitation, 36(12*), 1020–1026.

Cantor, J. B., Ashman, T. A., Schwartz, M. E., Gordon, W. A., Hibbard, M. R., Brown, M., Spielman, L., Charatz, H. H., & Cheng, Z. (2005). The Role of Self-Discrepancy Theory in Understanding Post – Traumatic Brain Injury Affective Disorders. *Journal of Head Trauma Rehabilitation*, 20(6), 527–543.

Carver, C. S., & Scheier, M. F. (1998). O*n the self-regulation of behavior.* Cambridge, U.K.: Cambridge University Press. In Siegert and Levack (2015).

Cloute, K., Mitchell, A., & Yates, P. (2008). Traumatic brain injury and the construction of identity: a discursive approach. *Neuropsychological Rehabilitation, 18(*5-6), 651–70.

Craig, P., Dieppe, P., Macintyre, S., & Michie, S. (2008). *Developing and evaluating complex interventions : new guidance*. Retrieved from http://eprints.ucl.ac.uk/103060/

Coetzer, R. (2008). Holistic neuro-rehabilitation in the community: is identity a key issue? *Neuropsychological Rehabilitation*, *18*(5-6), 766–83.

Corbin, J. & Strauss, A. (2008). *Basics of Qualitative Research Techniques and Procedures for Developing Grounded Theory (3rd ed.).* Thousand Oaks, CA: Sage.

Dawson S., Manderson L., Tallo V. (1993). *A Manual for the Use of Focus Groups.* Boston, MA: International Nutrition Foundation for Developing Countries. Full text available online at: http://libdoc.who.int/publications/1993/0963552228.pdf

Deci, E., & Ryan, R. (2000). The" what" and" why" of goal pursuits: Human needs and the self-determination of behavior. *Psychological Inquiry*, 11(4), 227–268.

Department of Health (November 2010). *Improving care for people with long term conditions: 'at a glance' information sheets for healthcare professionals: Goal setting and action planning, gateway ref: 15438.* England. Retrieved at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/215951/dh_124053.pdf

De Ridder, D. T. D. & de Wit, J. B. F. (2006). Self-regulation in health behavior: Concepts, theories, and central issues. In De Ridder, D. T. D. & de Wit, J. B. F. *Self-Regulation in Health Behavior* (p. 1–24). UK: John Wiley & Sons Ltd.

Doig, E., Fleming, J., Cornwell, P. L., & Kuipers, P. (2003). Approach to Community-Based Occupational Therapy for Adults With Traumatic Brain Injury. *American Journal of Occupational Therapy*, *63*(5), 559–568.

Ellis-Hill, C. S., Payne, S., & Ward, C. (2000). Self-body split: issues of identity in physical recovery following a stroke. *Disability and Rehabilitation*, *22*(16), 725–33.

Emmons, R. A. (2003). Personal goals, life meaning, and virtue: Wellsprings of a

    positive life. In C. L. M. Keyes (Ed.), *Flourishing: The positive person and the*

    good life (pp. 105–128). Washington, DC: American Psychological

    Association. Emmons. (Cited in McPherson, Kayes & Kersten, 2014).

Gauggel, S., & Billino, J. (2002). The effects of goal setting on the arithmetic

    performance of brain-damaged patients. *Archives of Clinical Neuropsychology,*

    17(3), 283–294.

Gendreau, A., & de la Sablonnière, R. (2014). The cognitive process of identity

    reconstruction after the onset of a neurological disability. *Disability and*

    Rehabilitation, 36(19), 1608–1617.

Gracey, F., Palmer, S., Rous, B., Psaila, K., Shaw, K., O'Dell, J., Cope, J., &

    Mohamed, S. (2008). "Feeling part of things": personal construction of self

    after brain injury. *Neuropsychological Rehabilitation, 18(*5-6), 627–50.

Gyurcsik, N. C, Estabrooks P. A. & Frahm- Templar, M. J. (2003). Exercise-related

    goals and self- efficacy as correlates of aquatic exercise in individuals with

    arthritis. *Arthritis & Rheumatism (Arthritis Care & Research),* 49: 306–13.

Hart, T., & Evans, J. (2006). Self-regulation and Goal Theories in Brain Injury

    Rehabilitation. *Journal of Head Trauma Rehabilitation,* 21(2), 142–155.

Higgins, E. T. (1987). Self-discrepancy: A theory relating self and affect.

    Psychological Review, 94, 319–340.

Holliday, R. C., Ballinger, C., & Playford, E. D. (2007a). Goal setting in

    neurological rehabilitation: patients' perspectives. *Disability and*

    Rehabilitation, *29*(5), 389–94.

Jones, F., Mandy, A., & Partridge, C. (2009). Changing self-efficacy in individuals
following a first time stroke: preliminary study of a novel self-management
intervention. *Clinical Rehabilitation, 23*(6), 522–33.

Karniol, R. & Ross, M. (1996). The motivational impact of temporal focus: Thinking
about the future and the past. *Annual Review of Psycholog*y, *44*, 593 – 620.

Keany, K., & Glueckauf, R. (1993). Disability and Value Change: An Overview and
Reanalysis of Acceptance of Loss Theory. *Rehabilitation Psychology, 38*(3),
199–210.

Kidd, L., Lawrence, M., Booth, J., Rowat, A., & Russell, S. (2015). Development
and evaluation of a nurse-led, tailored stroke self-management intervention.
BMC Health Services Research, 1–12.

Kübler-Ross, E. (1969). *On Death and Dying*. New York: Macmillan Publishing
Company.

Lawler, J., Dowswell, G., Hearn, J., Forster, A., & Young, J. (1999). Recovering
from stroke: A qualitative investigation of the role of goal setting in late stroke
recovery. *Journal of Advanced Nursing*, *30*(2), 401–409.

Leach, E., Cornwell, P., Fleming, J., & Haines, T. (2010). Patient centred goal-
setting in a subacute rehabilitation setting. *Disability and Rehabilitation, 32*(2),
159–72.

Levack, W. M. M., Boland, P., Taylor, W. J., Siegert, R. J., Kayes, N. M., Fadyl, J.
K., & McPherson, K. M. (2014). Establishing a person-centred framework of
self-identity after traumatic brain injury: A grounded theory study to inform
measure development. *BMJ Open*, *4*(5), 1–9.

Levack, W. M. M., Dean, S. G., McPherson, K. M. & Siegert, R. J. (2015). Evidence-Based Goal Setting: Cultivating the Science of Rehabilitation. In Levack, M. M. & Siegert, R, *Rehabilitation Goal Setting: Theory, Practice and Evidence* (pp. 21-44). Boca Raton, FL: CRC Press.

Levack, W. M. M., Siegert, R. J., Dean, S. G., & McPherson, K. M. (2009). Goal planning for adults with acquired brain injury: how clinicians talk about involving family. *Brain Injury*, *23*(3), 192–202.

Levack, W. M. M., Dean, S. G., Siegert, R. J., & McPherson, K. M. (2011). Navigating patient- centred goal setting in inpatient stroke rehabilitation: how clinicians control the process to meet perceived professional responsibilities. *Patient Education and Counseling,* 85(2), 206–13.

Levack, W. M. M., Taylor, K., Siegert, R. J., Dean, S. G., McPherson, K. M., & Weatherall, M. (2006). Is goal planning in rehabilitation effective? A systematic review. *Clinical Rehabilitation*, *20*(9).

Lloyd, A., Roberts, A. R., & Freeman, J. A. (2014). "Finding a Balance" in Involving Patients in Goal Setting Early After Stroke: A Physiotherapy Perspective. *Physiotherapy Research International. 19* (3), 147–157.

Leplege, A., Gzil, F., Cammelli, M., Lefeve, C., Pachoud, B., & Ville, I. (2007). Person-centredness: conceptual and historical perspectives. *Disability and Rehabilitation*, 29(20-21), 1555–65.

Locke, E. A., & Latham, G. P. (2002). Building a practically useful theory of goal setting and task motivation: A 35-year odyssey. *American Psychologist*, 57(9), 705–717.

Massey, O. T. (2011). A proposed model for the analysis and interpretation of focus groups in evaluation research. *Evaluation and Program Planning, 34*(1), 21–8.

Mawson, S., Nasr, N., Parker, J., Zheng, H., Davies, R., & Mountain, G. (2013). Developing a personalised self-management system for post stroke rehabilitation; utilising a user-centred design methodology. *Disability and Rehabilitation. Assistive Technology*, *9*(6), 521–528.

McClain, C. (2005). Collaborative rehabilitation goal setting. *Topics in Stroke Rehabilitation, 12*(4), 56–60.

McKenna, S., Jones, F., Glenfield, P., & Lennon, S. (2013). Bridges self-management program for people with stroke in the community: A feasibility randomized controlled trial. *International Journal of Stroke : Official Journal of the International Stroke Society*, (10), 1–8.

McPherson, K. M., Kayes, N. M. & Kersten, P. (2015). MEANING as a Smarter Approach to Goals in Rehabilitation. In Levack, M. M. & Siegert, R*, Rehabilitation Goal Setting: Theory, Practice and Evidence* (pp. 105-119). Boca Raton, FL: CRC Press.

Playford, E. D. (2015). Goal Setting as Shared Decision Making. In Siegert, R. J. & Levack, M. M*, Rehabilitation Goal Setting: Theory, Practice and Evidence* (pp. 89-104). Boca Raton, FL: CRC Press.

Playford, E. D., Siegert, R., Levack, W., & Freeman, J. (2009). Areas of consensus and controversy about goal setting in rehabilitation: a conference report. *Clinical Rehabilitation, 23(*4), 334–44.

