

**Unpacking the ‘Black Box’ of Patient-Centred Care in  
Neurological Rehabilitation: Exploring the Process of  
Setting Goals.**

*Fouzia Siddique*

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**UCL Doctorate in Clinical Psychology**

**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: Fouzia Siddique

Date: 31/08/2016

## Overview

This thesis is divided into three parts and focuses on exploring the processes involved in setting goals in neurological rehabilitation.

*Part one* of the thesis is a review of literature on the process of identity reconstruction following brain injury. Theoretical papers and qualitative studies were evaluated on the models of identity reconstruction discussed in them. The theoretical papers discussed three models in explaining identity reconstruction – a narrative approach, possible selves, and use of metaphors in acceptance and commitment therapy (ACT). The qualitative papers discussed four main areas that inform identity reconstruction – cognitive representations, body image, social constructionism and narratives, and social and occupational identities.

*Part two* of the thesis is an empirical paper that explored the process of goal setting at an inpatient ward. It includes the analysis and discussion of three main components, 1) video recordings of clinician-patient interactions with the use of a behaviour checklist developed for this purpose, 2) subjective experiences of staff, patients and carers in setting goals using rating scales, and 3) staff, patient and carer perspectives on encouraging and facilitating goal setting behaviour through the use of a newly designed goal setting tool. The research was conducted as a joint project with another Trainee Clinical Psychologist, Agata Aleksandrowicz.

*Part three* provides a critical reflection on the process of conducting this study. It discusses the conceptualisation of the project and the challenges and dilemmas in delivering patient centred care are also considered. The appraisal concludes with a reflection on the experience of conducting a joint research.

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**PART 1: LITERATURE REVIEW**

**The Processes in Identity Reconstruction Following Brain Injury.**

## **Abstract**

**Aims:** This review was carried out to identify key components in processes of identity reconstruction following a brain injury. The review sought to evaluate studies and any theoretical papers that explored this process and were identified following a systemic search of literature.

**Methods:** A systematic search identified 1163 studies. Sixty one full text articles were obtained, 15 of which were included in the final review. Studies on stroke and other reviews were not included in this review. Quantitative papers, mixed method studies, and other papers that did not include a substantial discussion of the process of identity reconstruction following a brain injury were also excluded from the review.

**Results:** Of the 15 papers identified following the search, three of the papers were categorized as theoretical and 12 papers were categorized as empirical studies. The theoretical papers discussed the role of narratives, possible selves and use of metaphors. The qualitative studies discussed their findings in light of theoretical models or specific aspects of identity such as cognitive reconstructions, body image, life narratives and social and occupational identities.

**Conclusions:** All the articles reviewed were limited in the generalisability and efficacy of the models and findings discussed. Experiences of grief, acceptance of injury, rebuilding social networks and recreating a valued place in the world while overcoming functional impairments and adjusting to cognitive deficits were some of the main processes that shaped identity reconstruction and contributed to living a meaningful life.

## **Introduction**

### **What is Identity?**

Identity defines the way people perceive themselves. It plays a key role in motivation and includes values, attitudes, ability, goals and goal directed actions and feelings that surround a unique representation of the self (Bryson-Campbell, Shaw, O'Brien, Holmes, & Magalhaes, 2013; Deci & Ryan, 2000; Ylvisaker, Mcpherson, Kayes, & Pellett, 2008). It consists of multiple physical and personal individual characteristics marked by a sense of 'who am I' and 'who I could be'. Identity also includes social selves, roles and characteristics derived from group memberships, including how people are viewed and treated by others in social relationships (Beadle, Ownsworth, Fleming & Shum, 2015; Cotton, 2012; Heller, Levin, Mukherjee & Reis, 2006; Ownsworth & Haslam, 2014).

Identity is what enables a sense of continued experience of the world, even as life events and circumstances change (Ylvisaker et al., 2008). However, aspects of identity are also known to undergo changes with the experience of momentous positive and negative life events, such as a major illness or traumatic event, significant life transitions like marriage or becoming a parent, external feedback from others, and psychotherapeutic interventions (Beadle et al., 2015). Literature suggests that development and growth of identity incorporates both a stable, generalized, core sense of self and a dynamic and malleable sense of self that adapts to myriad situations in the individual's environment (Muenchberger, Kendall & Neal, 2008). Typically, an autobiographical narrative lies at the heart of experiencing a coherent or unified sense of self, an 'inner sameness' or consistency, built out of these enduring yet transitioning personal and social identities (Heller et al., 2006; Muenchberger et al.,

2008; Ownsworth & Haslam, 2014). This narrative is created and expanded on throughout the lifespan. It includes a number of experiences and memories that are shaped and understood in the context of a socio-political, emotional and cognitive environment. Perspectives from philosophy, anthropology, sociology, psychology and neuroscience agree that this unified sense of self is composed of ‘multiple selves’. These selves together form a dynamic and coherent narrative as they interact with each other to create the individual sense of ‘I’ or ‘me’. As various selves are adopted and discarded over a lifetime, they also become imbued with the capacity to affect well-being and sense of productivity leading to the experience of living a content and valued life (Heller et al., 2006).

### **Impact of Brain Injury on Identity**

Acquired brain injury (ABI) can be the result of an internal event or a cerebrovascular accident such as bleeding or anoxia, infections such as meningitis, or a traumatic brain injury (TBI) (one of the main causes of death and disability in young people) as a result of an insult or trauma to the brain from an external force such as being hit by a metal pipe (Maas, Stocchetti & Bullock, 2008; Turner-Stokes, Nair, Sedki, Disler & Wade, 2005; as cited in Bryson-Campbell et al., 2013). Injury to the brain generally results in lifelong physical, cognitive, emotional, psychological, social or functional impairments directly impacting people’s personal and social identities due to an immediate change in the activities and roles they are able to perform (such as at work, being able to drive independently, parental role etc.), consequently affecting their sense of self (Bryson-Campbell et al., 2013; Coetzer 2008; Jumisko, Lexell & Söderberg, 2005; Ownsworth & Haslam, 2014). Individuals often report fatigue, headaches, sleep disturbances, amnesia, hemiplegia, anxiety, depression,

agitation, losses of inhibition, emotional control, reasoning and motivation, and an overarching sense of loss of self. Changes in personality are often lifelong (Bryson-Campbell et al., 2013; Cloute, Mitchell & Yates, 2008; Jumisko et al., 2005; Ponsford, Kelly & Couchman, 2014; Tyerman & Humphrey, 1984). Even mild brain injuries affect functioning which may not return to pre injury level (Myles, 2004) and survivors consequently face difficulties in returning to independent lives, work, and reintegrating into society (Bryson-Campbell et al., 2013).

Unsurprisingly, the nature of a brain injury and its resulting impact on the individual often leads to identity confusion, with a negative effect on aspects such as body image, social identity and relationships, work, study and leisure, as well as on self-concept and self-esteem (Cloute et al., 2008; Myles, 2004; Ownsworth & Haslam, 2014; Ponsford et al., 2014). Impairment in self-awareness as a result of injury further interrupts the processing and acceptance of these changes (Cloute et al., 2008; Coetzer, 2008). Evaluation of the self after an injury largely involves experiencing these changes negatively (Myles, 2004; Tyerman & Humphrey, 1984) which adds to distress and feelings of anger, frustration, irritation, anxiety, grief, loss and depression (Myles, 2004). Despite making significant gains and positive outcomes following rehabilitation, such as returning to work or finding a partner, individuals may continue to report a low quality of life with persistent difficulties in maintaining and establishing social roles and relations, sustained disruption of social networks, and loss of meaning even decades after the injury (Muenchberger et al., 2008; Nochi, 2000).

Failure to perform activities and roles to pre injury levels indicates a mismatch between pre injury and post injury self, leading to the experience of not being the same person. (Myles, 2004; Nochi, 1997; 1998). While there exist no universally

accepted definitions that define this loss of self or identity following a brain injury, research indicates that there is an awareness on the part of the individual that they are not the same person as they were before. This ‘experience of the self in relation to self’ is felt ‘different’ or ‘estranged’ or ‘disconnected’ from the previous identity with changes to functioning physically, cognitively, emotionally and socially (e.g. Chamberlain, 2006; Gracey et al., 2008; Myles, 2004; Nochi, 1997; 1998). Research suggests that discrepancies in post injury functioning and pre injury identity is at the centre of loss of a sense of self which is magnified by memory losses, changes in how others view and treat brain injured individuals, and grief over the lost self (e.g. Chamberlain, 2006; Gracey et al., 2008; Myles, 2004; Nochi, 1997; 1998; Tyerman & Humphrey, 1984).

### **The Study of Identity Following Brain Injury**

Although reports of changes in identity are not uncommon, particularly following a major life event, specific study of this change in brain injury is important. Brain injury impacts the functioning of those areas of the brain that are considered to be responsible for generating a sense of uniform but dynamic identity. It can also affect areas of the brain that are involved in perceiving, interpreting, managing and responding to further changes in identity that commonly occur over the lifespan following life events such as marriage, a mental health crisis, or losing a job etc. Thus, study of identity change in brain injury, informs the mechanisms of identity change in other areas as well (Thomas, Levack & Taylor, 2014).

Research into experiential accounts of identity in brain injury was neglected until recently due to a focus on rehabilitation as a means of re-acquiring optimal physical function from a biomedical perspective. This restricted exploration of recovery was

problematic as individual experience is directly linked to adjustment which in turn affects overall outcome and recovery in rehabilitation (Ownsworth & Haslam, 2014; Segal, 2010; Tyerman & Humphrey, 1984). Tyerman and Humphrey (1984) conducted one of the foremost studies that examined psychological aspects of rehabilitation by exploring changes in self-concept following severe head injury. Results showed 72% of the participants reported significant changes to them 'as a person'. Most of these changes were negative (anger, frustration, irritation, depression) but some positive changes (more accepting, tolerating, appreciative) were also reported. Additionally, participants also reported drastic changes in their lifestyle.

More recently, Beadle, Ownsworth, Fleming and Shum (2015) reviewed studies to evaluate evidence in existing research for changes in pre injury and post injury identity. Most of the 15 studies included in the review reported negative changes in self-concept arising due to discrepancies in who individuals were, who they are and who they wanted to be. This resulted in mental health concerns such as depression, anxiety, distress, and changes in self-concept and self-esteem. However, they also found reports of some positive changes and growth, for instance, patients rated themselves as more mature, satisfied or appreciative. Beadle et al. (2015) recommended the development of a validated measure for identity to account for the lack of consistency in terminology and in defining identity which contributed to some of the limitations of their review.

Similarly, another review by Ownsworth and Haslam (2014) examining the efficacy of intervention methodologies on self-concept following brain injury also found this lack of consistency in terminology problematic. Ownsworth and Haslam (2014) reviewed studies that used a quantitative measure to assess change in self-esteem or self-concept and found only 10 of the 17 studies demonstrated an



improvement in self-concept following intervention. Owing to the central role of identity reconstruction in adjustment (Douglas, 2010), Ownsworth and Haslam (2014) concluded their review with recommendations for more identity oriented interventions to aid improvements in recovery.

The lack of consistency in terminology has also meant that a vast number of studies, such as the above reviews, have explored reconstruction of identity by studying changes in self-concept or other related concepts. To address this, Thomas, Levack and Taylor (2014), conducted a review of 110 articles with the aim of clarifying the concept of *change in self-identity* following TBI and delineating it from related concepts. They found that change could occur at three potential levels, a) at the ‘component parts’ or the biological, psychological, social, political and cultural aspects of identity, b) in the ‘internal processes’ which comprised of a meaningful occupation, narratives or stories people tell of their lives, and self-awareness, and, c) as systematic disruptions in the organization of the self, both in the internal and the external world. Thomas et al., (2014) posited that losses and disruptions in the above areas following a brain injury affected the experience of identity as it existed pre injury, thus, necessitating a reconstruction. They concluded the review by citing this clarification as the first step towards operationalizing and working towards a tool to measure changes in identity following a brain injury.

In another key review that addressed the lack of understanding of recovery following brain injury, Levack, Kayes and Fadyl (2010) explored experiences of recovery in a metasynthesis of 23 studies. They found that loss and reconstruction of identity were the principal themes of recovery. Central to the experience of recovery were personal and social losses. Levack et al. (2010) explained that progress from experiences of loss was marked by a reconstruction of individual lives which included

reconstruction of self-identity, reconstruction of a place in the world through reintegration and adjustment in work, social and family lives, and personhood reconstruction to feel whole as a person and to be considered as such by other people. Levack et al. (2010) summarized all existing literature in the area and demonstrated this topic as an emerging area of research with a number of studies exploring lived experiences of survivors of brain injury to better understand the process of identity change and reconstruction at various levels and in different areas of life.

### **Deconstructing the Process of Identity Reconstruction**

Although research has started to closely examine accounts of survivors of brain injury, the process of identity reconstruction in the context of brain injury and neurological rehabilitation continues to remain somewhat vague and is yet to be fully explored and understood. Understanding the process of adjustment and identity reconstruction is critical to successful rehabilitation because development of identity over the lifespan, including resolution of major life stages and transitions, depends upon several cognitive and executive functions, a number of which are compromised following a brain injury (Hoogerdijk, Runge, & Haugboelle, 2011; Muenchberger et al., 2008). Moreover, subjective quality of life is a key factor in predicting recovery outcomes (Brown, Gordon, & Haddad, 2000 as cited in Segal, 2010) and individuals who continue to experience disrupted identities despite making positive gains in rehabilitation are more likely to experience continued mental ill health and report a lower quality of life (Cloute et al., 2008). In contrast, rebuilding a positive identity is associated with better quality of life following injury (Vickery, Gontkovsky, & Caroselli, 2005). Understanding the processes involved in the reconstruction of

identity following such a catastrophic event is central to making sense of the changes and regaining a sense of control and meaning (Muenchberger et al., 2008).

### **Aims of this Review**

The purpose of this review was to examine accounts of the process of identity reconstruction in acquired and traumatic brain injury as understood from literature with the aims of:

1. Evaluating studies that explored the process of identity reconstruction following a brain injury,
2. Evaluating the theoretical understanding of the process of identity reconstruction, and
3. Identifying the key concepts and themes discussed in these papers as constituting identity reconstruction.