Prescott, S., Fleming, J., & Doig, E. (2015). Goal setting approaches and principles used in rehabilitation for people with acquired brain injury: A systematic scoping review. *Brain Injury, 29(13-14), 1515-29.*

Rabiee, F. (2004). Focus-group interview and data analysis. *The Proceedings of the Nutrition Society, 63(*4), 655–660.

Rosewilliam, S., Roskell, C. A., & Pandyan, A. D. (2011). A systematic review and synthesis of the quantitative and qualitative evidence behind patient-centred goal setting in stroke rehabilitation. *Clinical Rehabilitation*, *25*(6), 501–14.

Schwarzer R. (1992). Self-efficacy in the adoption and maintenance of health behaviours: Theoretical approaches and a new model. In Schwarzer R. ed. *Self-efficacy: thought control of action, 1st edition.* Washington DC: Hemisphere Publishing Corp, 217–38. Cited in Scobbie et al. (2011).

Scobbie, L., & Dixon, D. (2015). Theory-Based Approach to Goal Setting. In Siegert, R. J. & Levack, M. M*, Rehabilitation Goal Setting: Theory, Practice and Evidence* (pp. 237-252). Boca Raton, FL: CRC Press.

Scobbie, L., Dixon, D., & Wyke, S. (2011). Goal setting and action planning in the rehabilitation setting: development of a theoretically informed practice framework. *Clinical Rehabilitation*, *25*(5), 468–82.

Scobbie, L., Wyke, S., & Dixon, D. (2009). Identifying and applying psychological theory to setting and achieving rehabilitation goals. *Clinical Rehabilitation, 23*(4), 321–33.

Siddique, F. (2016). *Unpacking the black box of client-centred care in neurological rehabilitation: exploring the process of setting goals and evaluation of a goal*

setting tool. Unpublished clinical psychology doctoral thesis, Department of
Clinical, Educational, and Health Psychology, University College London.

Siegert, R. J. & Levack, M. M. (2015a). *Rehabilitation Goal Setting: Theory,
Practice and Evidence*. Boca Raton, FL: CRC Press

Siegert, R. J. & Levack, M. M. (2015b). Concluding Comments, Current Trends and
Future Directions in Siegert & Levack, *Rehabilitation Goal Setting: Theory,
Practice and Evidence*. Boca Raton, FL: CRC Press.

Siegert, R. J., McPherson, K. M., & Taylor, W. J. (2004). Toward a cognitive-
affective model of goal-setting in rehabilitation: is self-regulation theory a key
step? *Disability and Rehabilitation*, *26*(20), 1175–83.

Siegert, R.J., O'Connell, C., Levack, W. M. M. (2015). Psychology, Goals and
Rehabilitation: Providing a Theoretical Foundation. In Levack, M. M. &
Siegert, R*, Rehabilitation Goal Setting: Theory, Practice and Evidence* (pp.
45-65). Boca Raton, FL: CRC Press.

Siegert, R., & Taylor, W. (2004). Theoretical aspects of goal-setting and motivation
in rehabilitation. *Disability & Rehabilitation*, *26*(1), 1–8.

Stewart, D. W., Shamdasani, P. N., & Rook, D. W. (2006). Analyzing Focus Group
Data. *Social Sciences*, 109–134.

Turner-Stokes, L., Williams, H., Abraham, R., & Duckett, S. (2000). Clinical
standards for inpatient specialist rehabilitation services in the UK. *Clinical
Rehabilitation*, *14*(5), 468–80.

Van De Weyer, R. C., Ballinger, C., & Playford, E. D. (2010). Goal setting in
neurological rehabilitation: staff perspectives. *Disability and Rehabilitation*,
32(17), 1419–27.

Wade, D. T., de Jong, B. A. (2000). Recent advances in rehabilitation. *British Medical Journal, 320(20*), 1385–1388.

World Health Organization. (2001). *International classification of functioning, disability and health.* Geneva, Switzerland: WHO.

Wright, B. A. (1960). *Physical disability: A psychological approach*. New York: Harper & Row.

Wright, B. A. (1983). *Physical disability: A psychosocial approach (2nd edition).* New York: Harper & Row.

Ylvisaker, M., McPherson, K., Kayes, N., & Pellett, E. (2008). Metaphoric identity mapping: facilitating goal setting and engagement in rehabilitation after traumatic brain injury. *Neuropsychological Rehabilitation*, *18*(5-6), 713–41.

Young, C. A, Manmathan, G. P., & Ward, J. C. R. (2008). Perceptions of goal setting in a neurological rehabilitation unit: a qualitative study of patients, carers and staff. *Journal of Rehabilitation Medicine*, *40*(3), 190–4.

Part 3: Critical appraisal

Introduction

This appraisal offers a reflective commentary on the design and the process of conducting the project from a perspective of action research. I comment on my role as a trainee clinical psychologist in conducting research in a medical setting. I also reflect on recruitment and data analysis, as well as comment on challenges and benefits of conducting clinical action research. Finally, I consider the benefits of conducting a research project jointly with another trainee (Fouzia Siddique) and offer suggestions for future research.

Given the fact that the goal setting tool described in the empirical paper was informed by the perspectives of participants, the current project can be considered action research. Action research is commonly used in healthcare settings particularly for the purposes of service improvement and development (Bennett, 1998). One of the defining aspects of action research is the direct involvement of stakeholders into the development of research and interventions. Meyer (2000) describes it as a type of research in which "researchers work explicitly with and for people rather than undertake research on them" (p. 178).

My role in the project

An important aspect of the process of conducting this project was my role as a trainee clinical psychologist. Although the aim of the project was to develop a tool that could be flexibly used by a multidisciplinary team, it is inevitable that it has been informed by my background in clinical psychology. Interpersonal skills, flexibility in responding to new situations, reflexivity and ability to listen to alternative views are thought to be core skills of a successful action researcher

(Hope, 1999). This set of skills, developed and fostered throughout clinical training, has greatly helped me in the research process.

Given the overlaps between the importance of skills in clinical practice and in research, I had to be aware of my role in this project. Being able to work across various professional boundaries is one of important characteristics of a successful clinical action researcher (Meyer, 2000). It would be unethical for us to provide a therapeutic service to patients in the ward, given our roles as researchers (Hart & Crawford-Wright, 1999). However, as discussed by Hart and Crawford-Wright (1999) it may be difficult to disentangle these roles when one holds both roles. At times, it was difficult not to adopt the role of a therapist, particularly when patients discussed their difficulties. Given that we (Fouzia Siddique and I) spent plenty of time in the ward, we established relationships with patients that were not subject to typical therapist-patient boundaries. Although I believe that the skills developed through training helped us in gathering quality, in-depth information, they may have also put us at risk of forming dual-role relationships, which could have been confusing for some patients (Hart & Crawford-Wright, 1999). Being able to observe each other during focus groups allowed us to reflect on our roles and to moderate our questioning style in order for it to fulfil our roles as researchers. Explicit establishment of our role limitations with patients allowed us to create realistic expectations of the scope of our roles.

I believe that approaching this project from a psychological perspective allowed us to disseminate psychological knowledge in a contextualised, systematic way. In addition, our knowledge of psychological theories, as well as our understanding of the impact of neurological disability on adjustment and identity

change, contributed to reinforcing a bio-psycho-social approach to neurological rehabilitation by prioritising psychological aspects of the impact of disability.

Recruitment

Given the fact that Professor Playford was a director of the unit at the time and had previously conducted research with unit staff and patients, we did not expect any difficulties with recruitment. The unit was based in a teaching hospital and we expected patients, carers and staff members to be familiar with research being undertaken in the ward. Unfortunately, my assumptions were challenged. In order to be included in the study, clinicians identified patients who fulfilled the inclusion criteria. Following this, we approached the patient, explained the purpose of the research and gained consent for participation. However, we did not anticipate possible difficulties with patients who may not have had the capacity to consent, or were simply too confused to fully understand what we asked of them. Our clinical psychology skills in assessing understanding and capacity proved particularly useful in this respect. In addition, having long, wordy consent forms was unhelpful and overwhelming to many patients, particularly those who experienced cognitive difficulties in processing information and problems with vision or reading, common following a stroke. This required spending additional time on recruitment, by reading information sheets to patients and explaining the purposes of research in a simple way. This was often challenging as patients had busy schedules during the day and were often too tired to concentrate in the evenings. On reflection, having shorter, more concise information sheets, perhaps complemented by visual information (e.g. pictures) would have been more suitable for his particular patient population.

Another important aspect of recruitment was the timing. We often approached patients during their first week in the ward and found many patients

declining to take part. A common explanation was that they were not interested in taking part, which was problematic for the study as one of the aims of clinical action research is to ensure that the proposed change is meaningful to participants (Meyer, 2000). As we later identified through the thematic analysis, feeling isolated and confused when arriving in a ward was common to most patients. At the time we did not factor that in to our recruitment process and after reflection within the research team we decided to allow patients time to settle before we approached them. Building and forming trust with participants is crucial in clinical action research, particularly when the researcher is external to the organisation (Meyer, 2000). Additional time allowed patients to become familiar with us and to understand our roles on the ward. It also allowed them to form relationships with other patients, making it less threatening for them to take part in a group discussion.

Organising focus groups with carers proved to be even more challenging. Family members often visited patients during the evenings or weekends. Although we were able to conduct focus groups outside of working hours, carers often did not feel they could prioritise taking part in a focus group over the time spent with their loved ones. It was a frustrating process, as we could fully understand their perspective. However, we were also aware that carers' involvement in goal setting and research is under-represented in the literature; therefore, it was important that we could capture them in our study (Levack, Siegert, Dean & McPherson, 2009). Unfortunately, we were unable to achieve the planned number of participants with our carer focus groups. As we mostly relied on contact with carers whilst at the ward, in hindsight, collecting their contact details and reminding them about the group by phoning a day before could have been more productive in recruiting a higher number of carers. Nevertheless, a low number of carers in the study reflects a

concern with carer-involvement in goal setting. Following neurological condition, family members are often the only people providing income and taking an active part in their loved one's rehabilitation can therefore be quite challenging. Future interventions should employ creative ways of involving carers in rehabilitation. Some of the suggestions offered by carers in the study included sharing information via email or organising family meetings outside of working hours, although carers realised that this could be challenging in a National Health Service setting.