## **Methods**

### **Search Strategy**

Studies for the current review were identified by conducting a systematic search of four databases - PSYCHINFO, MEDLINE, EMBASE and CINAHL. A combination of search terms were compiled from articles on brain injury that had been previously collected. These terms included but were not limited to identity, self – concept, brain injury, head injury, brain damage, acquired brain injury, traumatic brain injury, reconstruction, redefinition, and rebuilding. They were used to conduct keyword and related terms searches on the databases to capture various aspects of the review question. All variations of these terms and the option of ‘truncate’ were used in order to obtain a maximum number of relevant studies. Databases were searched

from inception to 16<sup>th</sup> December 2015. The search was limited to the English language and human subjects only.

### **Inclusion Criteria**

Papers were included based on the following inclusion criteria:

- All papers that discussed rebuilding of identity post injury in some detail were included.
- A paper was considered to provide a useful contribution to the review if it included some in depth discussion on reconstruction of identity, for example, as indicated by a main heading or sub heading dedicated to the topic in any one of the sections.

### **Exclusion Criteria**

Studies were excluded based on the following criteria:

- If the main topic discussed was a concept related to identity (self-concept or self-esteem) with no substantive discussion of identity reconstruction.
- If they only discussed the experience of loss of self without exploring the specific topic of how identity reconstruction might occur.
- If they only touched upon the topic of identity reconstruction post injury without detailing the processes (as outlined in the inclusion criteria).
- If they were stroke – specific studies. The search of the databases did not return studies specific to stroke and no stroke-specific studies were included from reviewing reference lists of articles. Moreover, processes of change, including identity have been examined independently and at length in stroke

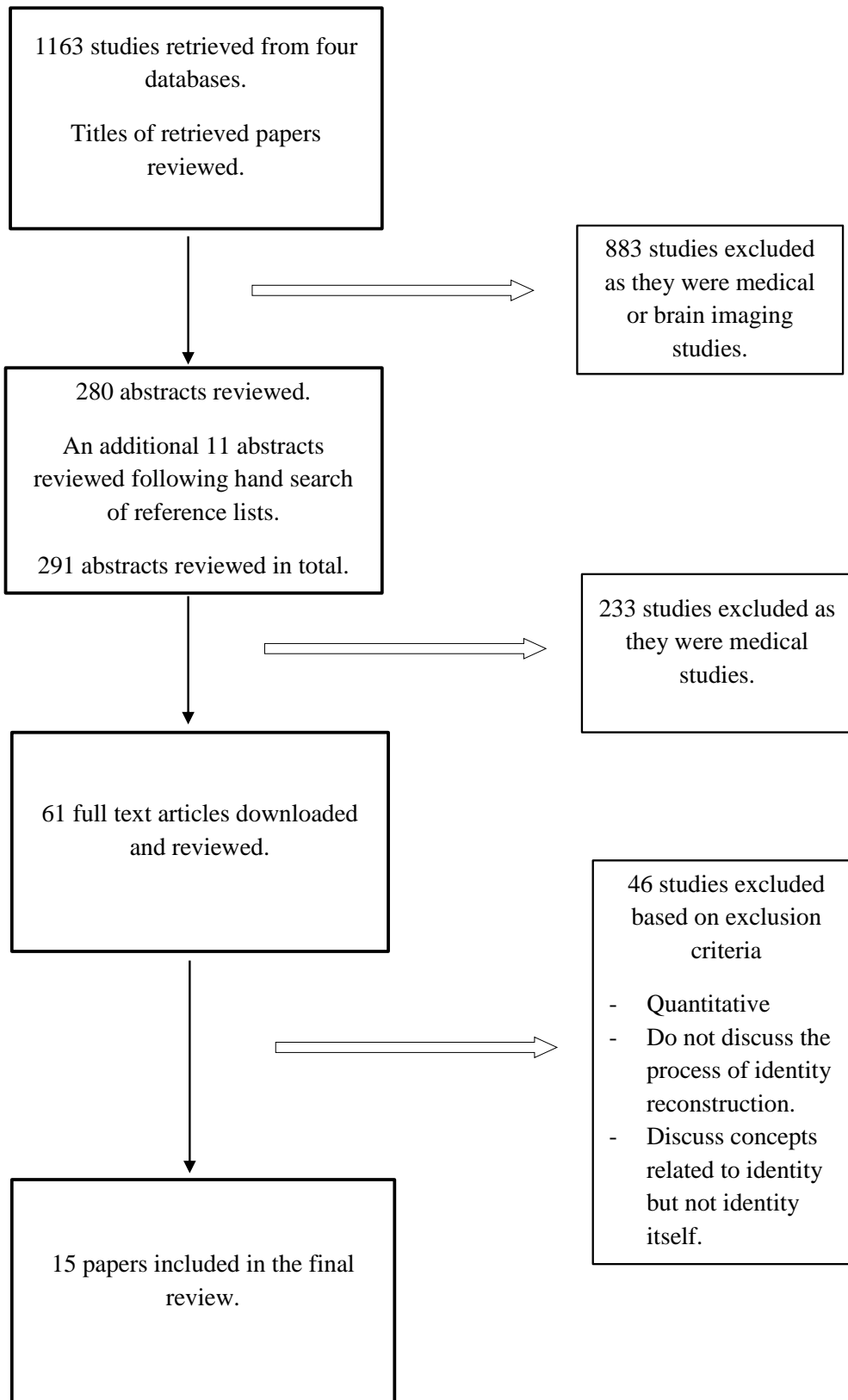
recovery and rehabilitation and form a distinct area of investigation on its own, thus falling outside the scope of this review.

- Meta syntheses and literature reviews in the area of identity reconstruction as they form independent areas of investigation within identity reconstruction literature in brain injury and were outside the scope of this review.
- Studies were also excluded if they only examined quantitative data. Mixed method studies that did not specifically explore identity reconstruction were also excluded.
- Unpublished theses and articles.

### **Study Selection**

The search strategy adopted for the review is depicted in Figure 1. All articles on acquired and traumatic brain injury with all levels of severity were considered. The systematic search of the databases returned a combined 1163 articles. Of these, 883 were excluded upon reviewing the title as they were either medical or brain imaging studies. Abstracts of the remaining 280 studies and articles were reviewed and reference lists were examined to identify any other relevant studies through a hand search. An additional 11 abstracts were reviewed following this. A further 23 studies were excluded as they primarily explored medical interventions for brain injury. Full text articles were obtained for the remaining 61 papers and these were read and reviewed twice before a further 46 articles were excluded based on the criteria outlined above. A total of 15 studies were included for the purpose of writing this review.

Figure 1. Flow chart outlining the search strategy and identification of articles.



## **Results**

The systematic search resulted in 15 papers being included in the final review. The results section is divided into two main parts – papers that discussed the theoretical basis for reconstruction of identity and empirical papers that analysed data from participants to understand this process.

All the empirical studies were evaluated on their participant size and method of data analysis. It was noted if studies explicitly stated and considered specific theoretical or therapeutic models in discussing the process of identity reconstruction and areas of life that were involved in rebuilding identity. Triangulation and reflexivity on the process, as well as the conclusions drawn by the studies were also evaluated to establish if the studies had considered limitations of salient findings reported in the results and possible bias in interpretation.

The theoretical papers that discussed the process of identity reconstruction were evaluated based on the extent to which conceptualization of the reconstruction of identity was comprehensively explained by the stated theoretical model and if the limits of the model were explored in understanding the process of identity reconstruction. The papers were also evaluated on the applicability of the models in supporting intervention practice, if the authors were able to recognise or suggest further development of secondary or tertiary models that could address the limitations of the primary model discussed in their paper, and the overall contribution of the model in understanding this process.

Where empirical papers discussed theory, this was indicated in the relevant section. The main contributions from these papers are summarized in Table 1.

*Table 1: Key contributions from relevant papers.*

	<i>No</i>	<i>Authors and Year</i>	<i>Method of data analysis</i>	<i>Summary of the paper</i>
<i>Theoretical Papers</i>	1	Heller, Levin, Mukherjee & Reis, 2006	N/A	Impact of brain injury on self. Discusses possible selves and narrative approach.
	2	Morris, 2004	N/A	Use of narrative approach to rebuild identity, Looking at narrative solutions and narrative research
	3	Myles,	N/A	Rebuilding self using RFT and ACT. Categorizes self into three - the conceptualised self, self as an ongoing process of verbal knowing, and self as context.
<i>Empirical Papers</i>	1	Brown, Lyons & Rose, 2006	Interpretive Phenomenological Analysis (IPA) on 24 interviews	Three main themes emerged – discovering the problems because of the trouble they were causing. Second theme was holes in memory – affected continuity of self. Final theme – redefining self – explaining behaviour with or without brain injury.
	2	Cloute, Mitchell & Yates, 2008	Discourse analysis of six interviews	Four main repertoires (themes) involved in co construction of identity following injury - medical



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			model referencing, dependence as intrinsic to TBI, TBI as deficit and progression and productivity as key life-defining features.
3	Gelech, & Desjardins, 2011	Thematic analysis of four patient interviews	Construction of self – public and private.
4	Gendreau, & Sablonnière, 2014	Coding of ten interviews using the CDMSII	The CDMSII as a heuristic for understanding identity reconstruction. Three stages of the identity integration process – categorization, compartmentalization and integration.
5	Hoogerdijk, Runge & Haugboelle, 2011	Construction of narratives from interviews using a narrative approach	Adaptation through developing new identity that is facilitated by occupations.
6	Jumisko, Lexell & Söderberg, 2005	Phenomenological hermeneutic method with 12 interviews	Main themes of losing one's way and building a new normal with social supports
7	Lennon, Bramham, Carroll, Mcelligott, Carton, Waldron, Fortune, Burke, Fitzhenry & Benson, 2014	Thematic analysis of interviews – nine participants with ABI and ten participants with SCI	Negative narratives were immediately followed by positive self- narratives indicating there had been opportunity for the positive narratives to be created.
8	Levack, Boland, Taylor, Siegert, Kayes, Fadyl & McPherson, 2014	Grounded theory for tool development. Focus group data from eight focus groups and 49	Talks about process involved in recovering sense of self identity – Three themes emerged (1) to feel like a whole person, (2) be treated with respect,

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		participants	validation and acceptance (3) have a place of value in the world.
9	Muenchberger, Kendall & Neal, 2008	Thematic analysis of six interviews	Identity reconstruction is a dynamic process of contraction, expansion and balance
10	Sivertsen & Normann, 2015	Case studies	Impact on brain injury on the body and changes in functionality.
11	Ylvisaker & Feeney, 2000	Case studies	Metaphoric identity mapping - Integrated cognitive subsystems and metaphors.
12	Ylvisaker, Mcpherson, Kayes & Pellett, 2008	Pilot testing for metaphoric identity mapping as an intervention	Application of metaphoric identity mapping including using it as an intervention

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## **Theoretical Understanding of Identity Reconstruction**

The three papers that explored a theoretical basis to understanding identity reconstruction following brain injury focused on three models to explain this – the role of narratives, the role of possible or multiple selves, and the use of metaphors.

### *Re-authoring Narratives*

Individuals' construction of their lives' narratives is intrinsic in giving meaning to the past and aspiring for a future (Eron & Lund, 1996 as cited in Morris, 2004). Morris (2004) discussed the construction of self through language, discourse, and its interactions with social structures. Similarly, Heller, Levin, Mukherjee and Reis (2006) also discussed the creation of self through narratives and posited that individual realities are organized by constructing and recounting this dynamically constructed tale of who one is and the people that form this world in the past, present and future

Morris (2004) explained that the self is seen as dynamic and changing. He argued that this view of the self allowed survivors of brain injury to re-author and rewrite their identities to understand how their current life stories could fit into their narratives from the past. While Heller et al. (2006) emphasised this relevance of re-authoring narratives following brain injury, they also suggested that memory gaps would interfere in this process. Additionally they claimed that such re-authoring of the individual narrative could take a substantial amount of time, often years. These limitations were not considered by Morris (2004).

Heller et al. (2006) also suggested that narratives emphasised in intervention (for example, of recovery versus disability) could either facilitate or stigmatise the process. Morris (2004) agreed that while stories could be used as a tool for empowering survivors

of brain injury, they could also be used as a means of reinforcing subjugation (from stories of disability and stigma in society). However, in applying the narrative approach, Morris (2004) postulated the role of narrative therapy as one that facilitated the process as opposed to stigmatising it because narrative therapy allowed patients to move away from a problem saturated and disability focused narrative.

Morris (2004) recognised that a narrative approach may not be suitable for everyone and added that its application, particularly in contributing towards a non-medical understanding of brain injury, required further exploration. Heller et al. (2006) agreed that re-authoring narratives allowed for new selves to be discovered and created while providing space to mourn the losses of the old selves, but did not explore the specific manner in which narratives could inform this process, instead focusing on the role of multiple selves (detailed in the section below). In considering the narrative approach, neither Morris (2004), nor Heller et al (2006) discussed its limits (or if any existed) in adequately explaining identity reconstruction. Although Morris (2004) acknowledged the unsuitability of a narrative approach for some people, he did not delve into the specific limitations the model might pose in application or other models that could overcome these shortcomings. Morris (2004), however, did consider some studies in discussing the successful application of the model but, once again, did not address the limitations raised by these studies in applying the model.

### *Possible Selves*

Heller et al. (2006) discussed literature and in particular, the work of Markus and Nurius (1986) in describing ‘possible selves’. These selves contain an individual's ideas of what the self would like to be or not based on cognitive representations of the self from the past and future. Positive and negative experiences and social environments shape

these representations and are known to significantly predict self-esteem and sense of personal control (Heller et al., 2006). However, Heller et al. (2006) did not explore the application of this model, nor did they explore other cognitive models that could inform the later stages of identity reconstruction in brain injury. Indeed Heller et al. (2006) discussed the model as lending only cursory relevance to the study of identity reconstruction and its potential application to brain injury. The specific concepts within the model, or its application were not discussed. Inadequate discussion on the role of possible selves in initiating the process of identity reconstruction also makes it difficult to comment on the significance of the model in understanding identity reconstruction as suggested by Heller et al. (2006).

#### *Acceptance and Commitment Therapy (ACT) - Using Metaphors*

Myles (2004) discussed the use of metaphors in ACT and its applicability to brain injury rehabilitation in reconnecting the perceived mismatch between the descriptors relating to aspects of identity, such as work, and the self (for example, hard-working versus lazy and its relation to professional versus unprofessional). Additionally, Myles (2004) emphasized the relevance of the separate components of this approach and its focus on acceptance and living a valued life in the present moment as the key to rebuilding identity following a brain injury. He further postulated that the provision of a safe space created in the experience of the 'self as context' would lay the foundation for accepting the changes in functioning, thus creating a path for successful adjustment and recovering the lost sense of self. However, Myles (2004) also did not explore the specific limitations of ACT in rebuilding identity based on an experience of the self from within. Nonetheless, Myles (2004) did argue for further research into the wider applicability of

the model by referring to emerging research in the field of neurological rehabilitation that has demonstrated successful application of the model in some settings.

The above papers presented a narrow and limited account of theoretical models that could inform identity reconstruction in brain injury. While Morris (2004) and Myles (2004) discussed some research that supports the use of their model as an intervention within rehabilitation, Heller et al. (2006) did not consider the strengths or limitations of a narrative approach or possible selves in rebuilding identity. Morris (2004) and Myles (2004), on the other hand, did not explore the limits of their models in detail or propose other models that could be integrated to account for those aspects of identity reconstruction that are not explained in a narrative or ACT approach.

### **The Understanding of Identity Reconstruction from Empirical Studies**

Twelve empirical studies were included in this review. They explored individuals' experiences of engaging in the process of rebuilding their identities. Studies varied in the depth and extent to which they scrutinised these experiences in order to understand some of the components that make up the process of rebuilding an identity. One of the studies also interviewed carers as participants, to understand this process. While some studies discussed the results in the light of existing theories on the reconstruction of identity, other studies discussed the role of different therapeutic models in facilitating the process of rebuilding identity. A few other studies addressed the development of social and occupational identities. Thus, the empirical studies reviewed in this part of the results section are divided based on these models used to explain and explore the process of identity reconstruction.

### *Cognitive Representations and Reconstructions*

Gendreau and de la Sablonnière (2014) explored the cognitive processes involved in identity reconstruction in their study using the Cognitive Development Model of Social Identity Integration (CDMSII) proposed by Amiot and colleagues. Gendreau and de la Sablonnière (2014) operationalized three of the four stages of CDMSII to analyse interview data, which posited that patients moved from the stages of categorisation of pre and post injury identity, to compartmentalising them, before integrating the two identities. Gendreau and de la Sablonnière (2014) postulated that the process of identity reconstruction was not a straight forward linear process and involved resistance to the new emerging identity. They also discussed the limits of their model and drew from the data in explaining how participants resolved conflicts in the emerging identity. While they utilized a specific model in coding and discussing their results, Gendreau and de la Sablonnière (2014) did not refer to results from another study conducted by Muenchberger, Kendall and Neal (2008) which found similar results from a thematic analysis of data.

In the study conducted by Muenchberger et al. (2008) to better understand the process involved in identity reconstruction, data from six participants was analysed. They found that all participants identified a pre injury identity and a post injury identity. Analysis highlighted fluctuations between three main processes of *contraction* of identity, *expansion* or broadening of identity, and a struggle to maintain a *balance* or equilibrium between the two. Muenchberger et al. (2008) did not discuss their findings in light of any relevant theoretical model of identity reconstruction, including the CDMSII which described a similar process of identity reconstruction and was used by Gendreau and de la Sablonnière (2014) to code their data.

As with other brain injury studies, both, Gendreau and de la Sablonnière (2014) and Muenchberger et al., (2008) worked with a small number of participants to arrive at their findings which hindered the application and generalisability of their findings. It is possible that reference to relevant theory (as in the case of Muenchberger et al., 2008) or other empirical studies (as in the case of Gendreau and de la Sablonnière, 2014) may have added to the strength of the findings from both the studies and addressed some of the limitations of a small sample size and generalisability.

Furthermore, Gendreau and de la Sablonnière (2014) acknowledged that their limited data was insufficient in demonstrating the various stages suggested in their proposed model as part of identity development. They recommended an in depth, longitudinal study with more participants to address this limitation. Neither, Muenchberger et al. (2008) nor Gendreau and de la Sablonnière (2014) presented a detailed reflexive account of their research which made it difficult to gauge their bias in coding their data during analysis. However, Gendreau and de la Sablonnière (2014) did consider several limitations. Muenchberger et al. (2008) did not explore limitations in detail nor a potential for bias in analysis. While Gendreau and de la Sablonnière's (2014) study was limited, it was also one of the first studies to apply a comprehensive theoretical model of identity reconstruction in exploring direct accounts of identity reconstruction obtained from brain injured individuals.

Perhaps, the best-known work on uncovering the components of identity reconstruction arises out of metaphoric identity mapping and the information processing model proposed by Ylvisaker and colleagues. As a basis for their model, Ylvisaker and Feeney (2000) used Teasdale and Barnard's (1993) interacting cognitive subsystems (ICS) approach which described nine cognitive subsystems that code information. Ylvisaker



and Feeney (2000) suggested that therapy should aim to generate and expand the positive mental models available in these subsystems to manage difficult emotions and behaviour. Their seminal work on metaphoric identity mapping drew heavily from this understanding of the ICS. Ylvisaker's model also used metaphors and Markus and Nurius's (1986) 'possible selves' to help clinicians understand the patient, set meaningful and realistic goals, and overcome barriers such as mental blocks or difficulties in engagement (Ylvisaker & Feeney, 2000; Ylvisaker, McPherson, Kayes & Pellett 2008).

Ylvisaker and Feeney (2000) presented three case studies that applied metaphoric identity mapping with patients and they concluded that metaphors might not work for everyone and clinicians were only able to facilitate in identifying a metaphor that patients would like to use as part of their identity mapping. In a second pilot study by Ylvisaker et al. (2008), ten participants from three rehabilitation centres took part in an intervention that involved metaphoric identity mapping. Only five of the participants completed the intervention and data collected from interviews was subject to grounded theory analysis. Data was also obtained from observations, field notes, and interviews and focus group with clinicians. While patients found the model helpful, clinicians found it hard to deliver, despite training. The authors discussed the limitation of their models and agreed that additional training for clinicians was necessary in delivering this model. However, the authors did not account for limitations in the form of additional resources of time, money and prior knowledge in facilitating an understanding of metaphors, possible selves and cognitive subsystems and the central role it played in formulating and asking questions that would help in obtaining a rich metaphor.

While Ylvisaker and Feeney (2000) and Ylvisaker et al. (2008) acknowledged limitations in applicability of their model, they did not address limitations of accessibility

and flexibility of the model. They also did not provide a detailed reflexive account that explored bias in interpretation of data and other methods to account for shortcomings. Due to the small sample size, data obtained from these two studies was limited in providing an accurate reflection on the efficiency and efficacy of the model. However, the model was one of the first attempts at integrating different conceptions of identity development and reconstruction to inform rehabilitation practices in the treatment of brain injury.

### *Body Image and Identity Reconstruction*

Brain injury can often result in varied levels of impairment in the body, some of which affect functioning permanently. Sivertsen and Normann (2015) discussed three case studies to highlight themes of loss and grief over the abilities the bodies used to perform and that participants believed they had taken for granted. The three participants also described their affected body parts as detached from the rest of their body and objects interfering with daily living. Sivertsen and Normann (2015) acknowledged a lack of exploration in and inclusion of body image in reconstructing identity while rehabilitating the body and suggested that meaningful activities carried out in rehabilitation may be one way towards this reconstruction. In a previous study by Jumisko, Lexell and Söderberg (2005) participants referred to experiencing the body as a hindrance due to its limitations, and as something that “couldn’t be trusted”.

Sivertsen and Norman (2015) discussed their findings in light of literature, and particularly, Gallagher's work (2012) in describing a sense of self in the present created through the sense of agency, ownership and body schema obtained from an integrated somatosensory network. Jumisko et al. (2005) did not discuss the role of body image in

reconstructing identity post injury any further, nor did they discuss specific models or existing literature on body image and identity reconstruction.

Sivertsen and Normann (2015) postulated based on Gallagher's work (2012) that reconstruction of identity post injury involved readjusting beliefs about the functions the physical body was able to perform which often changed significantly following a brain injury. They stated that this could be quite challenging as recovery and rehabilitation following injury are a time of uncertainty where patients are often testing their motor functions and relearning skills. While Sivertsen and Normann (2015) were only able to present three cases that explored the role of body image in identity reconstruction, their paper is one of the few to discuss this aspect of identity in detail with reference to relevant literature in the area.

#### *Social Constructionism and Narratives*

Brown, Lyons and Rose (2006) adopted a social constructionist approach in interpreting their findings obtained by conducting interpretive phenomenological analysis (IPA) on data obtained from 24 interviews of patients with brain injury. While the study emphasized a continuity in the experience of self, Brown et al. (2006) appeared to over-emphasise literature reporting loss of sense of self which contrasted with their findings. Reflexivity and triangulation were well demonstrated in the study but did not account for this bias. Brown et al. (2006) also discussed the trend in identity literature on brain injury to focus on this loss and recommended a focus on the gains when examining the process. Although, their study did not replicate findings from other studies in demonstrating the loss of self, thus, limiting the application of their results, it did demonstrate the presence of alternative narratives within the process of reconstructing identity.

In a separate study conducted by Lennon et al. (2014), data obtained from nine interviews and analysed using thematic analysis demonstrated that negative narratives were immediately followed by positive ones, indicating some success in re-authoring narratives. Participants discussed learning new skills in rehabilitation and considered that they had been made stronger and more accepting as a result of their injuries. However, Lennon et al. (2014) also advised caution in generalising results of their study due to the small sample size. The study discussed previous research that demonstrated similar results and presented a reflexive account of the process including the possibility of bias in the analysis as participants were also engaged in rehabilitation during the course of the study and more likely to access positive narratives.

Although limited, both Brown et al. (2006) and Lennon et al. (2014) discussed the nature of narratives and alternatives to the dominant discourse of loss or negativity while exploring the experience of identity reconstruction with patients.

### *Social and Occupational Identity*

A few studies also focused on the process of rebuilding social and occupational identities. In Jumisko, Lexell, and Söderberg's, (2005) study that interviewed 12 people, one of the themes described losses of relationships, friends and colleagues as a result of limited social engagement and opportunities to participate meaningfully or perform old roles. However, patient's also reported a deepening of relationships with friends and family who provided support to them through the injury and recovery. Similarly, Cloute, Mitchell and Yates (2008) interviewed six survivors of brain injury along with two significant people from their support network and found that participants experienced TBI to be a deficit and intrinsically tied to dependence, thus requiring a significant amount of support and care from other people in making sense of life after injury. Both studies

highlighted the reliance on medical professionals and significant others in doing this. In another study conducted by Gelech and Desjardins (2011) examining the reconstruction of self in ABI, two life history interviews were carried out with four participants. Thematic analysis of the data highlighted a public aspect of the self which was engaged in trying to establish new connections in the environment.

Jumisko et al. (2005) discussed these findings in the context of human suffering as opposed to models of identity reconstruction. Cloute et al. (2008) stated that a specific model of identity reconstruction was unavailable to them to discuss interventions. This claim could be criticised as other studies have been able to discuss different models that may find application in rehabilitation and inform intervention practices. Gelech and Desjardins (2011), on the other hand, emphasized the preliminary nature of their work and recommended exploratory studies on the processes involved in recovery to better understand the rebuilding of the self post injury.

Cloute et al.'s (2008) study also found that participants reported productivity as key in redefining their lives, creating meaning, and achieving progress from their initial states post injury. Work was seen as the primary indicator of this progress and productivity. Similarly, Gelech and Desjardins (2011) found that participants held on to some aspects of their previous social identity of work and reconfigured it to forge a new identity.

In a separate study exploring the role of occupational identity in adaptation following a brain injury, Hoogerdijk, Runge, and Haugboelle, (2011) found one of their main themes of return to work was closely tied to the experience of return to normality. Hoogerdijk et al. (2011) concluded that their study indicated adaptation to be an individual struggle that continued after rehabilitation and discharge from hospital. They

concluded that engaging in familiar occupations helped in this struggle towards reconstructing identity. Not only did Hoogerdijk et al. (2011) discuss their findings in light of Schkade and Schultz's Occupational Adaptation Framework (cited in Hoogerdijk et al., 2011), they also recommended longitudinal studies that could explore this aspect of identity reconstruction in greater detail while addressing the limitations of sample size and data observed in their study.

In another qualitative study that explored recovery themes, Levack et al. (2014) conducted eight focus groups with 49 survivors of TBI and found rebuilding of social networks and lives as crucial in developing a sustained sense of self following the injury. Absence of acceptance from significant others contributed to feelings of depersonalization and break down in relations due to social withdrawal, change in interests or decreased capacity to cope in certain social situations. By contrast, reconstructed social networks contributed to experiencing a coherent recreated identity and sense of self. Participants stated that productivity and contribution to society, as well as a vocational identity all contributed in recreating a valued place in the world which was often experienced as lost following a brain injury. Since Levack et al. (2014) had primarily conducted their research as an exploratory study to inform the development of a tool to measure these changes, they concluded by suggesting that their findings could be used to design robust measures that are able to tap into a wider understanding of recovery in identity reconstruction.

### **Forming a Coherent Reconstruction of Identity – A Summary**

Several common themes were observed across the literature that was reviewed. Brain injury was consistently reported to lead to a sense of discrepancy and loss. Participants described their losses in detail in a number of areas such as function, body,

occupations, roles, social relations etc. The sense of discrepancy between current and pre injury identity was reported to be magnified by memory loss. Present identity also felt constricted and limiting. Moving forward from these initial experiences of loss, participants then described attempts at reconstructing their identities to rebuild their lives.