Although most staff members in the ward agreed to take part in our study, staff focus groups could only be organised outside of therapy times. This meant that staff members had to sacrifice their lunch breaks or time after work to take part in research. This was, perhaps, the greatest challenge during this project. We expected that staff would be willing to take part, given that the study was conducted in a teaching hospital. However, we did not realise how stressed the team were, working under pressure in an under-staffed unit. Asking them to sacrifice free time, even if only for half an hour, appeared to be too much to ask, particularly given the fact they had already often been leaving work after their contracted times. Due to the limited choice of timing for staff focus groups, this might have undermined the empowering nature of the action research project.

Involving patients in the development of the tool

Involving disempowered groups and shifting the balance of power from a recipient or "subject" to an active contributor is an important aspect of the "empowering" type of action research (Hart & Bond, 1996). This was particularly important in the current study, which argued that a move away from medical paternalism is an important aspect of collaborative goal setting and rehabilitation (McClain, 2005).

Conducting focus groups in an inpatient ward with patients who have marked neurological handicaps was challenging at times. However, we aimed to maximise the opportunities for including patients who had cognitive and communication difficulties, given that their views are often under-represented in research and given that patients with cognitive and language difficulties are more likely to face social isolation (Sherratt, Worrall, Hersh, Howe & Davidson, 2015). Involving them in research could empower them to take part in social activities, as well as model active participation in goal setting, which is often limited for this patient group (Sherratt et al., 2015). Goal setting approaches that are focused on patient-centeredness and identity reconstruction have been shown to be particularly useful for patients with cognitive and communication difficulties (Doig, Fleming, Cornwell & Kuipers, 2003; Ylvisaker & Feeney, 2000), despite common preconceptions that goal setting with this population is particularly challenging, which often results in their exclusion from studies (Baird, et al., 2010; Lloyd et al., 2014). This poses implications for future research and should encourage fellow researchers to maximise opportunities to include patients, who are able to take part in group discussions despite their limitations. This is also in line with reinforcing a patient-centred model of care in accordance with a bio-psycho-social approach to rehabilitation.

Involvement in focus groups also produced additional gains for some patients. A few patients commented on how valuable it was to be able to discuss with other patients ideas and experiences with regards to goal setting. Given limited time for staff to educate patients about goal setting, taking part in focus groups allowed opportunities for normalisation of their feelings and learning about the process from more experienced patients. Hearing patients' comments made me appreciate their role as direct contributors to the study and to the tool in particular,

rather than recipients, or "subjects" of research. This was finalised in including participants' quotes in the final version of the tool. It also highlighted the fact that the findings from focus groups were meaningful to participants, which is particularly important in action research (Meyer, 2000).

Influence of the research on the multidisciplinary team

One of the benefits of conducting action research in a clinical, as opposed to laboratory setting, was the opportunity to observe the influence of the project on the dynamics of the multidisciplinary team. At the beginning of our involvement in the project, we met with mixed reactions from the team. Some team members were happy to take part in a project aimed at development and improvement of the service and some appeared to express concern regarding possible scrutiny of their work. Although Professor Playford introduced us to the team, we were seen as "outsiders" and we had an impression that some staff members found us to be intrusive. On reflection, we were guided by our assumption that the rehabilitation team was fully committed to taking part in the project, which was not grounded in evidence. Informed participation, commitment to change and a clear understanding of the need to change are vital elements of action research (Meyer, 2000). This also reflects a "bottom-up" approach to improving services (Lax & Galvin, 2002). In hindsight, given that the research idea was generated by the unit director (Professor Playford), it is possible that some staff members did not feel empowered as they did not take part in creating the idea for change. For some, this might have felt imposed upon, which could explain some of the initial resistance.

Another aspect of action research is that the need for change is generated and negotiated by participants (Hart & Bond, 1996). The fact that the project was led by the team director, as well as the power difference between staff and the director,

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might have added to the perceived scrutiny and implied that the existing situation at the ward was unsatisfactory. Although many staff members were committed to improving the service, others may have felt unappreciated. This was potentially further exacerbated by the timing of the project. We arrived in the ward during a stressful time for all staff. Many worked overtime and were potentially at risk of "burnout". Interestingly, during staff focus groups I did not find myself adopting the role of a therapist as much as during the patient focus groups. This was potentially caused by me perceiving myself as their colleague, more than as a researcher or therapist. In hindsight, allowing staff to vent their frustrations and possibly exploring their expectations and their understanding of the project, would have been helpful in developing a trusting relationship with them.

Our continued presence on the ward and persistence in keeping close contact with staff allowed us to develop a more positive relationship with them. As the study developed, we felt more included, which positively affected our enthusiasm about the project, as well as the recruitment and staff's commitment to making change. Nevertheless, this was extremely difficult to achieve on a busy inpatient ward, which highlights the challenges of conducting "real life" research in clinical settings within the NHS.

Although making time to attend focus groups was challenging for staff, they commented that the project encouraged them to explicitly address goal setting as an item for the service agenda. This, in turn, provided momentum for continuing these discussions outside of focus groups, during clinical governance and business meetings. We observed that following the training of staff, they started using different vocabulary when discussing goal setting. They spoke about identity, roles of patients and patient-centeredness more often. In addition, they adjusted their key-

worker interview by including questions and wording from the tool. According to Reason (2003), successful action research can lead to changing specific cultures in which the research is conducted. It is therefore possible that some changes resulting from the introduction of the tool were not directly observable by the research methods and that the effects of the tool "infiltrated" other areas of rehabilitation.

Taking part in focus groups provided staff members with a scheduled time to discuss their ideas about the process of goal setting, which they might have otherwise not been able to prioritise for various institutional reasons. It provided an opportunity for them to find out about areas of agreement and disagreement, potentially increasing collaboration and increasing understanding of different perspectives within the team (Bennett, 1998). Future research aimed at enhancing goal setting interventions should be approached from a systems perspective and should explore the effects of interventions not only on patients and outcomes, but also on the impact on the collaboration within multidisciplinary teams, as well as interactions between staff teams, patients and families (Siegert & Levack, 2015).

Analysis of qualitative data

One of the first steps of Thematic Analysis (Braun & Clarke, 2006) is data reduction. Miles and Huberman (1994) describe this step as "a form of analysis that sharpens, sorts, focuses, discards, and organizes data in such a way that 'final' conclusion can be drawn and verified." Following collection of a large amount of data from ten focus groups, I was overwhelmed by the sheer amount of codes and ideas that were identified during the analysis, particularly given the fact that I was a novice qualitative researcher and I had not had prior experience of managing data of this magnitude. Rabiee (2004) normalises the feelings of being overwhelmed with large data sets from focus groups, particularly among novice researchers, and

suggests focusing on the purposes of the study as a helpful strategy in selecting

important parts of data. "Discarding" data posed the greatest challenge for me during

the analysis. Without prior experience of managing large datasets, initially

everything appeared important. Being influenced by previous experience of

conducting quantitative research, which relies on objectivity and transparency of

data, rejecting data made me feel as if I was not providing an honest reflection of my

findings.

I was concerned that my knowledge of the topic, as well as clear aims to

improve goal setting in the ward would influence data analysis. Given the fact that

Professor Playford had conducted research on goal setting, which focused on

questions between achievability vs ambitiousness of goals, as well as patient-

centeredness of goal setting (Playford, Siegert, Levack & Freeman, 2009), I was

inevitably influenced by these ideas during data collection and analysis. Subjectivity

is unavoidable in qualitative research and "bracketing" one's values and

preconceived ideas is one of the ways of managing it (Elliott, Fisher & Rennie,

1999). Explicit discussion of these preconceptions with my research partner, as well

as the research team, allowed for mutual monitoring and trying to set aside these

preconceptions when we approach data collection and data analysis. Nevertheless, as

the project was not 'purely' exploratory and focused on improving existing practice,

it is likely that some of my influences have impacted on the analysis of the data and

partly dictated the choice and interpretation of final themes.

Supervision and consultation with an expert in qualitative research helped me

understand the iterative and complex nature of qualitative data analysis. I was able to

reframe reduction of data from a worry to seeing it as a conscious, systematic aspect

of qualitative analysis. By focusing on steps of indexing and charting suggested by

Rabiee (2004) and using visual methods of data reduction, such as cutting extracts and visually arranging them under codes and themes, as well as cutting and pasting extracts using Microsoft Word table, allowed me to get a better understanding of my reasoning behind theme selection and prioritisation.

Sustainability

As a result of commitment for change by participants, action research lends itself well to the sustainability of health interventions (Lax & Gavlin, 2002). This could be likened to the idea of intrinsic goals discussed in the empirical paper (Deci & Ryan, 2000). In line with this view, patients who pursue goals that are important to them are more likely to adhere to their treatment plans. Similarly, participants involved in action research are more likely to maintain interventions, to which they contributed in developing. Given the external role of the researcher, following the completion of the study, the tool was handed over to the staff team. Although during the duration of the study, there was a core group of permanent staff members, the ward operated on a rotational basis. This meant that there was a high rate of staff turnover. Without the appropriate structures to support the incorporation of the tool in the usual practice of goal setting, it remains questionable whether its sustainability will be maintained over time, despite the direct involvement of participants in its development.