Participants engaged in concentrated efforts to relearn skills, explore new avenues and pursue opportunities that would ultimately result in an expanded identity. They described the significance of a social support network in carrying out this task and also identified the need to restore lost connections and build new ones. This process of rebuilding was described as a lengthy one with participants often finding themselves moving between rebuilding their identity and mourning for what was lost from their pre injury identity.

Participants described being able to contribute meaningfully to society, to be accepted by others and to have a sense of worthiness or value as foundational in being able to form a coherent identity and draw on inspiring metaphors to enable them to rewrite a narrative account of their lives.

Papers that were reviewed often explored common themes that arose from patients' accounts of reconstructing identities. Since identity is understood to have various domains and facets, it is expected that exploration of its reconstruction following a major life event such as a brain injury would probe into or uncover one or several of these aspects. Some of the reviewed papers also indicated this by investigating the concept of 'many' or 'possible' selves. Brain injury can divide the life of an individual into a before and an after due to the impact it can have on their sense of agency.

Themes of loss were common to most of the studies reviewed as were themes of rebuilding lives and identities by trying to understand and accept the injury and find

meaning again using aspects of the pre injury identity as a continued foundation for recreating a valued life. This search for meaning marks the beginning of the process that many patients undergo in reconstructing their identities. .

## **Discussion**

### **Summary**

A total of 15 theoretical and empirical articles were identified for the purpose of this review with the aim of evaluating and identifying the key concepts in identity reconstruction. Three papers discussed theoretical underpinnings to identity reconstruction and 12 papers explored the process of identity reconstruction in brain injury.

The three theoretical papers outlined the role of narrative approaches, the cognitive representations of multiple or possible selves, and the application of ACT and use of metaphors in facilitating this process. While the papers supported the relevance of the various models by referring to empirical studies that demonstrated successful application of the models in neurological rehabilitation settings, they did not consider alternative or integrated models to account for limitations in their proposed models.

The 12 empirical papers explored identity reconstruction from direct experiences of the patients, by analysing in depth interviews conducted with them. A number of these papers discussed their findings in light of pre-existing models of identity reconstruction that could be applicable to brain injury. The most comprehensive of these models were cognitive representations that explored the stages of a narrowed identity following injury, which expanded to include new information as time progressed. The apparent dichotomy between the two identities was managed through a steady effort to integrate and balance



them. On the other hand, Ylvisaker presented an integrated model of cognitive subsystems, possible selves and metaphors to explain the process of identity reconstruction and recommend intervention based on this model.

Some studies also discussed damage to sensory, perceptual and cognitive networks and systems which directly impacted body image by affecting motor, premotor and coordination networks often permanently changing control over movement and other bodily functions. Losses as a result of these changes were observed to be irreversible. Other studies focused on construction of life narratives as intrinsic in giving meaning to the past and aspiring for a future (Eron & Lund, 1996 as cited in Morris, 2004). The narrative approach rooted in social constructionism, viewed reality as pluralistic with varied individual worldviews (Morris, 2004) and this model explained the negative and positive narratives available to people in rebuilding their life.

Loss of social relations and disruption of social networks following a brain injury is also well documented. Indeed, the central role of social identity is evident from its capacity to predict well-being following ABI (Ownsworth & Haslam, 2014). A number of studies discussed this loss. Participants remarked that significant people in their social circle had the capacity to enable this reconstruction or undermine it, since being treated with respect and value was responsible in contributing to the participants feeling a complete person again. Findings also indicated that a final key development in this process was observed to be the capacity to build a place in the world, particularly as a number of participants reported losing their place in the world after their injury. Productivity and progress often came to be defined by return to meaningful work that represented an integration of the old and new reconfigured occupational identity

While most of the studies presented robust findings and discussions of the results, including relevant literature and models, the sample size was limited and affected generalisability of the findings, as is often the case with most studies in neurological rehabilitation,. This also made it difficult to establish efficacy of intervention models when they were proposed. All authors expressed caution in the use of these models and interpretation of their results due to these limitations.

A number of studies identified accepting the injury, losses, and consequent change in identity as the first step towards reconstruction of identity. In mourning for their losses, participants also described recognising those aspects of identity that continued to exist, as well as those that could be resumed through other activities. This formed the foundation on which participants found themselves reconstructing their identities and assimilating new ones. While participants continued to initially compartmentalize their old and emerging identities, over time, some of them were able to integrate these identities to form a coherent one. However, a large number of participants also reported that they continued to fluctuate between their old and new sense of self.

### **Clinical Implications**

Designing interventions for brain injury is a complex task as areas of the brain that play a critical role in formation and experience of the self are often affected. Moreover, impairments in executive functions impact the capacity to gather and integrate information to reform identity (Ownsworth & Haslam, 2014). The mental models associated with identity undergo drastic and often irreversible changes due to resulting impairments. Similarly, some of the changes may be beneficial while others may be adverse. These changes as well as feedback from rehabilitation professionals soon after the injury may give rise to a conflict between the preinjury identity and the information

being received from the environment about current identity. This unconscious identity battle may become evident in difficult to manage behaviour displayed by patients. Hence, rehabilitation practices that are able to build new associations and models of self to bridge this gap between pre injury and post injury identity may contribute to better, more positive outcomes (Ylvisaker, & Feeney, 2000).

Most individuals have a number of identities that interact with each other in a congruent manner. A larger repertoire of identities can function as a buffer in the event of a brain injury or another catastrophic life event that results in the loss of some of the parts of an individual's identity. This also means that a number of other facets of identity that have not been lost can be utilized while reconstructing identity and as a means for directing and motivating this reconstruction. (Heller et al., 2006; Ylvisaker et al., 2008). A larger repertoire of possible selves affects behaviour and outcome because people are more likely to participate in activities that are consistent with their self-concept (Heller et al., 2006). A narrative of recovery allows people to cope with changes in self and identity (Nochi, 1998). Additionally, interventions that are able to demonstrate that social life can continue to be meaningful, despite the differences from its pre injury manifestation, help in rebuilding confidence and creating a new social identity (Paterson & Stewart, 2002). These varied aspects of identity form a framework within which the injury is interpreted and assimilated into a coherent narrative of the self (Heller et al., 2006).

Major changes in identity often become apparent following discharge from hospital (Muenchberger et al., 2008). Exploring these facets of a patient's identity as well as allowing a space for grieving the loss of some of these facets and integrating them in rehabilitation are thus necessary for better and far reaching outcomes that continue beyond the hospital (Heller et al., 2006). In adjusting to life following brain injury considerations need to be made for rehabilitation to be effective, which contextualizes a

person in a medical, familial, social and vocational context. Successful practical goals around relearning skills do not just depend upon the physical and cognitive abilities of the patient but also on those aspects of their identity that have the capacity to accept and take this learning further. They are tied into the family and social support available to the patient in realizing these goals (Heller et al., 2006).

Holistic rehabilitation that aims at working towards living a fulfilling life necessarily needs to include at its core the opportunity to redefine the self (Ownsworth & Haslam, 2014). Rehabilitation professionals contribute to this development of a positive post injury identity (Paterson & Stewart, 2002). Indeed traditional approaches are now being redesigned to incorporate identity (Morris, 2004), which is acquiring a discernible place in rehabilitation programmes (Thomas et al., 2014). New models such as Ylvisaker's metaphoric identity mapping and Gracey et al's., Y-shaped model have been proposed in the past few years (Thomas et al., 2014; Ylvisaker & Feeney, 2000; Ylvisaker et al., 2008). However, the impact of these shifting rehabilitation practices on identity has not yet been the main focus of investigations into recovery in brain injury (Ownsworth & Haslam, 2014).

### **Future Research**

A key barrier to including change in identity as a central aspect of rehabilitation lies in the way it is defined, operationalized and measured in clinical settings. Additionally, this transformation of identity is referred to in several different ways in the literature, such as loss of self, loss of sense of self, loss of personhood, loss of identity or loss of self-identity. It is also associated with other terms such as self-concept, self-esteem, self-awareness, self-confidence etc. An important step would then be to clarify the definition and concepts included in change in identity as well as the various facets of

identity that are likely to be affected by a brain injury (Thomas et al., 2014). When brain injury is defined in a purely neurological language, it is stripped of its wider personal, psychological and social contexts and consequences leading to a restricted understanding and treatment of injury which is largely focused on medical symptoms (Morris, 2004).

Expanding research into brain injury and identity helps to highlight the centrality of identity in recovery (Biderman, Daniels-Zide, Reyes, & Marks, 2006). While the significance of identity is beginning to be researched through outcome studies in brain injury, there is limited empirical support for identity reconstruction interventions in brain injury rehabilitation. A contrast between treatments available and an individual's sense of identity may lead to an inadequate rehabilitation programme that is more likely to be unsuccessful and even unhelpful by increasing distress instead of addressing it, thus risking the possibility of a negative attitude to treatment (Klinger, 2005; Ylvisaker et al., 2008). On the other hand, several studies (for example, Nochi, 2000) demonstrate the possibility of creating a positive identity following injury which contributes to better outcomes (Klinger, 2005; Vickery et al., 2005). There has been little exploration of intervention techniques that can help clients in reconstructing their identities. On the contrary, an impairment focused language, as is commonly used in rehabilitation, contributes to the redevelopment of identity as essentially arising from a 'damaged self' perspective (Kovareky, Shaw, & Adingono-Smith, 2007; Ylvisaker et al., 2008). This becomes particularly significant as clients are often unaware of deficits arising from their injury. The resulting stumbling blocks in rebuilding identity due to resistance or denial contributes further to poorer outcomes (Yeates, Henwood, Gracey, & Evans, 2007; Ylvisaker et al., 2008).

Another significant area of study that has been mostly ignored relates to understanding the experiences of family members and carers of people with brain injury (Levack et al., 2010; Segal, 2010). Since a robust social support network is repeatedly observed as a key to successful outcomes in a holistic recovery plan (eg. Levack et al., 2010 ; Thomas et al., 2014 etc), it is imperative that significant family members and carers who support individuals in the immediate aftermath of a brain injury as well as over their lifetime are included in the process of understanding and designing interventions for identity reconstruction (Levack et al., 2010; Segal, 2010).

Recovery rarely follows a linear pathway and reconstruction of identity can be a significantly idiosyncratic process (Muenchberger et al., 2008; Thomas et al., 2014). Numerous studies that have explored the subjective experiences of identity following brain injury have, however, demonstrated commonalities across the spectrum. But the processes involved in rebuilding identity post injury, particularly as it transitions over the life span through various life stages, is not well understood. Exploration of this area is necessary in designing relevant interventions (Muenchberger et al., 2008). Additionally, not all patients experience this loss uniformly and some are better able to cope with it and rebuild a new identity. The reasons for these differences are unclear. (Myles, 2004; Thomas et al., 2014). Important directions for future research in the area can also include longitudinal studies with the objective of understanding which factors may contribute towards an understanding of changes in identity after brain injury and also delineating theoretical and therapeutic frameworks associated with such factors (Levack et al, 2010; Thomas, et al., 2014).

## **Limitations**

A few limitations do exist in this review. While a systematic search was undertaken to gather all relevant articles on identity reconstruction, the lack of consistency highlighted above meant that potentially relevant studies that used different terminology (such as personality change) may have been missed. This would also be true if studies used other associated terms such as self-concept or self-awareness. A lack of consistency in terminology and defining identity was also observed while conducting the systematic search and this served as a hurdle in the review. However, most of the articles pertinent to the topic of the review were retrieved from the search to allow for a comprehensive picture of current literature exploring the process of identity reconstruction to be reported in the review. Additionally, most of the studies considered for this review had a fairly small number of participants, as is usually the case with studies in brain injury. Understandably, this does have an impact on the generalisability of what was reported in the studies and in this review. Finally, as mentioned in the exclusion criteria, this review did not include specific studies on stroke as extensive research into stroke has meant a large number of articles on the role of identity in treatment already exist. It might be helpful for this topic to be considered separately for a review in order to improve current empirical understanding of identity in stroke literature.

## **Conclusions**

Identity plays a major role in how people understand themselves and relate to others (Muenchberger et al., 2008). Brain injury affects identity by causing changes in traits, abilities and capacity to perform pre injury roles that make up an individual's identity. Thus, a key part of rehabilitation lies in facilitating identity reconstruction. Historically, this part has often been neglected (Heller et al., 2006) as reduction of

impairment and improving function have taken precedence (Morris, 2004).

Understanding this period of transition is central to facilitating holistic rehabilitation (Muenchberger et al., 2008).

Reconstructing identity ultimately involves accepting changes in lifestyle and future goals. It is also marked by rediscovering a place in the world and a sense of self. Positive adjustment in the long term is achieved from a balance between continuity and change as individuals reconnect with values that contribute to their sense of fulfilment resulting in the formation of an adaptive self (Ownsworth & Haslam, 2014; Ylvisaker et al., 2008). People find meaning from new roles, interests or priorities post injury, often as result of involvement with support and advocacy groups. This contributes to enhanced self-esteem and improved life satisfaction (Douglas, 2013; Haslam et al., 2008; Nochi, 2000; Ownsworth & Haslam, 2014). Moreover, addressing the conflict between cognitive processes such as memory and executive functions and emotional concerns such as anxiety, anger and depression allows for a more cohesive identity to be reconstructed along with the reestablishment of healthy social support networks leading to successful reintegration in the community (Dewar & Gracey 2007).

Successful rehabilitation that culminates in redefining the self is facilitated by strong social support networks, particularly family. It is also facilitated by a space to grieve for the lost self (manifesting as denial, anger and depression), accepting the injury, and learning to cope with the loss by adapting previous coping styles (Coetzer, 2008; Fraas & Calvert, 2009; Klinger, 2005). On the other hand, withdrawal, diminished support systems and a negative sense of self interfere with the reconstruction of identity and prevent individuals from living meaningful lives (Ellis Hill & Horn, 2000).



In recent years, change in identity has acquired significant importance in emerging literature discussing the impact of brain injury. This has been marked by a shift towards more person centred rehabilitation programmes that encourage treating the patient as a whole person as opposed to simply focusing on bodily functions and movement (Ben Yishay 2000; Lepledge et al 2007 as cited in Segal, 2010 and Thomas et al., 2014 ). The move towards client centred care has meant that findings from studies exploring patient experiences of brain injury and self-reported changes in identity are now treated with more credibility and importance than ever before (Levack et al., 2010; Myles, 2004; Thomas et al., 2014). Additionally, it is increasingly recognized that changes in identity may contribute to poorer outcome in rehabilitation as well as lead to a number of mental health concerns following injury (Cantor et al. 2005; Ylvisaker et al., 2008). Consequentially, these concerns have heightened the importance placed on change in identity, marking it as a central issue for clients with brain injury (Levack et al., 2010). Identity reconstruction is, thus, fundamental to successful adjustment following a brain injury (Douglas, 2010).

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**PART 2: EMPIRICAL PAPER**

**Unpacking the ‘Black Box’ of Patient-Centred Care in Neurological Rehabilitation:  
Exploring the Process of Setting Goals.**

## **Abstract**

**Aims:** The aim of the study was to explore and examine the processes and experiences of goal setting at an inpatient rehabilitation unit by video recording and rating goal setting sessions. Another aim of the study was to explore staff, patient and carer perspectives in encouraging patient centred goal setting behaviour by using a newly introduced tool for the purpose of facilitating these behaviours.

**Methods:** Data was collected using three different methods. Goal setting sessions were video recorded and the interactions were coded using a checklist of behaviours. The checklist was compiled from structured observation tools in patient centred care. Simple rating scales were used to record the experience of the sessions. Results from the rating scales were reported using simple descriptive statistics. Focus groups were used to explore staff, patient and carer perspectives in use of a tool that enabled patient centred behaviour. Data from the focus groups was analysed using thematic analysis.

**Results:** The behaviour checklist coded four categories of behaviour – goal setting, goal setting related patient-centredness, generic patient centred behaviours and documentation. A fifth category of behaviours observed from the recorded sessions were also noted. Patients, carers and staff also reported experiencing the sessions as satisfactory with sufficient support and involvement in treatment planning. Focus group results identified three main themes of benefits, barriers and suggestions for using the tool.

**Conclusions:** Exploratory research into the processes involved in setting collaborative goals is crucial in identifying factors that contribute to successful outcomes. The checklist of behaviours could be further developed and used to train and monitor staff. The goal setting tool may be useful as a teaching aid to develop and encourage these behaviours.

## **Introduction**

### **Goal Setting in Neurological Rehabilitation**

One of the fundamental features of all rehabilitations processes, including neurological rehabilitation, is goal setting (Holliday, Antoun & Playford, 2005). It is considered an essential feature of best practice in all areas of rehabilitation. (Barnes & Ward, 2000; Playford et al., 2000; Wade, 2009). Goal setting can be defined as a process of decision making which usually entails patients and staff engaging in dialogue to come to a common agreement on behaviour targets and main priorities for the patient, as well as a desirable level of performance to work towards for achieving these targets in a specific time period (Playford, 2014; Scobbie, Wyke & Dixon, 2009).

Despite the significance of goal setting in rehabilitation, there is very little documented evidence on how institutions and organizations go about this process. Research in goal setting has flourished in recent years. However, there is still a lack of consensus on the process and practice of setting goals (Levack & Siegert, 2014). Researchers continue to question what constitutes the main components of goal setting in neurological rehabilitation. Contemporary research studies have highlighted the need for further enquiry and exploration in this area in order to answer these questions in a satisfactory manner. Furthermore, varying conditions and variation in chronicity usually signify differing needs, and this may require different goal setting processes for these needs to be addressed efficiently and effectively (Playford et al., 2000).

As goal setting continues to grow in importance, two important trends have been observed in the literature. One of them is the importance of conducting research on goal setting, grounded in sound psychological theory (Scobbie et al., 2009; Siegert, McPherson & Taylor, 2004; Siegert & Taylor, 2004) drawn from theories of goal setting

in the fields of education, sport, social cognition, personality and organizational psychology. These theories have also received attention in rehabilitation research in order to help develop stronger conceptual and theoretical frameworks (Siegert, O'Connell & Levack, 2014). The second trend has been the shift to person centred goal setting due to its growing popularity as the preferred approach in rehabilitation despite a lag in implementing it (Barnard, Cruice & Playford, 2010; Levack, Dean, Siegert & McPherson, 2011; Parry, 2004).

### **What is Patient Centred Care?**

While there does not exist a universal definition for person centred care in research, one of the most comprehensive reviews of tools for measuring patient centred care (De Silva, 2014) defines it as a system that supports patients to make informed decisions and choices regarding their health care, including who they may invite to participate in delivering it (e.g. relatives, carers). Such a system encourages healthcare services to work in partnership with patients during assessment and planning in order to meet both health goals and patient needs. A key component of this is holding patients and families at the centre of the decision making process and providing choices in order to encourage independence and autonomy, paving the way for efficient and effective self-management plans. Patient centred care is often viewed as a holistic approach to health that takes into consideration individual preferences, needs and social circumstances to design personalised health plans and solutions that are best suited for each individual patient (Bright, Boland, Rutherford, Kayes & McPherson, 2012; Brown et al., 2014; De Silva, 2014).

## **Patient Centred Care and Goal Setting**

Goal setting is an essential feature of the decision making process that ensures engagement of patients in their recovery, thus promoting patient centred care (Doig, Fleming, Cornwell & Kuipers, 2009; Holliday et al., 2005). Patient centred care through goal setting aids in improving outcome and patient autonomy by strengthening patient participation. A shared undertaking of setting goals allows for personally meaningful goals to be specified (Dwamena et al., 2012; Holliday, Cano, Freeman & Playford, 2007). However, there is no single defined way of going about the process of setting goals and several different approaches are used by professionals which usually involve an agreement on achievable tasks and the steps in performing these tasks (Playford et al., 2000; Wade, 1999).

Historically, goal setting was carried out by therapists and the goals were handed to patients, to be fulfilled. As clinical rehabilitation advanced during the 1970s, there was also increased concern regarding patient participation in clinical decision making, which had not been the focus of previous research. Becker, Abrams, and Onder (1974) suggested that processes for enhancing patient participation in goal setting could improve adherence to treatment regimes, while Trieschmann (1974) linked patient participation in goal setting to ethical obligations such as working towards outcomes that were individually meaningful and valued by patients. Decades later, Webb and Glueckauf (1994) questioned the widespread notion that patients with brain damage and neurological difficulties were unable to make decisions regarding their goals and, should have these set for them by professionals. Their study demonstrated an increase and maintenance of therapeutic gains amongst those patients who were given the opportunity to have a higher level of involvement as compared to a low- involvement group.

Goal setting has evolved into a more collaborative process over the years as the importance of patient participation has come to light through research (Webb & Glueckauf, 1994). Change in guidelines for setting goals in rehabilitation have reflected this shift (Turner-Stokes, Williams, Abraham & Duckett, 2000). Growing evidence (Baker, 1990; Hall & Dornan, 1988; Wensing, Jung, Mainz, Olesen & Grol, 1998; Williams & Calnan, 1991) suggests that these interpersonal factors outlined under patient centred care are highly valued by patients. Patient centredness as a model of working in rehabilitation gives respect to the patient and allows the individual and family to take responsibility for their treatment thus facilitating engagement. This has been found to increase adherence to task, improve satisfaction, increase goal attainment and sense of control over treatment and improve overall outcome (Latham, Mitchell & Dossett, 1978; Leach, Cornwell, Flemming & Haines, 2010; Levack, Dean, Seigart & McPherson, 2006; Locke & Latham, 2002).

### **The Current Practice of Setting Goals**

A survey conducted on behalf of the British Society for Rehabilitation Medicine concluded that most of the rehabilitation services in the UK used goal setting routinely and involved patient, families and carers in the process (Turner-Stokes et al., 2000).

However, another detailed nationwide survey of the goal setting methods used in rehabilitation across UK was conducted by Holliday, Antoun and Playford in 2005 to answer questions surrounding the process of setting goals. It found that a majority of services discussed goals for patient within a multi-disciplinary team without the presence of patients. The survey also uncovered that less than 5% of the services used any standard goal setting questionnaire to establish goals. It was found that there was little to no input from patients in the development and evaluation of goals and information about these

processes was rarely discussed with them. A problem oriented approach was the most popular with clinicians and only 60% of the patients received a written copy of their goals.

Another study conducted by Barnard, Cruice and Playford (2010) explored the nature of interaction between practitioners and patients while establishing goals in neurological rehabilitation and identified that therapist led conversations guided this process and focused on achievability of goals.

### **Barriers to Patient Centred Care**

Despite the drive towards patient centred care and its centrality in viewing what constitutes successful rehabilitation, there seem to be barriers to achieving this in rehabilitation. As collaborative goal setting has the potential to improve performance (Locke & Latham, 2002) by integrating motivation, emotion and identity into the rehabilitation process (Siegert et al., 2004), it becomes important to identify and address these barriers.

A study conducted by Leach, Cornwell, Fleming and Haines (2010) found that a key aspect of therapist led and patient focussed rehabilitation practices that differentiated it from therapist controlled rehabilitation practice was education provided to patients and families. Practitioners of therapist led and patient focused groups emphasized the need for continuous education throughout rehabilitation to support the patient and families. Therapists also reported that setting goals at the level of impairment instead of the level of participation or values made it easier to measure and report outcomes objectively.

Patient centred goal setting can lead to increased motivation but barriers can also arise due to reduced ability to communicate which directly impacts patient participation

in setting goals. Patients could also present with 'unachievable' or 'unrealistic' goals (Doig et al., 2009; Fleming & Strong, 1995; Leach et al., 2010). Hafsteinsdottir and Grypdonck (cited in Leach et al., 2010) suggest that the discrepancy between goals outlined by patients and therapists is due to the difference in how recovery is defined by both groups and continuous education throughout the process of rehabilitation can help address this gap in understanding.

Another study by Barnard et al. (2010) suggested further training for staff to help identify and manage resistance in order to ensure increased participation from patients and manage covert disagreements better. Barriers of client passivity, impairments in cognition and self-awareness as a result of the brain injury, and time constraints, within the wider contexts of organizational culture and dominating models of practice, are also contributing factors in not being able to adopt a fully patient centred approach (Bright et al., 2012; Doig et al., 2009; Fleming & Strong, 1995; Siegert & Taylor, 2004).

There is a large amount of variation in how goal setting is practiced in different services and this is seen to be directly related to the lack of an in-depth theoretical basis to setting goals in rehabilitation. Few detailed studies of effectiveness have been carried out that examine the various interacting components involved in this process (Leach et al., 2010). Additionally, the specific task of setting goals is often limited to being outlined as a collaborative process that encourages patients to set personally meaningful goals for themselves after negotiation with the health care professionals or team. Practitioners continue to report a disconnection in goals set in the hospital and goals that may be personally meaningful to the patient and transferable to their life after discharge (Playford et al., 2009) particularly as these goals increase in complexity upon discharge (Siegert & Taylor, 2004) due to a shift in focus from physical disability to reintegration into community (Kuipers, Foster, Carlson & Moy, 2004). Effective involvement of patients



necessitates further exploration into the process of setting goals in order to facilitate patient centred goal setting, inform training practices, and investment of resources (Parry, 2004).

### **Rationale and Significance**

In treating the patient as an expert in their illness, a patient centred approach allows them to define their problems and goals, creating a sense of control, enhancing self-determination and increasing participation (Pollock, 1993). Thus, goal setting practice should preferably facilitate patient centred care. Growing evidence also points to the effectiveness of adopting a client centred approach to goal setting in neurological rehabilitation (Scobbie & Dixon, 2014).

However, the above studies suggest that involving patients in the process of goal setting is advancing haltingly and may be due to limited instruction on how this could be achieved. Research into the components of patient centred care in goal setting and neurological rehabilitation is limited. This also has an impact on how these components parts are understood and operationalised in order to deliver patient centred rehabilitation. Clinicians continue to work within their limited resources and understanding while trying to ensure patient participation (Bright et al., 2012).

Rehabilitation has often been described as a 'black box' due to this complexity which makes it difficult to identify specific factors that may contribute to a successful (or unsuccessful) outcome (Levack, et al., 2014). There is a pressing need to evaluate current practice in goal setting, including informal approaches to setting goals. These approaches could then be used to provide recommendations and develop better methods that allow for more opportunities for patients to guide their recovery (Prescott, Fleming, & Doig, 2015).

While studies have tried to investigate patient participation, few studies have examined how participation happens. One way of studying this is through analysing interactions as they occur in order to understand how collaboration takes place through negotiation and discussion, as well as what other factors may play a role in the final decisions made regarding goal setting (Barnard et al., 2010; Prescott, et al., 2015). Additionally, exploring patient, staff and carer perspectives is also essential in addressing some of the barriers and encouraging the use of collaborative tools that can improve the outcome of rehabilitation.

Addressing the gap between participation and personal relevance would be crucial in securing patient involvement in treatment and in augmenting self-governance in the long term management of neurological conditions while addressing common barriers (Prescott et al., 2015). This study was an attempt to address this gap by analysing clinician-patient interactions in the goal setting process, and by exploring patient, staff and carer perspectives on facilitating goal setting behaviours with the use of a newly introduced collaborative tool.

### **Aims of this Research**

Based on the above, the three main aims of this study were:

1. To explore the processes of goal setting by observing patient-clinician interactions in video recorded sessions of goal setting and coding them systematically using a checklist of behaviours,
2. To examine the subjective experiences of the goal setting process and sessions by asking staff, patients and carers to rate the sessions using simple rating scales, and

3. To analyse patient, staff, and carer perspectives on using a newly designed patient centred goal setting tool. This tool was developed as part of a joint research project with Agata Aleksandrowicz (2016) for the purpose of facilitating patient centred goal setting behaviours.