Benefits of a joint project

This study was part of a joint project with another trainee, Fouzia Siddique. It made me appreciate the power of teamwork and reinforced the accuracy of the saying that "two heads are better than one". As the project developed, we both learnt to adapt behaviours and ways of working in order to achieve the common goal that

we both set for ourselves. We faced multiple difficulties from the initiation of the project, through ethics, recruitment and data collection. We spent numerous evenings and weekends working on the development of the tool and I believe we both put all our hearts (and brains) into this project. This made me appreciate how important it is to foster positive relationships when conducting research, as it can otherwise be a frustrating and lonely process.

Joint working also reflects the nature of clinical research, which rarely is undertaken as an independent endeavour. Joint projects provide an opportunity for sharing ideas, for improving reflexivity and introducing differences. We often shared contrasting views, which through discussion and supervision, allowed us to approach the study from various perspectives and potentially reduced bias. Introducing a new intervention in a small, close, busy team would likely be more challenging were I to conduct this research on my own. Sharing the emotional load of conducting research in a clinical setting allowed me to distance myself from the systemic difficulties that we encountered and allowed for a better focus on the aims of study.

Conclusion

This study incorporated views of patients, carers and staff members in the development of a patient-centred goal setting tool with theoretical underpinnings. Despite multiple challenges encountered along the way, it made me appreciate the value of qualitative research methods in clinical health studies. The style of action research empowered participants in being involved in the development of the service, as well as contributed to a wider change of the service culture. Future research could focus on incorporating the views of stakeholders in developing services and interventions in order to maximise opportunities for achieving meaningful change.

References

Alhojailan, M. I., & Ibrahim, M. (2012). Thematic Analysis : A Critical Review of

    Its Process and Evaluation. *WEI International European AcademicConference*

    Proceedings, (2011), 8–21.

Baird, T., Tempest, S., & Warland, A. (2010). Service users' perceptions and

    experiences of goal setting theory and practice in an inpatient

    neurorehabilitation unit. *The British Journal of Occupational Therapy*, *73*(8),

    373–378.

Bennett, B. (1998). Increasing collaboration within a multidisciplinary

    neurorehabilitation team: the early stages of a small action research project.

    Journal of Clinical Nursing, *7*(3), 227–31.

Braun, V. and Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative*

    Research in Psychology, 3, (2),77-101.

Deci, E., & Ryan, R. (2000). The" what" and" why" of goal pursuits: Human needs

    and the self-determination of behavior. *Psychological Inquiry*, 11(4), 227–268.

Doig, E., Fleming, J., Cornwell, P. L., & Kuipers, P. (2003). Approach to

    Community-Based Occupational Therapy for Adults With Traumatic Brain

    Injury. *American Journal of Occupational Therapy*, *63*(5), 559–568.

Elliott, R., Fischer, C. T., & Rennie, D. L. (1999). Evolving guidelines for

    publication of qualitative research studies in psychology and related fields. *The*

    British Journal of Clinical Psychology / the British Psychological Society, *38*

    (Pt 3), 215–29.

Hart, E., & Bond, M. (1996). Making sense of action research through the use of typology. *Journal of Advanced Nursing*, *23*(1), 152–159.

Hart, N., & Crawford-Wright, A. (1999). Research as therapy, therapy as research: ethical dilemmas in new-paradigm research. *British Journal of Guidance & Counselling*, *27*(2), 205–214. doi:10.1080/03069889908256265

Hope, K. (1999). Starting out with action research. *Nurse Researcher*, *6*(2), 16–26.

Lax, W., & Galvin, K. (2002). Reflections on a community action research project: Interprofessional issues and methodological problems. *Journal of Clinical Nursing*, *11*(3), 376–386.

Levack, W. M. M., Siegert, R. J., Dean, S. G., & McPherson, K. M. (2009). Goal planning for adults with acquired brain injury: how clinicians talk about involving family. *Brain Injury*, *23*(3), 192–202.

Lloyd, A., Roberts, A. R., & Freeman, J. A. (2014). "Finding a Balance" in Involving Patients in Goal Setting Early After Stroke: A Physiotherapy Perspective. *Physiotherapy Research International. 19* (3), 147–157.

McClain, C. (2005). Collaborative rehabilitation goal setting. *Topics in Stroke Rehabilitation, 12*(4), 56–60.

Meyer, J. (2000). Using qualitative methods in health related action research. *BMJ*, *320*(January), 178–181.

Miles, M. B., & Huberman, A. M. (1994). *Qualitative data analysis: an expanded sourcebook*. Sage Publications. Cited in Alhojailan, M. I., & Ibrahim, M. (2012). Thematic Analysis : A Critical Review of Its Process and Evaluation. *WEI International European AcademicConference Proceedings*, (2011), 8–21.

Playford, E. D., Siegert, R., Levack, W., & Freeman, J. (2009). Areas of consensus

and controversy about goal setting in rehabilitation: a conference report.

*Clinical Rehabilitation, 23(*4), 334–44.

Rabiee, F. (2004). Focus-group interview and data analysis. *The Proceedings of the*

Nutrition Society, *63*(4), 655–660. doi:10.1079/PNS2004399

Reason, P. (2006). Choice and quality in action research practice. *Journal of*

Management Inquiry, *15*(2), 187–203.

Sherratt, S. Worrall, L., Hersh, D., Howe, T & Davidson, B. (2015). Goals and Goal

Setting for People with Aphasia, Their Family Members and Clinicians. In

Levack, M. M. & Siegert, R*, Rehabilitation Goal Setting: Theory, Practice*

and Evidence (pp. 325-344). Boca Raton, FL: CRC Press.

Siegert, R. & Levack, M. M. (2015) Concluding Comments, Current Trends and

Future Directions. In Levack, M. M. & Siegert, R*, Rehabilitation Goal Setting:*

Theory, Practice and Evidence (pp. 373-379). Boca Raton, FL: CRC Press.

Ylvisaker, M., & Feeney, T. (2000). Reflections on Dobermanns, poodles, and social

rehabilitation for difficult-to-serve individuals with traumatic brain injury.

Aphasiology, *14*(4), 407–431.

Appendix A

The exact search terms for literature review databases

Database	Search terms used
MEDLINE	"self-management" AND "self-efficacy or Self Efficacy/" AND "brain injury or Brain Injuries/" OR "Brain Damage, Chronic/ or brain damage" OR "head injur*" OR "Epilepsy/ or Central Nervous System Diseases/ or neurologic* disorder* or Nervous System Diseases/ or Brain Diseases/" OR "neurologic* condition*" OR "multiple sclerosis or Multiple Sclerosis/" OR "Stroke/ or stroke"
PsychINFO	"self-management exp Self Management/" AND "self-efficacy or exp Self-Efficacy/" AND "exp Brain Damage/ or exp Traumatic Brain Injury/ or brain injury or exp Head Injuries/" OR "exp Nervous System Disorders/ or exp Epilepsy/ or exp Cerebrovascular Accidents/ or neurologic* disorder* OR "neurologic* condition*" OR "multiple sclerosis or exp Multiple Sclerosis/" or "stroke"
CINAHL Plus	"self-management" AND "self-efficacy" AND "brain injur*" OR "brain damage" OR "head injur*" OR "neurologic* disorder*" OR "neurologic* condition*" OR "epilepsy" OR "multiple sclerosis" OR Stroke"
PubMed	"self-management" AND "self-efficacy" AND "stroke" OR "neurologic* condition*" OR "neurologic* disorder*" OR "multiple sclerosis" OR "epilepsy" OR "brain injur*" OR "head injur*"

Appendix B

Outline of each trainee's contribution to the joint study.

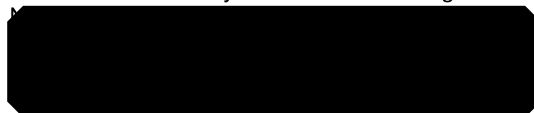| Joint work	My individual work
Recruitment	Synthesis of theories
Co-facilitation of focus groups	Qualitative data analysis
Design of the goal setting tool	Write-up

Appendix C

Ethical Approval

NHS
Health Research Authority

Research Ethics Service

NRES Committee London - Queen Square
HRA NRES Centre Manchester
Barlow House
3rd Floor
4 Minshull Street
Manchester
M1 3DZ

25 June 2015

Dr Diane Playford
Reader and Honorary Consultant Neurologist
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Dear Dr Playford

Study title:	**Goal Setting in Neurological Rehabilitation: Development and Evaluation of a Goal Setting Tool.**
REC reference:	**15/LO/0585**
IRAS project ID:	**172799**

Thank you for your letter of 19 June 2014, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager, ████████████████████████████████ ████████████████████nder very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Confirmation of ethical opinion

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

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

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

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

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

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

Sponsors are not required to notify the Committee of approvals from host organisations

Registration of Clinical Trials

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

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

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

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

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

Ethical review of research sites

NHS sites

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

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [UCL Insurance Certificate]	1	11 March 2015
Interview schedules or topic guides for participants [Interview schedule for focus groups]	2	06 March 2015
IRAS Checklist XML [Checklist_17062015]		17 June 2015
Other [Fouzia_S CV]	1	06 March 2015
Other [Cover Letter and Clarifications]		16 June 2015
Participant consent form [Consent Form Carers Part 1]	3	09 June 2015
Participant consent form [Consent Form Carers 2]	3	09 June 2015
Participant consent form [Consent Form Patients Part 1]	3	09 June 2015
Participant consent form [Consent Form Patients Part 2]	3	09 June 2015
Participant consent form [Consent Form Staff Part 1]	3	09 June 2015
Participant consent form [Consent Form Staff Part 2]	3	09 June 2015
Participant information sheet (PIS) [Information Sheet Carers Part 1]	3	09 June 2015
Participant information sheet (PIS) [Information Sheet Carers Part 2]	3	09 June 2015
Participant information sheet (PIS) [Information Sheet Patients Part 1]	3	09 June 2015
Participant information sheet (PIS) [Information Sheet Patients Part 2]	3	09 June 2015
REC Application Form [REC_Form_13032015]		13 March 2015
Referee's report or other scientific critique report [Reviewer's comments]	1	30 January 2015
Research protocol or project proposal [Research Protocol]	3	09 June 2015
Response to Request for Further Information		
Summary CV for Chief Investigator (CI) [CI CV]	1	06 March 2015
Summary CV for student [Agata_A CV]	1	06 March 2015
Summary CV for supervisor (student research) [Educational Supervisor CV]	1	06 March 2015
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Protocol Flowchart]	2	06 March 2015
Validated questionnaire [Outcome measures]	2	06 March 2015

Statement of compliance

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

After ethical review

Reporting requirements

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

- Notifying substantial amendments

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

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

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Training

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

15/LO/0585	Please quote this number on all correspondence

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

Yours sincerely

███████████████████████

Enclosures: "After ethical review – guidance for researchers" *[SL-AR2]*

Copy to: ███████████████████████

Appendix D

Information sheets and consent forms

Project ID: 15/LO/0585

Information Sheet for Part 1 of the Study – Patients

This study is divided into two parts. This information sheet is about Part 1 of the study.