## **Methods**

### **Setting**

The setting of this study was an in-patient rehabilitation unit at a national hospital that specializes in rehabilitation of patients with neurological deficits. The rehabilitation process implemented on the unit adheres to clinical standards for specialist rehabilitation outlined by the British Society of Rehabilitation Medicine. Patients are referred to the unit from general practitioners, consultants and other hospitals at an average rate of 160 per year. Approximately a third of the patients present with stroke, a third with multiple sclerosis, and a third with non-traumatic spinal cord lesions. A small percentage of patients also present with other neurological conditions (central nervous system tumours and peripheral nerve disease).

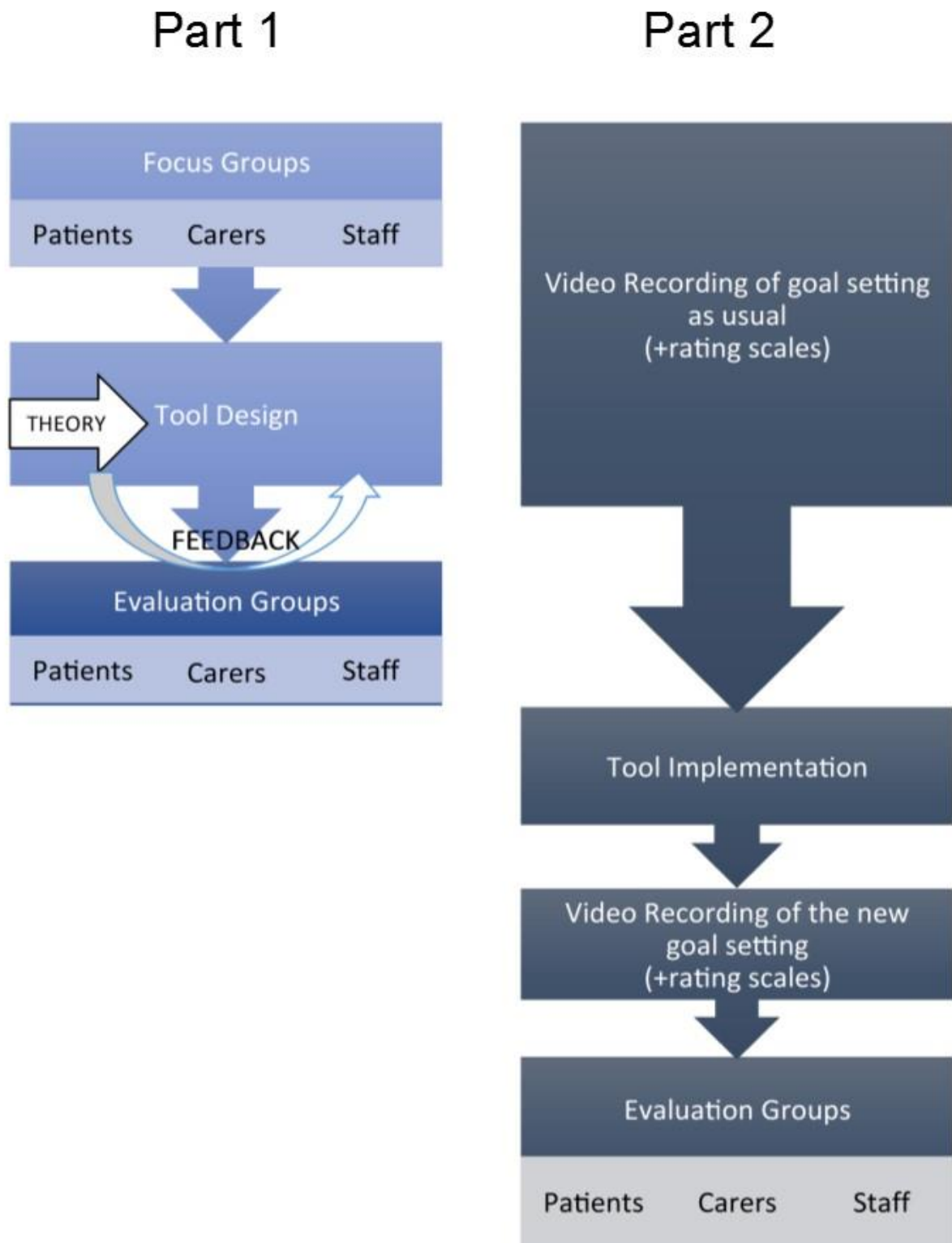
The current goal setting practices on the ward involve the patient meeting the team on admission. Patients work with the team for a week, at the end of which the team set goals for patients, based on discussions that take place informally in the first week. These goals are discussed in the staff meeting, which patients can choose to attend. They are revised and refined at the full multidisciplinary team (MDT) meeting before being given to the patients in writing at their 'goal setting session'. Progress on goals is then monitored on a fortnightly basis in review meetings. Patient participation may thus be limited as a result of a lack of a prescribed structure to ensure understanding and engagement in this process.

## Design

Neurological rehabilitation is a complex form of intervention involving several people, therapies and variables, each of which can affect the patient's individual response to treatment. The UK medical research council (MRC) guidelines for conducting research for complex interventions to develop them systematically indicate that theory identification and development is the first step towards carrying out an exploratory feasibility or pilot study to test the assumptions of the identified theory before conducting a full-scale randomized control trial (RCT) and disseminating it to a wider region (Craig et al., 2012). The first part of this joint research focused on creating a goal setting tool based on existing theories and literature in goal setting. This was led and written by Aleksandrowicz (2016) (see Figure 1 and Table 1 in Appendix A, also see sample goal setting pack in Appendix G).

The second part of this study, was a *mixed methods* study, aimed at examining clinician-patient interactions and the experience of goal setting. For this purpose, the study had three main parts. In the first part, existing goal setting practices on the ward were video recorded over a period of nine months. Data collected from the videos was analysed using a coding checklist (Appendix D) that was developed for this purpose. Such direct observation and examination of the interaction processes is one of the most commonly used methods in conducting research into patient centred care (De Silva, 2014).

Figure 1. Flowchart outlining Part 1 and Part 2 of the study design.



In the second part of the study, rating scales were distributed after each recorded goal setting session to document the experience of the sessions. Data collected from rating scales was reported using descriptive statistics.

In the third part of the study, evaluation focus groups were conducted with patients, carers and staff to explore the contributing factors in enhancing patient centred goal setting behaviours with the help of the newly designed goal setting tool introduced during this time period (Aleksandrowicz, 2016). The tool was meant to aid the process of setting goals. An interview schedule was used to guide the discussion in the focus groups (Appendix F). Data collected from focus groups was analysed using thematic analysis.

## **Recording and Analysing Videos**

### *Participants*

Participants in the various video recordings ranged from three people (patient and two staff members) to seven people (patient, staff members including nurses, and carers) depending upon who was present to attend the sessions (staff, patient, or carers).

### *Method of Data Collection*

Observation of encounters between patients and professionals through video recordings is often used when studying complex interactions involving decision making, such as the goal setting sessions in this setting. As a main component of patient centred care revolves around communication, direct observation allows for this to be examined while exploring other aspects involved in the process of shared decision making. De Silva (2014) carried out an extensive review involving 921 studies to examine the evidence for commonly used approaches and tools in measuring patient centred care and found observation (through audio and video recording) to be the most commonly used approach

when studies were focused on exploring such complex interactions (De Silva, 2014). While there is some concern for the validity of the interactions due to the presence of a recording device, research has indicated that participants often forget about the presence of such devices and it is unlikely to have a significant impact on the encounter. Additionally, it has been found that participants may even welcome the recording device if it contributes towards improving treatments (Martin & Martin, 1984).

Seventeen goal setting sessions lasting between 20 minutes to an hour were recorded using a video recording device. These sessions involved the MDT, patients, and sometimes, carers or family members as well. Sessions were recorded over a period of nine months. The newly designed goal setting tool was also introduced during this time and was incorporated into sessions recorded in the later stages of data collection.

#### *Method of Data Analysis: Compiling a Behaviour Checklist for Coding Data*

De Silva's (2014) extensive review identified coding systems, checklists and rating scales as some of the main methods of analysing data obtained from recorded or direct observations. Data obtained from video recordings is commonly analysed using coding systems or behaviour checklists that are developed from the data itself or from theory and previous research. Although researchers can vary widely in which of these coding methodology informs their analysis, it is often informed by existing practices in the research area. For example, studies on play in children are often known to utilize video observations as data, which is analysed or coded with the help of well researched and widely used checklists of behaviour (Jewitt, 2012). This practice is also known as quantitative observation (Barker, Pistrang & Elliot, 2002).

For the purpose of analysing data for this study, a checklist of goal setting and patient centred behaviours was compiled. A key step in developing such a measure is

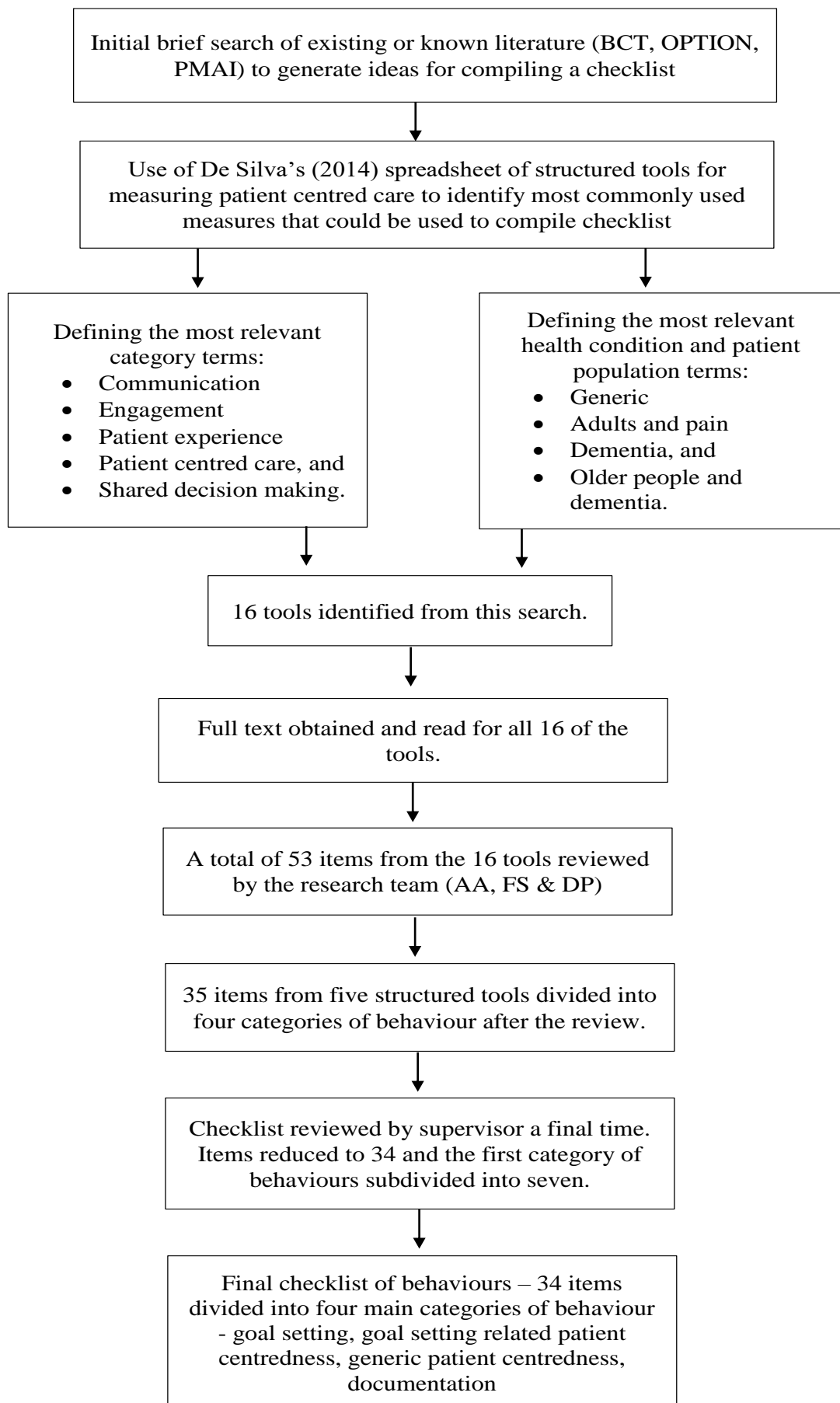
defining the specific behaviours that are to be observed and recorded. These behaviours can usually be defined, both from previous literature and research as well as from the data itself (Barker et al., 2002). In order to define the behaviours for this checklist, literature and tools on behaviour change and patient centred care, such as the Behaviour Change Taxonomy (BCT, Michie et al. 2013), Dyadic OPTION instrument (Melbourne, Sinclair, Durand, Legare & Elwyn, 2010), Four Habits Coding Scheme (Krupat, Frankel, Stein & Irish, 2006), and Participation Method Assessment Instrument (PMAI, Baker et al., 2001) were initially reviewed. This was done to gain an understanding of common tools used to measure patient centred care.

Following the initial review, the preliminary list of behaviours for the checklist was compiled using a spreadsheet document published with De Silva's (2014) comprehensive review for measuring patient centred care (see Figure 2 for summary of this process). This document listed 160 of the most common structured tools used in research to measure patient centred care (accumulated from reviewing around 200,000 studies published between 2000 and 2013). The tools included in the list measured holistic patient centred care or one of the six most commonly recurring components of patient centred care reported in literature. These components were experience, dignity, activation, self-management, shared decision making and communication (De Silva, 2014).

Tools listed in the document were divided into options that could be selected (or unselected) to identify measures for one or more category of patient centred care, a specific health condition or patient population, and country of origin of the measure.



Figure 2: Process of compiling the behaviour checklist



The categories selected under the option of patient centred care for identifying measures that would inform the compilation of the checklist were communication, engagement, patient experience, patient centred care, and shared decision making. The health condition and patient population defined were generic, adults and pain, dementia, and older people and dementia. This search identified 16 tools in the spreadsheet. No country of origin was specified.