1. Title

Goal Setting in Neurological Rehabilitation – development of a goal setting tool (Part 1).

2. Invitation

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 and discuss it with others 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.

3. What is the purpose of the study?

This study is part of the Doctorate in Clinical Psychology Research at University College London. It is being conducted to find a way of involving patients in goal setting in partnership with staff. The main aim of this study is to develop a new goal setting pack. We also aim to explore patient-staff interactions when goals are set. The first part of the study will involve development of the goal setting pack and the second part will involve its evaluation.

This is the first part of the study. It has two separate portions that you can participate in. One of them will involve video recording of the goal setting session between the patient and/or carer/relative and staff. The second one will involve participation in focus groups where ideas about goal setting and how it can be improved will be shared among participants.

4. Why have I been chosen?

You have been chosen because you are admitted on the ward and will be or are currently undergoing neurological rehabilitation. We want to know what your ideas about goal setting are and what you would find helpful to be included in our new tool for setting goals.

5. Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be 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. Decisions to withdraw at any time, or a decision not to take part, will not affect your future medical care.

You can choose to take part in the video recording of the goal setting session, or the focus group, or both these tasks, or neither.

As this study also involves carers, you will also be asked if you agree for your carer to be contacted to participate in this study. Your own participation in the study will not be affected if you do not agree to your carer being contacted to participate in the study.

6. What will happen to me if I take part and what do I have to do?

You make take part in both parts of the study if you stay long enough as an inpatient but most people will only participate in one. You will be approached again and asked to consent if you are able to participate in both parts.

This is part 1. It will involve two tasks. You can choose to take part in both of these tasks or only one of them. For the first task, you will be asked to take part in a 'focus group'. This is a group of 5 to 6 people. You will be joined by other inpatients on the ward. Researchers will ask about your understanding of goals, how you think they are set, and what important things you think should be part of your goals. The focus group will last between 1 – 1.5 hours.

If you consent to the second task, we will also video record a goal setting session between you and members of staff, which is part of your usual care. This will only record the goal setting process as it takes place and no one else will be present in the room during the session. Afterwards, you will be asked to fill in a short rating scale, which will ask about your experience of taking part in the session. You will also be asked to complete two short questionnaires.

Focus groups will be audio recorded and typed up for analysis. Transcriptions will be analysed for common ideas. Your name and other information will be removed from it. The results will help in the construction of the goal setting pack. Another focus group will be conducted to review this pack and will help in its final construction. That means that you might take part in two focus groups in total. The videos will be observed to understand what happens during goal setting sessions with the view of improving goal setting practice on the ward.

You can choose to participate in either one, or both, or none of these tasks. If you lose the ability to consent during the study, you will be withdrawn from taking part. No further data will be collected and the data collected with the consent will be used in the study.

All the information will be stored safely in locked cabinets and only the research team will have access to it. All data will be stored securely at the ████ the duration of the study. Dr Diane Playford will be responsible for the safety and security of the data. Research data are retained by UCL in their capacity as sponsor for 20 years after the research study has ended. Data is then securely destroyed.

7. What are the alternatives for treatment

Currently goals are set regularly as part of the rehabilitation process on the ward.

8. What are the possible disadvantages and risks of taking part?

The disadvantages of taking part in this study is that it will require a few hours of your time However, we will ensure that this does not prevent you attending treatment sessions.

9. What are the possible benefits of taking part?

There are no clear benefits to you from taking part in a focus group. The information we get from this study may help us to produce a better goal setting tool for you and introduce training for staff. There is a possibility of benefiting from sharing experiences within a group.

10. What if something goes wrong?

If you wish to complain, or have any concerns about any aspect of the way you have been approached or treated by members of staff you may have experienced due to your participation in the research, National Health Service or UCL complaints mechanisms are available to you. Please ask your research doctor if you would like more information on this.

In the unlikely event that you are harmed by taking part in this study, compensation may be available.

If you suspect that the harm is the result of the Sponsor's (University College London) or the hospital's negligence then you may be able to claim compensation. After discussing with your research doctor, please make the claim in writing to the Dr Diane Playford who is the Chief Investigator for the research and is based at the ████████████████████. The Chief Investigator will then pass the claim to the Sponsor's Insurers, via the Sponsor's office. You may have to bear the costs of the legal action initially, and you should consult a lawyer about this.

11. Will my taking part in this study be kept confidential?

All information which is collected about you during the course of the research will be kept strictly confidential. Any information about you which leaves the hospital will have your name and address removed so that you cannot be recognised from it.

Your Neurology Consultant will be informed that you are taking part in the study, unless you prefer that they are not informed.

12. What will happen to the results of the research study?

The results of the research will be available in the spring 2016. They will be published in a medical journal the following year. They will also be submitted to University College London as a doctoral dissertation. You will not be identified in any report/publication.

13. Who is organising and funding the research?

University College London is funding the research.

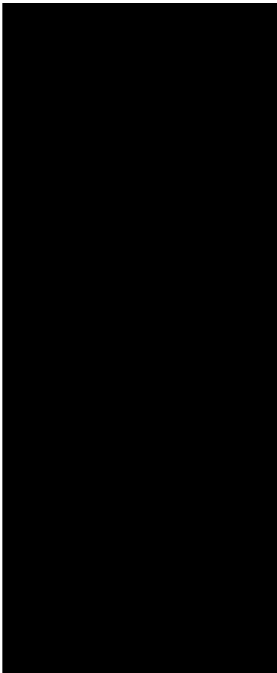**14. Who has reviewed the study?**

The study has been reviewed by the ████████████████████████

15. Contact for Further Information

████████████████████

If you require any further information please contact Dr Diane Playford, ████████████████

If you decide you would like to take part then please read and sign the consent form. You will be given a copy of this information sheet and the consent form to keep. A copy of the consent form will be filed in your patient notes, one will be filed with the study records and one may be sent to the Research Sponsor.

You can have more time to think this over if you are at all unsure.

Thank you for taking the time to read this information sheet and to consider this study.

6. I agree to participate in audio-recorded focus groups and for possible use of verbatim quotations in the research paper. The transcripts of the recordings will be fully anonymized and will not be associated with any patient-identifiable data.
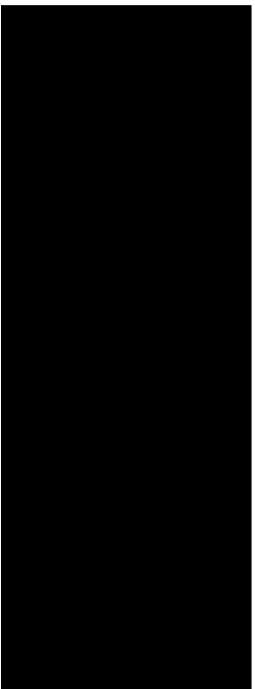
☐

7. I agree to take part in the above study.

☐

Name of Patient /Carer/   Date   Signature
Staff Member

Name of Person   Date   Signature
taking consent

Name of Chief Investigator   Date   Signature
(if different to the person taking consent)

When completed: 1 for participant; 1 (original) for researcher site file; 1 to be kept in medical notes.

Project ID: 15/LO/0585

Participant Identification Number for this trial:

CONSENT FORM – Patients - Part 1

Title of Project: Goal Setting in Neurological Rehabilitation – development of a goal setting tool (Part 1).

Name of Researcher: Agata Aleksandrowicz, Fouzia Siddique, Dr Diane Playford

Please tick all the boxes that apply

1. I confirm that I have read and understand the information sheet dated.................(version..........) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.   ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.   ☐

3. I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from the sponsor of the trial (University College London) and responsible persons authorised by the sponsor, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.   ☐

4. I understand that my participation in both the focus groups and the video taping of goal setting session is optional and participation in one does not affect the other. I can choose to participate in either one, or both, or none of them.   ☐

5. I agree to participate in sessions of goal-setting, which will be video and audio-recorded. The recordings will be kept securely and will be protected by the encryption software.   ☐

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Project ID: 15/LO/0585

Information Sheet for Part 1 of the Study – Carers

This study is divided into two parts. This information sheet is about Part 1 of the study.

1. Title

Goal Setting in Neurological Rehabilitation – development of a goal setting tool (Part 1).

2. Invitation

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 and discuss it with others 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.

3. What is the purpose of the study?

This study is part of the Doctorate in Clinical Psychology Research at University College London. It is being conducted to find a way of involving patients in goal setting in partnership with staff. The main aim of this study is to develop a new goal setting pack. We also aim to explore patient-staff interactions when goals are set. The first part of the study will involve development of the goal setting pack and the second part will involve its evaluation.

This is the first part of the study. It has two separate portions that you can participate in. One of them will involve video recording of the goal setting session between the patient and/or carer/relative and staff. The second one will involve participation in focus groups where ideas about goal setting and how it can be improved will be shared among participants.

4. Why have I been chosen?

You have been chosen because you are a carer/relative of someone who has been admitted on the ward and will be or is currently undergoing neurological rehabilitation. We want to

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know what your ideas about goal setting are and what you would find helpful to be included in our new tool for setting goals.

5. Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be 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. Decisions to withdraw at any time, or a decision not to take part, will not affect the future medical care of your relative who is admitted to the ward. Please note that your relative would have also consented to us contacting you for this study prior to us speaking with you. However, it is up to you to decide whether or not you wish to participate in this study.

You can choose to take part in the video recording of the goal setting session, or the focus group, or both these tasks, or neither.

6. What will happen to me if I take part and what do I have to do?

You make take part in both parts of the study if your relative stays long enough as an inpatient but most people will only participate in one. You will be approached again and asked to consent if you are able to participate in both parts.

This is part 1. It will involve two tasks. You can choose to take part in both of these tasks or only one of them. For the first task, you will be asked to take part in a 'focus group'. This is a group of 5 to 6 people. You will be joined by other carers/relatives. Researchers will ask about your understanding of goals, how you think they are set, and what important things you think should be part of your goals. The focus group will last between 1 – 1.5 hours.

If you consent to the second task, we will also video record a goal setting session between you and members of staff, which is part of your usual care. This will only record the goal setting process as it takes place and no one else will be present in the room during the session. Afterwards, you will be asked to fill in a short rating scale, which will ask about your experience of taking part in the session.

Focus groups will be audio recorded and typed up for analysis. Transcriptions will be analysed for common ideas. Your name and other information will be removed from it. The results will help in the construction of the goal setting pack. Another focus group will be conducted to review this pack and will help in is final construction. That means that you might take part in two focus groups in total. The videos will be observed to understand what happens during goal setting sessions with the view of improving goal setting practice on the ward.

You can choose to participate in either one, or both, or none of these tasks. If you lose the ability to consent during the study, you will be withdrawn from taking part. No further data will be collected and the data collected with the consent will be used in the study.

All the information will be stored safely in locked cabinets and only the research team will have access to it. All data will be stored securely at the ████████ r the duration of the study. Dr Diane Playford will be responsible for the safety and security of the data. Research data

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are retained by UCL in their capacity as sponsor for 20 years after the research study has ended. Data is then securely destroyed.

7. What are the alternatives for treatment

Currently goals are set regularly as part of the rehabilitation process on the ward.

8. What are the possible disadvantages and risks of taking part?

The disadvantages of taking part in this study is that it will require a few hours of your time However, we will ensure that this does not prevent you attending treatment sessions. You will also be asked to talk about the impact of your relative's or your condition on your life and the goals you would like to work towards, which some people can find difficult.

9. What are the possible benefits of taking part?

There are no clear benefits to you from taking part in a focus group. The information we get from this study may help us to produce a better goal setting tool for you and introduce training for staff. There is a possibility of benefiting from sharing experiences within a group.

10. What if something goes wrong?

If you wish to complain, or have any concerns about any aspect of the way you have been approached or treated by members of staff you may have experienced due to your participation in the research, National Health Service or UCL complaints mechanisms are available to you. Please ask your research doctor if you would like more information on this.

In the unlikely event that you are harmed by taking part in this study, compensation may be available.

If you suspect that the harm is the result of the Sponsor's (University College London) or the hospital's negligence then you may be able to claim compensation. After discussing with your research doctor, please make the claim in writing to the Dr Diane Playford who is the Chief Investigator for the research and is based at the ▮▮▮▮▮▮▮▮. The Chief Investigator will then pass the claim to the Sponsor's insurers, via the Sponsor's office. You may have to bear the costs of the legal action initially, and you should consult a lawyer about this.

11. Will my taking part in this study be kept confidential?

All information which is collected about you during the course of the research will be kept strictly confidential. Any information about you which leaves the hospital will have your name and address removed so that you cannot be recognised from it.

12. What will happen to the results of the research study?

The results of the research will be available in the spring 2016. They will be published in a medical journal the following year. They will also be submitted to University College London as a doctoral dissertation. You will not be identified in any report/publication.

13. Who is organising and funding the research?

University College London is funding the research.

14. Who has reviewed the study?

The study has been reviewed by the ▮▮▮▮▮▮▮▮

15. Contact for Further Information

If you require any further information please contact Dr Diane Playford ▮▮▮▮▮▮

▮▮▮▮▮▮▮▮

If you decide you would like to take part then please read and sign the consent form. You will be given a copy of this information sheet and the consent form to keep. A copy of the consent form will be filed in your patient notes, one will be filed with the study records and one may be sent to the Research Sponsor.

You can have more time to think this over if you are at all unsure.

Thank you for taking the time to read this information sheet and to consider this study.

Project ID: 15/LO/0585

Participant Identification Number for this trial:

CONSENT FORM – Carers - Part 1

Title of Project: Goal Setting in Neurological Rehabilitation – development of a goal setting tool (Part 1).

Name of Researcher: Agata Aleksandrowicz, Fouzia Siddique, Dr Diane Playford

Please tick all the boxes that apply

1. I confirm that I have read and understand the information sheet dated................(version............) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐

3. I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from the sponsor of the trial (University College London) and responsible persons authorised by the sponsor, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐

4. I understand that my participation in both the focus groups and the video taping of goal setting session is optional and participation in one does not affect the other. I can choose to participate in either one, or both, or none of them. ☐

5. I agree to participate in sessions of goal-setting, which will be video and audio-recorded. The recordings will be kept securely and will be protected by the encryption software. ☐

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6. I agree to participate in audio-recorded focus groups and for possible use of verbatim quotations in the research paper. The transcripts of the recordings will be fully anonymized and will not be associated with any patient-identifiable data. ☐

7. I agree to take part in the above study. ☐

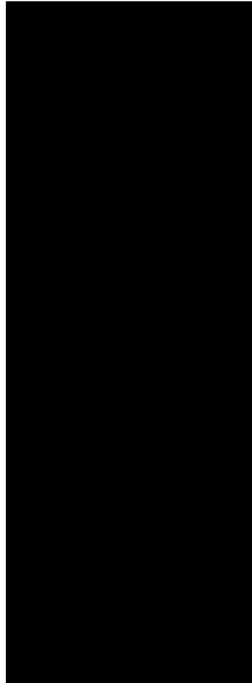| Name of Patient /Carer/ Staff Member | Date | Signature |

| Name of Person taking consent | Date | Signature |

| Name of Chief Investigator *(if different to the person taking consent)* | Date | Signature |

When completed: 1 for participant; 1 (original) for researcher site file; 1 to be kept in medical notes.

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Project ID: 15/LO/0585

Information Sheet for Part 1 of the Study – Staff

This study is divided into two parts. This information sheet is about Part 1 of the study.

1. Title

Goal Setting in Neurological Rehabilitation – development of a goal setting tool (Part 1).

2. Invitation

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 and discuss it with others 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.

3. What is the purpose of the study?

This study is part of the Doctorate in Clinical Psychology Research at University College London. It is being conducted to find a way of involving patients in goal setting in partnership with staff. The main aim of this study is to develop a new goal setting pack. We also aim to explore patient-staff interactions when goals are set. The first part of the study will involve development of the goal setting pack and the second part will involve its evaluation.

This is the first part of the study. It has two separate portions that you can participate in. One of them will involve video recording of the goal setting session between the patient and/or carer/relative and staff. The second one will involve participation in focus groups where ideas about goal setting and how it can be improved will be shared among participants.

4. Why have I been chosen?

You have been chosen because you are a member of staff involved actively in patient care and setting goals on the in-patient ward at

We want to know what your ideas about goal setting are and what you would find helpful to be included in the new tool for setting goals.

5. Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be 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. Decisions to withdraw at any time, or a decision not to take part, will not affect your work.

You can choose to take part in the video recording of the goal setting session, or the focus group, or both these tasks, or neither.

6. What will happen to me if I take part and what do I have to do?

As a member of staff you make take part in both parts of the study. You will be approached again and asked to consent if you are able to participate in both parts.
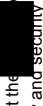
This is Part 1. It will involve two tasks. You can choose to take part in both of these tasks or only one of them. For the first task, you will be asked to take part in a 'focus group'. This is a group of 5 to 6 people and you will be joined by other members of staff from the ward. Researchers will ask about your understanding of goals, what you think they involve and how you think they are set. The discussion will focus on your involvement and experience of setting goals for your patients on the ward and what things you think are important and should be addressed when setting goals. The focus group will last between 1 – 1.5 hours.

If you consent to the second task, we will ask you to video record a goal setting session between you and patient and/or carer/relative. This will only record the goal setting process as it takes place and no one else will be present in the room during the session. You will also be asked to provide your patient or carer/relative with a short rating scale following the session and complete one yourself.

Focus groups will be audio recorded and typed up for analysis. Transcriptions will be analysed for common ideas. Your name and other information will be removed from it. The results will help in the construction of the goal setting pack. Another focus group will be conducted to review this pack and will help in is final construction. That means that you might take part in two focus groups in total. The videos will be observed to understand what happens during goal setting sessions with the view of improving goal setting practice on the ward.

You can choose to participate in either one, or both, or none of these tasks. If you lose the ability to consent during the study, you will be withdrawn from taking part. No further data will be collected and the data collected with the consent will be used in the study.

All the information will be stored safely in locked cabinets and only the research team will have access to it. All data will be stored securely at the ███████ r the duration of the study. Dr Diane Playford will be responsible for the safety and security of the data. Research data are retained by UCL in their capacity as sponsor for 20 years after the research study has ended. Data is then securely destroyed.