Full text articles were obtained for studies that included these 16 tools in their publication. Relevant items or behaviours were identified from these tools and compiled into an initial checklist of behaviours consisting of 53 items. The checklist was discussed between the researchers (AA & FS) and the supervisor (DP) and repetitive items were removed from the list. Five tools contributed in the compilation of the finalised checklist. These tools were the Four Habits Coding Scheme (Krupat et al., 2006) Dyadic OPTION instrument (Elwyn et al., 2003; Melbourne et al., 2010), Participation Method Assessment Instrument (PMAI, Baker et al., 2001; Northen, Rust, Nelson, & Watts, 1995), Decision Making Instrument (Weiss, & Peters, 2008), and the Behaviour Change Taxonomy (BCT, Michie et al. 2013).

A total of 35 items and behaviours compiled from these tools were divided into four main categories of behaviour - goal setting, goal setting related patient-centredness, generic patient centredness, and documentation (see Appendix D). The items on the checklist were further discussed and reviewed with the supervisor (DP) and the first category of goal setting behaviours was divided into seven subcategories – scene setting, problem identification, solution finding, goal setting, information provision, problem solving, and regular monitoring. The final checklist consisted of 34 items divided into four categories of behaviour with the first category further subdivided into seven types of behaviour.

The consistency threshold for the occurrence of the behaviours defined in the checklist was set relatively low and defined as more than two clear occurrences of the indicated goal setting or patient centred behaviour. The behaviours were marked as simply present or absent on the checklist.

For analysing the data, 15 of the 17 recorded videos were coded as two of the videos were excluded upon further discussion with staff. The reason for excluding one of the videos was severe impairment in communication skills of the patient who was recorded. A second video was excluded upon clarification from staff that the session recorded was a review session as opposed to a goal setting session. The researchers (AA & FS) coded one video jointly using the checklist and discussed disagreements. A second video was coded independently and inconsistencies and disagreements in the coding were discussed between the researchers (AA & FS), before being discussed with the supervisor (DP) until consensus was reached.

The remaining videos were coded independently using the checklist by one of the researchers (FS). The second researcher (AA) noted examples of behaviours for each category and sub category of behaviour defined in the checklist, as opposed to marking behaviours as present or absent. As a result, inter-rater reliability of the checklist has not been established.

## **Rating Scales**

### *Participants*

All participants who participated in the first part of the study (video recording of goal setting sessions) were invited to rate their experience of the session. However, not all participants returned these scales or consented to completing them. A total of 12 patients

and six carers returned their rating scales. As staff participated in more than one recording of the goal setting sessions, they also provided ratings for more than one session. A total of 47 completed rating scales were returned by staff members.

#### *Method of Data Collection*

Simple Likert rating scales were created for patients, staff and carers to measure their subjective experience of the goal setting session in terms of shared treatment planning. These rating scales were created from a list of patient satisfaction measures assembled by De Silva (2014), as well as literature on patient centred communication and patient participation in neurological rehabilitation and goal setting (e.g. Baker, Marshak, Rice & Zimmerman, 2001; Barnard et al., 2010; Elwyn et al., 2013; Epstein et al., 2003; Leach et al., 2010; Lindberg et al., 2013; Lloyd, Roberts & Freeman, 2014). The rating scales addressed areas such as the relevance of goals, confidence in achieving them, support in pursuing them, perceived autonomy of the experience of goal setting, and overall satisfaction with the process.

#### *Method of Data Analysis*

The rating scales were analysed using simple descriptive statistics.

### **Focus Groups**

#### *Participants*

A total of five focus groups were conducted. Two focus groups were conducted with staff. Twelve staff members participated in the first of these focus groups and four staff members participated in the second. A further two focus groups were conducted with carers. Three carers participated in the first focus group and four carers participated

in the second focus group. Finally, one focus groups was conducted with patients and five patients participated in this group.

#### *Method of Data Collection*

*Focus groups* were used to collect data on encouraging goal setting behaviours by using a newly designed goal setting tool (Aleksandrowicz, 2016). Focus groups are used for an in depth understanding of people's perceptions, opinions, and the ways in which they make meaning (Levers, 2006). They are considered a useful method of data collection for exploratory studies and for evaluating new health programmes (Dawson, Manderson & Tallo, 1993). These groups were conducted consecutively during the video recording of sessions. Interview schedules were used to guide the discussion in these focus groups (Appendix F) and these were refined from the interview schedules used in a previous study by Holliday, Ballinger and Playford (2007). The groups lasted between 30 to 45 minutes and the discussions were recorded with the use of two audio recording devices.

#### *Method of Data Analysis*

*Thematic analysis* is a widely used qualitative analytical method. It is a method for “*identifying, analysing and reporting patterns (themes) within data*” as defined by Braun and Clarke (2006). It is one of the primary methods used to consolidate and describe data. It is also considered to be more accessible than other qualitative methods of analysis and provides a rich, detailed and complex account of the data (Braun & Clarke, 2006). Simple *thematic analysis* was used to examine focus group data as opposed to other qualitative methods such as a grounded theory approach that is used primarily for generating a model or theory, which was not the purpose of this study (Charmaz, 2006; Glaser & Strauss, 1967).

Data from the focus groups was transcribed by research assistant volunteers who also contributed to the credibility of the analysis by coding themes from transcripts they had been assigned to transcribe. The transcripts were checked for accuracy by the researcher (FS). This also provided an opportunity to familiarize with the data before coding it for themes. Data from each participant group (patient, carer, and staff) was first grouped together and coded separately for initial themes. This was done independently by both the researchers (AA & FS). The emerging themes were discussed between the researchers and the research assistant volunteers before being discussed with the supervisor (DP). Similar themes across the three groups of participants were then refined and assimilated into one group in the final analysis by the researcher (FS) following these discussions. The final themes and subthemes were also discussed with the second researcher (AA) and supervisor (DP).

The themes that emerged were indicative of the participants' understanding and experience of setting goals in their rehabilitation using a tool that could support this process. Such a detailed exploration was also the first step in conducting a pilot test on the goal setting tool and revising it based on the findings of this study.

## **Procedure**

The section is divided into three sections to reflect the three main phases of the study, the recruitment process, data collection, and the process of analysing data.

### *i. Recruitment Process*

All data for the study was collected at the in-patient ward at the hospital. All therapy staff on the ward, patients admitted to the ward who had capacity to consent, and carers and relatives of the admitted patients were eligible to participate in the study. Only those patients who had limited cognitive and communication skills which would affect

their participation were excluded from the study and not approached for consent upon the recommendation of the therapy team.

All participants on the ward were approached to take part in the discussion. The staff members were approached and introduced to the study in a team meeting. The patients and carers were approached after an initial discussion with their key workers about capacity, cognitive ability and communication skills. All participants were provided with information sheets and consent forms and up to 24 hours to consider their participation in the study. For patients who were unable to sign their consent forms, verbal consent was obtained in the presence of a third staff member who also signed the consent form as a witness. Verbal consent was also obtained and documented for some carers who were unable to return the consent forms. All participants were able to choose if they wished to participate in the video recordings or focus groups or both. Patients and family members or carers were made aware that choosing to participate or not in one or both parts of the study would not affect their treatment (or their relative's treatment) on the ward.

A total of 50 participants took part in the video recordings of goal setting sessions and in focus groups, which were conducted to collect data for this study. Of these, 18 were patients on the ward, 14 were carers of patients admitted to the ward, and the remaining 18 were staff members. As staff members formed part of the MDT comprising physiotherapists, speech and language therapists, occupational therapists, clinical psychologists, social workers, nurses and neurology consultants involved in delivering intervention to patients, several staff members were present in more than one video recording and also took part in the focus groups for staff. Similarly, some of the patients and carers who took part in the video recordings also took part in the focus group discussions.

*ii. Data collection*

Data for the study was collected from video recordings, rating scales and focus groups. A video camera was set up before the goal set session took place for patients who had consented to participate in the recording. Rating scales were distributed at the end of each of the recorded sessions. The focus groups were organized separately with staff, patients and carers during this time and depending upon availability.

*iii. Data Analysis*

A total of 15 videos were analysed using the compiled behaviour checklist. Disagreements in the coding of these videos was discussed with the supervisor (DP). Data from the rating scales was analysed using simple descriptives to highlight the main findings. Data from the focus groups was coded independently by the two researchers (AA & FS). Themes were discussed with the research volunteers who had transcribed it. The accrued themes were then discussed with the supervisor and organized into three main themes with several subthemes (Table 4).

An iterative process guided the study and field notes collected during the process of conducting the research contributed to a richer analysis of data by documenting important information and observations during data collection.

### **Credibility Checks**

Analysis was carried out by two researchers (AA & FS) who coded the data for the videos and focus groups. The two researchers coded one video jointly and one video independently before discussing disagreements. The remaining videos were coded independently by one of the researchers (FS) using the checklist of behaviours. The second researcher (AA) recorded up to two examples of behaviours corresponding to the various categories and sub categories of behaviours defined in the checklist.



Data from the five focus groups was coded independently by both the researchers. Themes were further discussed with research assistant volunteers who transcribed the data from the focus groups. All disparity in coding data from the videos and the focus groups was discussed with the supervisor (DP) who had previously conducted studies using video recordings and focus groups as data. Additionally, the field notes written during data collection also provided important contextual information for analysis.

### **Ethical Considerations**

Full ethical approval for the study was granted by NHS London Queen's Square Joint Research Ethics Committee (see Appendix B)

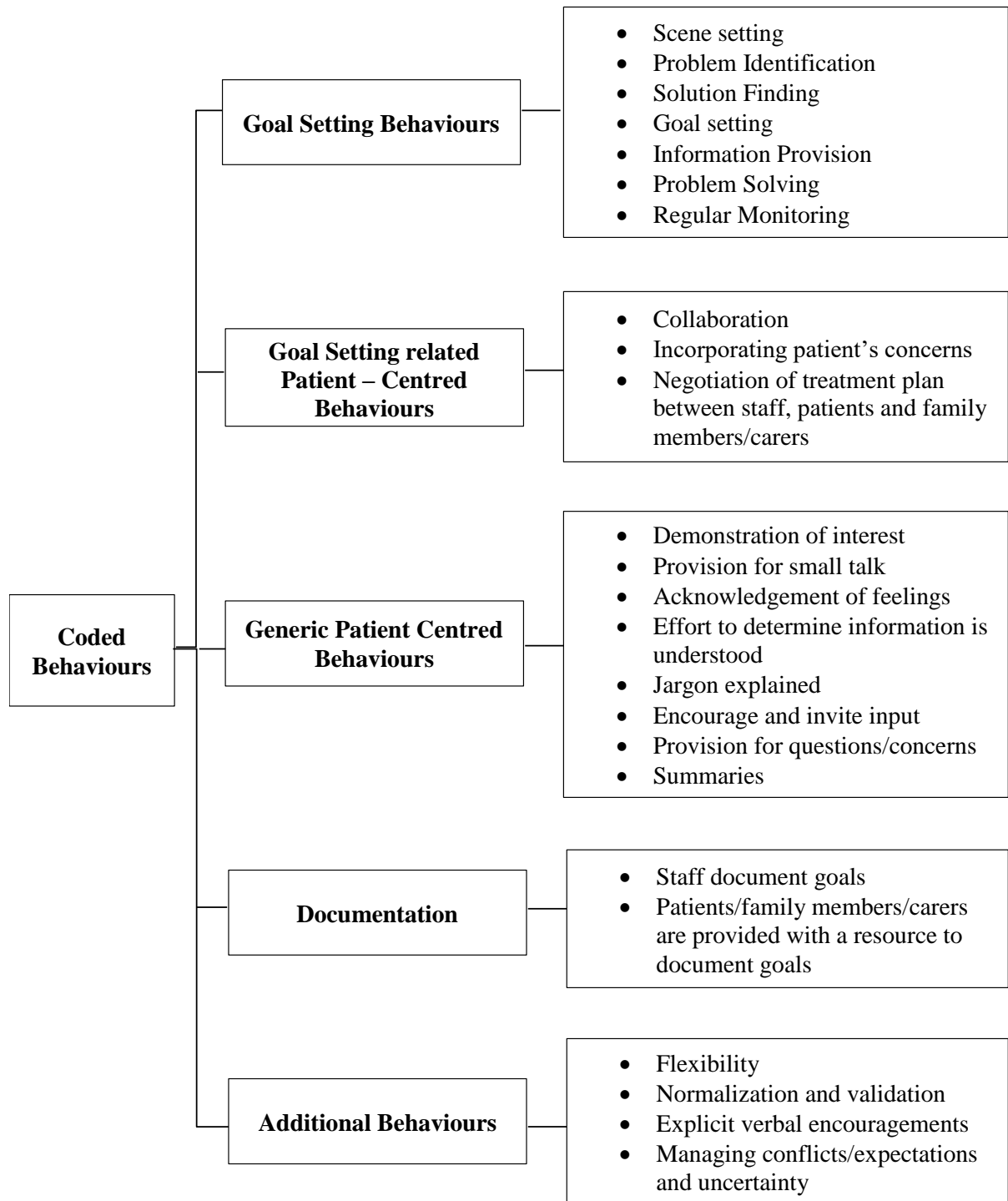
## **Results**

The results section below is divided into three main parts based on data obtained from the video recordings, ratings scales and focus groups. For the first part of the results, data from video recordings was coded and analysed to explore patient clinician interactions in the process of setting goals.

### **Coding and Analysis of Videos based on a Checklist of Behaviours**

The final checklist of behaviours compiled from tools for measuring patient centred care was composed of four main parts. The analysed data was divided into these four parts and an additional set of behaviours not identified in the compilation of the checklist. Figure 3 presents a diagrammatic summary of the behaviours coded in analysing the video recordings.

Figure 3: Diagrammatic representation of coded behaviours.



i. *Goal Setting Behaviours*

Under this section, seven main kinds of goal setting behaviour were described and coded.

a) ***Scene setting*** – Scene setting behaviours introduced and explained goal setting and treatment planning on the ward, collaboration and the role of the patient and carers or family members, and the concept of short term and long term goals. This was done in the goal setting session by one of the members of the assigned therapy team. Coding of the videos identified this as usually occurring in the beginning of the session and following a similar approach in explanation as the below examples.