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7. What are the possible disadvantages and risks of taking part?

The disadvantages of taking part in this study is that taking part in a focus group will require a few hours of your time. However, we will try to ensure that this does interfere with your clinical duties.

8. What are the possible benefits of taking part?

There are no clear benefits to you from taking part in a focus group. The information we get from this study may help us to produce a better goal setting tool for patients and introduce training for staff. There is a possibility of benefiting from sharing experiences within a group.

9. Will my taking part in this study be kept confidential?

All information which is collected about you during the course of the research will be kept strictly confidential. Any information about you which leaves the hospital will have your name and address removed so that you cannot be recognised from it.

10. What will happen to the results of the research study?

The results of the research will be available in the spring 2016. They will be published in a medical journal the following year. They will also be submitted to University College London as a doctoral dissertation. You will not be identified in any report/publication.

11. What if something goes wrong?

If you wish to complain, or have any concerns about any aspect of the way you have been approached or treated by members of staff you may have experienced due to your participation in the research, National Health Service or UCL complaints mechanisms are available to you. Please ask your research doctor if you would like more information on this.

In the unlikely event that you are harmed by taking part in this study, compensation may be available.

If you suspect that the harm is the result of the Sponsor's (University College London) or the hospital's negligence then you may be able to claim compensation. After discussing with your research doctor, please make the claim in writing to the Dr Diane Playford who is the Chief Investigator for the research and ▓▓▓▓▓. The Chief Investigator will then pass the claim to the Sponsor's insurers, via the Sponsor's office. You may have to bear the costs of the legal action initially, and you should consult a lawyer about this.

12. Who is organising and funding the research?

University College London is funding the research.

13. Who has reviewed the study?

The study has been reviewed by the ▓▓▓▓

14. Contact for Further Information

If you require any further information please contact Dr Diane Playford ▓▓▓▓

If you decide you would like to take part then please read and sign the consent form. You will be given a copy of this information sheet and the consent form to keep.

You can have more time to think this over if you are at all unsure.

Thank you for taking the time to read this information sheet and to consider this study.

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Project ID: 15/LO/0585

Participant Identification Number for this trial:

CONSENT FORM – Staff - Part 1

Title of Project: Goal Setting in Neurological Rehabilitation – development of a goal setting tool (Part 1).

Name of Researcher: Agata Aleksandrowicz, Fouzia Siddique, Dr Diane Playford

Please tick all the boxes that apply

1. I confirm that I have read and understand the information sheet dated.................... (version............) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐

3. I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from the sponsor of the trial (University College London) and responsible persons authorised by the sponsor, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐

4. I understand that my participation in both the focus groups and the video taping of goal setting session is optional and participation in one does not affect the other. I can choose to participate in either one, or both, or none of them. ☐

5. I agree to participate in sessions of goal-setting, which will be video and audio-recorded. The recordings will be kept securely and will be protected by the encryption software. ☐

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6. I agree to participate in audio-recorded focus groups and for possible use of verbatim quotations in the research paper. The transcripts of the recordings will be fully anonymized and will not be associated with any patient-identifiable data. ☐

7. I agree to take part in the above study. ☐

_____   _____   _____
Name of Patient /Carer/   Date   Signature
Staff Member

_____   _____   _____
Name of Person   Date   Signature
taking consent

_____   _____   _____
Name of Chief Investigator   Date   Signature
(If different to the person taking consent)

When completed: 1 for participant; 1 (original) for researcher site file; 1 to be kept in medical notes.

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Appendix E

Interview schedules for focus groups

1. Initial set of focus groups

- **PATIENTS**

  o What are your views on the current ways of goal setting at the unit?
    - Is goal setting important? Why? What's its function?
    - What happens in goal setting sessions?
    - What types of goals are important to be set?
      - (Life goals vs. rehab goals?)
      - (Are you provided with a written version?)
  o Do you feel actively involved in the goal setting process?
    - What is your role in the session?
    - What is the role of the staff?
    - Would you like to be more/less involved?
    - Do staff ever speak about you without involving you in the discussion? How do you feel about that?
  o How could current ways of goal setting be improved?
    - What would you like to talk about in goal setting sessions?
    - Details:
      - (Getting into nitty-gritty or broader goals?)
      - (Staff jumping too quickly to say that the goal is not possible?)
    - Would it be helpful to have a tool?

- **STAFF**

  o What are your views on the current ways of goal setting at the unit?
    - Is goal setting important? Why? What's its function?
    - What happens in goal setting sessions?
    - Are patients provided with a written version?
  o Do you feel patients are actively involved in the goal setting process?
    - What is your role in the session?
    - What is the role of the patient?

- ▪ Would you like patients to be more/less involved?
  - How would it affect your work?
- o What would you like to be talked about in goal setting sessions?
  - ▪ What types of goals?
    - Life goals vs. rehab goals?
  - ▪ How important is it for goals to be realistic and achievable?
    - Getting into nitty-gritty or broader goals?
- o How could current ways of goal setting be improved?
  - ▪ What kind of support would you like to receive in the introduction of the new pack?

- **CARERS**
  - o What are your views on the current ways of goal setting at the unit?
    - ▪ Is goal setting important? Why? What's its function?
    - ▪ What happens in goal setting sessions?
  - o Do you feel actively involved in the goal setting process?
    - ▪ What is your role in the session?
    - ▪ What is the role of the staff?
    - ▪ Would you like to be more/less involved?
  - o How could current ways of goal setting be improved?
    - ▪ What do you think should be talked about in goal setting sessions?
      - What types of goals?
      - Life goals vs. rehab goals?
    - ▪ Would it be helpful to have a tool?

2. **Review and feedback focus groups (same for all participants):**
   - o What do you think of the new goal setting tool?
   - o How do you think the new tool can improve goal setting?
   - o Do you think it is understandable and easy to use? If not, how can it be improved?
   - o What are your expectations of implementing/using the new goal setting tool?
   - o What might be the barriers to its successful implementation? Have you got any ideas on how they could be overcome?

Examples of the stages of the analysis process

1. An extract of a coded transcript

Facilitator 1: And what about the meeting where you come into the session?

Patient 1: Well they do have a day when you meet your key workers

Facilitator 2: Oh okay, so were the goals sort of given to you or was there a session where you…

Patient 1: No, you have a chat…

Chat with the team

Facilitator 2: … you have a chat, yeah….

Patient 1: I had a chat with the occupational therapist and she prints out what we've discussed, and that's in my file. Then the next week, you try and achieve those goals. Short term and long term. It's a challenge, it's a challenge innit?

Printed goals

Short tetm and long-term goals

Patient 3: Definitely.

Patient 1: If you don't challenge yourself, no one else is going to do it.

You need to challenge yourself

Patient 3: In our position, when we first, I wasn't… the first meeting of goal setting, you want somebody to tell you, in a professional manner, what to do. You just can't think of your own goals. And once they have, then you can agree. We do have a meeting with the patient and the key worker and then you can put your views across, and they ask you as well, what would you like to…. become of this rehab, what would you like to do. And people say, maybe perhaps, go out.

Needing guidance in goal setting – wanting professional's help initially

Goals-what you like to do

Facilitator 2: That's a very useful thing you're saying (name). That when you come in it's very difficult to know what your goals are. What makes it difficult? What's difficult? And I guess (name) might be in this situation now, cause you haven't had your goals set.

Patient 2: Yeah, I feel all a bit…I need someone to tell me, what's going to happen, so I know what I'm doing.

Need someone to tell you what's going

Patient 3: Yeah you want somebody to give you a hand and …

Patient 2: Guidance.

Patient 3: guidance, yeah.

Facilitator 2: So that kind of guidance, that kind of information from others is helpful.And how does it help you set your own goals, what does it, what is it about that…

Patient 3: … Well you would come up with ideas what you would need. The goal setting is similar to what would you want to do in every day to day life. And we would only go for tasks that we would do when we're at a hospital, and that's for instance, it could be going out shopping independently that we might find struggling or we don't have a clue what to do, you know, we feel we've lost the confidence now. Things like that, so it's not really difficult, but you would have different things, goals that you want to do.

Facilitator 2: So are staff members helpful in sort of pinning down those goals that maybe you want to go shopping, you want to be doing those things, but actually breaking these down into little steps, what can you do here on the ward to get to this higher goal.

Patient 1: they're very clever, the way they do it, it is very clever.

Patient 3: You're just talking, from a discussion you'll come up with a goal. So I mean, they'll ask you, what would you like to do, or what do you like to do in your spare time and you think 'oh I like going shopping'. Normally I'd go out shopping but it's made it difficult for me as the way I am to do things, and they'd point out what would you normally do on a daily basis, and that's where you get your answer and question, by talking. It doesn't have to be shopping, it could be something that you do indoors.

Facilitator 2: But that's still is…meaningful for you.

Patient 3: Yeah, tasks that you normally do. Like making a cup of tea or get your own dinner.

Patient 1: Yeah, that's right, that is it.

Facilitator 2: Yeah and you see it's very clever how they do it. So what do you think they're doing?

Patient 1: The whole thing is like a jigsaw. You do a little bit of physio, a little bit with the occupational therapy, and psychologist you sit and talk to for 30 minutes and they are then meeting and

to happen-guidance

Patients come up with their ideas

Goal setting=same as every day life

Only chose goals to do at the hospital

Lost confidence

Clever process

Talking and discussion

What you do every day

Tasks you normally do every day

Goal setting – like a jigsaw

Staff know patients

they get to know the people inside out, they get to know the patients. There's aggressive patients, there's depressed patients, people that don't want to get out of bed and people… right, you can tell the focused people who want to get better, because they're sitting in here, right? And that's you, you and me. That's the people that… we're focused to do anything they say. Other people….

Focused patients in focus group

2. Extract from the table of codes and themes for staff focus groups during the analysis

Aspirational goals	Linking exercises with goals	Focus Group 1: • So it will be quite nice to then, to be able to like what I did in today's session, and how that helps me to work towards my goals. Because a lot of the times it's really abstract, isn't it? Certainly in physio, you might be doing something like really minute and abstract on their shoulder or something. And they're like "oh how is this actually fitting in with being able to, I don't know, my work as a cashier" or something But then, the more they are on board with those every little bits, if they got something like that to refer to, you know, to again..that'd be quite good. Yeah. Focus group 2: • I think it'd be good for you to go goal meeting because you don't know what we are working towards (inaudible) in the sessions. (rehab assistants) (…) Cause you know, like I'm doing a 1:1 session with them, as well as doubles, it would be useful to know what we actually are…why we were doing what we were doing, and what we were aiming to achieve, but cause I don't go to those meetings… • I think sometimes patients, don't really…this is what my experience –not going to the goal meetings-but…some patients when I'm them, they will be like, "what is the relevance to me doing this?". "I want to be able to walk so why am I on a slideboard?" or why am I learning this trasfer, because all I wanna do is be on my feet. So I don't know, maybe sometimes, they need to be, discussed with them more. That's not like, that's not a long term goal, but it is part of the goal towards getting where they want to get eventually. And I think sometimes there's a lack of understanding about that. They think it's pointless to like learn how to slide across onto a commode, when all they want to be able to do is stand, turn around and sit down there, so... Feedback focus group:

- Member 6: One of the problems…ummm…with the engagement and goals from an OT point of view is, they hope, they think "oh when I'm walking I will be able to do that". They don't get the concept that if we're working on it to strengthen and help with their coordination that is an exercise in itself.
- Member 2: So the model (inaudible) the kind of identifying life goals, ADL goals and essential basic goals, that sort of fits in with kind of what the literature is saying but we don't formally present it like that at the moment do we, but that could be certainly something we could try maybe isn't it? Umm, like the goal setting thing that was done last year, talked about having sort of aspirational life goals, which I think sometimes we forget a little bit about, and…
- Member 5: We don't tend to, I mean, I guess the long-term goals someone has, stuff that might be working towards maybe, it's not usually documented that kind of clearly
- Member 2: … [when speaking about ICF and impairments] and we never link goals to that, but actually that's where those identity and life goals would most often fit. So if there's an issue around, kind of, more than just a participation restriction, bit more of a environmental, or you know, something cultural…
- Member 2: No, it's not that we don't do it, it's just that we maybe don't consistently do it. It's easier to write a wash dress or work or a communication goal than…
- Member 2: It's harder to link it to an impairment…
- Member 5: Yeah it's the structure, I think with the database that we use, it's quite structured that you, I don't know whether…where it would kind of fit…
- Member 2: If you think about it from an ICF point of view though, umm, what we… again, we fill like lots of impairments, activity, limitations, participation restrictions, and then we sort of kind of, chuck a few bits of environment as a bit "(inaudible) 40, lives in a flat, worked as a cleaner…" Member 2: … and we never link goals to that, but actually that's where those identity and life goals would most often fit. So if there's an issue around, kind of, more than just a participation restriction, bit more of a environmental, or you know, something cultural…
- I think one of the good things about it, is that actually, it takes, it feels to me it takes the pressure of us, from saying to patients at the

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		beginning you can't possibly have that in your long term goal cause you're not going to achieve it. Whereas actually if they're owning it, and we're reviewing it, regularly... I don't, I think that's less of a issue for putting in unrealistic thing in a long term goal. • Yeah, whereas at the moment, we're kind of making that decision on their behalf.
Education about goal setting	Patients don't have enough information More preparation (Tool/pack) would be useful	Focus group 1: • I think... perhaps the patients don't have.. erm.. enough information on it. Maybe it needs to be a little bit more prep work rather than just going "right we are going to the goal set" • Which is maybe a pack would be useful and I know that it has been trialled? But perhaps , sometimes I wonder whether it becomes a surprise to the patients around goal setting. It's explained within the goal set, but do we need to do more preparation without sort of they arrive with more ideas and goals and aims as well. • I feel similar. I think they are unprepared when they come in here. So don't know what to expect. • and what's expected of them as well, I think, that's sometimes is not clear to them. • I think sometimes the patients, if you start talking to them about goal setting even prior to the actual goal setting meeting. They never really come across it before and when you start talking about it they're like "oh won't you tell me, you're the therapist", you know, again, again not all of them, but they are not exactly sure what it's all about. And I said to the patients, how about you think about what you want to get out from this admission and try to get the ball rolling Focus group 2 • They should probably have more written information.. around goals and the purpose of it. Feedback focus group: • Cause I think everyone who comes in here has got an idea of what they want to work on, before they arrive. However unrealistic or realistic that may be, but I think they do.
Collaboration	Engagement Complex patients Patients need help of staff	Focus group 1: I suppose it's like when you get to know them, then you realise, oh my goodness, there is this issue, this is why they are not coming to the session. Or all of these other kind of issues which impact on their engagement.. Cause when we are setting these goals, by thinking that, if everything goes smoothly, this is where they should be • So I think part of the problem would be with more cognitive patients is that if they have an awareness of their cognitive problems. So setting goals around that is quite challenging isn't it?

	Letting patients find out their limits-awareness	You need that time to kind of develop more insight into their problems before they can be a bit more on board with goals in that area which is why mobility is such a[inaudible].
		• so that the patient feels like they're involved, but it's also because their problems are so complex, it helps us to break down to exactly what we were working on as well.
		• the best goals that you get for the set is like when the patient is really insightful to your own problems but also realistic
		• I think there are just some patients who just can't seem to do without quite a lot of support. Where we got other patients that are completely able to do X,Y,Z. But it's the ones struggle with it, and I don't know, don't know whether….
		• the most common goal our client, patient say is that they want to walk(…)they might not have insight into that they may have some memory difficulties or difficulties in concentration or all of thiese kind of planning issues, and.. so it's kind of trying then to bring in awareness to that by just even and so, it's not always generated from them, I find, especially some of the cognition goals particularly.
		• And also our interpretation of their want is obviously we have the benefit of having the clinical experience so what might be more realistic than what they would want to do. Let's say they want to walk, and then they have no movement in their legs, never have movement in their legs for six months or something. And then it's trying to find find a middle ground, still working towards something like that, trying to work out what's achievable as well. The time factor they got, it's difficult to try and find that balance in between.
		• I mean, the other part of it is, do you let patients set goals that you know and think that it's realistic and give them, and also trying to help them come around to the idea that perhaps that was an ambitious goal. It's that fine balance isn't it, cause you don't want to be in there whacking it all"oh no that's not going to be realistic" because they need that motivation, they need to work towards something. So should we be setting perhaps more over ambitious goals than letting them see themselves, when they're not achieving them it's just more of a reality.
		Focus group 2:
		• And I think it could be a little more flexible based on our clinical reasoning when they are a bit more complex, or say, motivational or inside issues which could take months to come. But

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		then we got to go down a slightly different route then so that they really engage.
		• erm but I think having a time frame is helpful. Erm but then whether we could engage them a little bit more in the process…
		• And I think it could be a little more flexible based on our clinical reasoning when they are a bit more complex, or say, motivational or inside issues which could take months to come. But then we got to go down a slightly different route then so that they really engage.
		• Yeah, it's probably a big factor. I think sometimes as well, you know, over time if people, even if, say they put down a long term goal that might be, something that you think is going to be really, really hard to achieve or it might not be possible, then over the time, if their relatively short term goals which are like, you know, the smaller steps. Then sometimes, you might, they might, then say, further down the line "oh I can't believe I thought that I would be able to do that when I, you know, actually if I know that that's, you know, I might not be able to get to that. So they, inside, I think, there's a battle sometimes (inaudible).
		• We often have ideas in mind of what we might be thinking broadly. And then. I think when they it's really to get to get them involved to know what their expectations are and for them to kind of have it in their words as well cause they got, you know ideas and things. So I think, even if you got like a few things jott down the long term goal you can't just.. you know.. you can then adjust it to what they're saying. But it does take time.
		• A lot of patients don't know what they want to work on next. They need ideas.
		• With the more cognitive ones we do need to give them a lot of ideas of what they can be doing. And that's kind of getting their agreement that they have to work on it.
		Feedback focus group:
		• The tricky thing always is that, you know, like anything in life…some of this will engage with some people and some people, it doesn't really matter what you do or how you do it, you know probably, so ummm…
		• Member 2: The thing is, if we make it too much about clinical flexibility, then it could run the risk of it not being used, because if we don't make it part of our standardised practice. A little bit like, I think, we need to either properly buy into categories of goals or not, maybe spend a bit more time as a team talking about how we're going to do it cause that is a bit of a change.

	Motivation	Focus group 1
		• So I think, my experience, again, they know that whilst they are here, they need to do something to improve their mobility and they will focus on it. And then if they think they are not achieving that, they are not going to be happy, they are going to be angry, they are not satisfied. If they are doing well, actually they are going to carry on with their goals.
		• It can be quite demotivating isn't it as well? When you don't reach the goal.
		Focus group 2:
		• And finding out what they really.. what has been motivating them. If there…there's really something they like to get back to. We can talk perhaps about how we could break it down and work towards and then sometimes that helps them to see perhaps what is realistic, maybe within a time frame.
		• I think it depends, I think it depends on the patient as well. What their expectations are.. Some people, we probably do things, erm, very much in the same way, you know, we do modify it for different people but I don't know if we do that enough. You know, the way we do accommodate perhaps different, not just around communication, but around maybe there around how much motivated their perhaps other limitations are

Appendix G

Main pages of the goal setting tool (some of the spare goal and goal review

pages were removed)

Appendix H

The list of goal setting principles developed by Prescott et al. (2015).