*“At the end of the first or second week (of your admission) we all sit down, as much of the team as is around and talk about, one, what we want and what you want to achieve, while you are here with us, so some targets and some goals that you want to work towards. And then, two, we have a think about how long you might be with us as well, okay?”*

*“So in this session, we talk about how long you are going to be here and we set goals for you to achieve by the end of the admission. We call them long term goals and they will get followed up in the community to carry on working with you... And then every two weeks we set some short term goals which will help you in achieving the long term goals. It helps to focus the admission on what you want to achieve and what needs to be achieved. Does that make sense?”*

*“Your whole stay here is about preparing for life out of here. So it’s not just about what you can do now but also thinking about what you want to do in the future as well. And that might be hard to work out, how you are going to get there but that’s*

*our job really to think about ways you might be able to do that. So have a think and if you have any ideas just let us know”*

In the above examples, staff differentiated between the hospital stay and life after discharge in thinking about short term and long term goals, although sometimes without labelling them as such. Difficulties in coding were noted when staff did not explicitly label working together with the patient and families as a collaborative approach while explaining their role in helping the patient set goals that are important or meaningful to them or when staff did not label goals as short term and long term when explaining them.

**b) *Problem identification*** – Behaviours under this category identified main areas of concerns for the patients, how these concerns affected the patient and family members’ lifestyle, and what the importance of these concerns was for the patient. Staff also explored additional goals relevant to rehabilitation that were otherwise not identified by the patient or family member under this category.

*“When we first talked, when you were on the other ward, you told us about a couple of key things that you wanted to get better...”*

*“You used to travel, what are you thinking about in terms of getting back to that? It is important to know what your priorities are for now and for the future.”*

*“What is your number one priority in day to day life?”*

However, in sessions when discussion of interests was treated as inconsequential, goals were based on discussions within the therapy team and focused on goals that therapists expected patients to achieve before discharge. Coding such didactic conversations was challenging as the checklist was primarily designed to capture patient centred communication which involved a more open two way communication.

A combination of open ended and close ended questions were generally used to identify, explore and finalize goals that were most relevant to patients in *collaborative* sessions that demonstrated these behaviours clearly, as opposed to instructive sessions that would often be focused on meeting goals identified by the rating system used on the ward to document goals.

c) ***Solution finding*** – These behaviours were defined as those that assisted patients in identifying goals by discussing information in various contexts that supported the identification of goals. This involved discussing and considering the relevance of initial assessments carried out on the ward in the first week of admission, use of examples in identifying goals, discussion of past roles and responsibilities, discrepancies in current and desired abilities, and consideration of other life goals while setting goals for rehabilitation.

*“So when we first talked, so when we came over to see you on the other ward, you talked to us a little bit about a couple of the key things that you really wanted to get better. And some of it has already started to happen actually. So what we’ve done already is we’ve gone through a list of what we found from our assessments about what problems we’ve come across. So things like to do with the weakness in your arm, the sensory problems in your arm and the leg, problems with your balance, problems with getting to the loo... and how that affects your daily activities, so what you can do and what you can’t do and what you were doing before. So now the next bit is to try and identify the big goals you want to work on between now and when you go home.”*

Sessions that demonstrated these behaviours clearly often explained the initial assessments and continued to use its findings in discussing previous roles and abilities as

well as desired achievements. In some of the later recorded sessions, questions around identity also started to be incorporated while exploring past abilities and roles.

However, it was noted that solution finding behaviours were less consistent and clear when coded, in comparison to other goal setting behaviours. Often solution finding discussions were combined with other types of behaviours, particularly problem identification behaviours, thus making it harder to code these behaviours in a consistent manner.

**d) Goal setting** – This behaviour included writing goals that could be understood by the patients and family members, and preferably using the patient’s own words. A clear distinction in coding these behaviours was observed in sessions that demonstrated them and those that did not. Sessions that did not demonstrate these behaviours often started by listing goals the therapy team had put together before asking the patient about what they wanted to add to the list. Collaborative sessions, on the other hand, involved staff asking the patient how they would like to frame a particular goal for the purpose of documentation.

*“What do you think?” “How would you like to word it?”*

*“I’m trying to put this in your words... feel free to change it...”*

Most staff members demonstrated this behaviour consistently over the course of data collection by asking a variation of the above questions.

**e) Information provision** – This category coded staff behaviour that provided additional information about the goals being set either by explaining the rationale behind specific goals or by breaking down goals into manageable, measurable, and achievable steps.

*“It is kind of like a map, all of those things will contribute to that, I agree with you. Toileting and self-care and being able to turn yourself in bed, they will contribute to being independent”*

*“We were thinking we might not be able to get you walking in twelve weeks, but we will start by working on getting you to stand up, that’s the first step in walking, isn’t it.”*

*“In the next two weeks, what would you like to work on, if we are thinking of the stepping stones to the big goals?”*

This behaviour did not take place consistently in the sessions that were recorded at the start of the study. However, as data collection progressed, most sessions began to discuss long term goals which were then divided into short term goals and broken into stages or steps.

In some instances staff were also able to link the relevance or rationale of the goals being set to life after discharge and introduce the notion of continuity in treatment and the transferability of goals from the ward to the community, however, this behaviour was harder to code on the checklist due to a lack clarity in defining continuity within the category of behaviours on the checklist.

**f) Problem solving** – This category coded behaviours involved in discussing barriers and facilitators to achieving specific goals as well as generating strategies for overcoming potential barriers or increasing facilitators in working towards goals.

*“And what do you feel is stopping you from doing that at the moment?”*

*“What would help you with it?”*

*“Some bits will be tricky, like using the knife, but we can use different types of equipment.”*

While the above were noted as good examples of this behaviour, a discussion on barriers and facilitators, and strategies to overcome and increase each of them respectively was often not initiated or explored in detail in most sessions. Personal strengths and weaknesses that could enable or hinder goals were not discussed in any of the recorded sessions.

**g) Regular monitoring** – This category of behaviours was simplest to code and often demonstrated by making arrangements for a review session in two weeks or by explaining to the patients and family member that goals can be updated and revisited at various times during the course of admission.

*“So if we are looking at 12 week admission, we’ll be looking at how much progress we have made with your arm and leg around 6 weeks’ time and then review your remaining stay.”*

**ii. Goal Setting Related Patient Centredness**

The next set of behaviours focused on goal setting behaviours that appeared to be related to patient centredness as well. This category coded behaviours such as collaboration, incorporation of patient’s concerns while exploring goals, and negotiation and agreement on the treatment plan.

*“We have also thought about certain areas for goals but these are completely changeable to what you want and what is important to you.”*

*“We are just trying to think of a way we can capture that you want to improve your balance and that also shows that your balance has improved.”*



*“So we were thinking that could take three weeks, but this is not us deciding for you, it is not set in stone, you can tell us what you think about it.”*

*“What you were saying before about getting tired, do you think it will be... you know how we have talked about fatigue and managing that and T (staff member) has talked about pacing... do you think it will be helpful...?”*

A collaborative approach indicated to the patients and family members that the staff were present to provide the support needed for them to undertake meaningful activity that may have become interrupted due to their injury. It was differentiated from a top down approach which usually involved close ended questions.

### *iii. Generic Patient Centred Behaviours*

This category recorded behaviours that indicated generic patient centredness. The recorded behaviours included:

- a. Body language and verbal indicators of interest and encouragement recorded by observing *nodding*, or using continuers such as, *“Go on”* or *“Hmm”*.
- b. Efforts to clarify information and ensure the patient had understood what was being said, often observed, for example, by *pausing* to give time to the patient to absorb the information, or by *explaining jargon* such as goal setting, or short term goals and long term goals
- c. Provision of space for small talk and to raise concerns or ask questions, for example, *“Do you have any questions so far?”* Occasionally, however, the provision of this space to ask questions was not conveyed to the patient or family member.
- d. Acknowledgment of difficult feelings. This was observed to occur less consistently, than other patient centred behaviours that were observed at

regular intervals throughout the session, in all recorded sessions. On occasion, feelings of loss and grief were not acknowledged or acknowledgement of feelings would often be accompanied with focusing on an outcome or a solution, particularly when a challenging goal was being discussed.

*“A lot of people have that worry, but I suppose it is about giving you as much independence while you are here.”*

- e. Invitation to patient and family members or carers to contribute to the decision making process.

*“What would be helpful for you?” “What is important to you?”*

*“Do you want to change that goal to something more achievable in shorter time or do you want to stick out for the longer term one?”*

- f. Summarizing of the goals and sessions. This was also observed as occurring inconsistently in the recorded sessions and often at the very end of the session when a list of short term and long term goals was read out. A summary of other details discussed in the session was not observed in all the recorded sessions that were analysed.

#### iv. *Documentation*

This category coded behaviour that enabled recording the details of the sessions, particularly the goals, by using a tangible method such as, writing out a list of goals or providing a resource to patients and carers to record the goals. In coding this behaviour, it was observed that all sessions included providing the patients a printed copy of the agreed goals at the end of the session. However, an additional resource to record details was often not provided to patients and carers. In sessions that utilized the new goal setting

tool, patients and family members or carers had this resource in the booklet to document session details or goals.

v. *Additional Behaviours not Defined in the Checklist*

A few of the behaviours not defined in the compiled checklist were also observed in the analysis of the recorded videos. While these behaviours were not coded on the checklist, they were recorded separately during analyses of the videos. While some of these behaviours did not occur in a majority of the sessions, when they did occur, they appeared to support collaboration and reinforce patient centredness, particularly in situations that involved a difference of opinion. In some instances, the absence of these behaviours was also noticeable, such as the absence of normalization or validation of feelings of loss and grief following a brain injury. The behaviours were coded separately upon observation as follows:

a) ***Flexibility*** – This behaviour indicated flexibility in setting goals and in updating or reviewing them as treatment progressed. It was observed to be demonstrated by most participating clinicians in all recorded sessions. This flexibility was often indicated in various ways, such as -

*“...in case there are any changes in this area and you want to set goals later, I am always around.”*

*“Maybe you can try and see what that feels like over the weekend (at home), and then we can discuss it again (before discharge).”*

b) ***Normalization and Validation*** – This behaviour was recorded separate from acknowledging difficult feelings the patient may express. It involved explaining that the patients’ feelings, particularly of loss of pre-injury roles and bodily functions were understandable and experienced by most people with a brain injury.

c) **Explicit encouragement (particularly for previous achievements)** – This behaviour recorded expressions of explicit encouragement for previous achievements.

*“You did really well the other day, in the kitchen.”*

d) **Conflict management** – This category of behaviours included managing differences in opinion on treatment, goals etc., managing expectations for what may be achieved during the admission, and managing uncertainty about certain goals. Below is an example of one such interaction.

*Clinician, “Our initial thinking is that, the stairs might be difficult...”*

*Patient, “No I don’t think so.”*

*Clinician, “Let’s practice, let’s try, and see where we get.”*

This behaviour was observed to play a significant role in resolving conflicts in certain ‘difficult’ sessions that included a substantial amount of disagreement between the clinicians and patient’s understanding on the nature of the injury and its impact on functioning.

### **Analysis of Data from Rating Scales**

To examine the experience of goal setting, simple rating scales were used to collect data from patients, carers and staff members. These scales were distributed after each recorded goal setting session. This data was analysed using simple descriptive statistics, and is reported below.

#### *Patients and carers ratings*

Twelve patients and six carers returned their rating scales. Descriptive statistics are presented in Table 1 and Table 2. A majority of the patients reported that they felt the

goal setting process was a partnership between them and staff members all the time. Patients also reported that staff listened and responded to their queries in a way that they could understand. All carers reported feeling that their relative had been treated with respect and dignity throughout the session and most of the patients also reported similarly. Carers also reported that they felt they had an opportunity to speak about their concerns. Most patients and carers reported that staff made efforts to discuss goals that were relevant and meaningful to the patient throughout the session. Carers reported that they were provided with a sufficient amount of information to help in rehabilitation and agreed with patients that they felt supported in following their rehabilitation plan.

#### *Staff ratings*

A total of 47 responses were received from staff members for the 15 goal setting sessions that were analysed. Descriptive statistics for these responses are presented in Table 3. Staff reported that the goal setting process was perceived as a partnership most of the time. Additionally, staff felt patients could share responsibility for the goals that were set in the session most of the time. They also felt that they had involved the patient in the discussion and agreed that goals discussed were relevant to the patients.

Staff also reported that it was relevant to include activities and tasks most important to the patient in negotiating a treatment plan and tried to do this as often as possible. While most staff members agreed that they felt supported in including the patient in setting their goals, some staff disagreed and did not feel that they were supported in involving patients in goal setting.

Table 1: Mode, range, mean and standard deviation for patient ratings.

<i>Rating on</i>	<i>Mode</i>	<i>Range</i>	<i>Mean</i>	<i>Standard Deviation</i>
Perception of partnership	4	2	3.58	0.67
Provision to voice concerns/questions	4	2	3.67	0.65
Appropriate response to queries from staff	4	1	3.92	0.29
Satisfaction with role in process	4	1	3.67	0.49
Preferences about decisions respected	4	1	3.75	0.45
Treated with respect and dignity	4	1	3.83	0.39
Perception of relevance of goals	4	1	3.83	0.39
Opportunity to discuss everything	4	1	3.92	0.29
Perception of support	4	1	3.92	.29
Satisfaction with treatment	4	1	3.83	.39
Satisfaction with involvement in treatment	4	3	3.58	.90
Purpose of goal set explained	4	1	3.92	.29

Table 2: Mode, range mean and standard deviation for carer ratings.

<i>Rating on</i>	<i>Mode</i>	<i>Range</i>	<i>Mean</i>	<i>Standard Deviation</i>
Treated with respect and dignity	4	0	4	.00
Involved in care	4	1	3.83	.41
Provision to talk to staff (for relative)	4	1	3.67	.52
Provision to talk to staff (for self)	4	1	3.50	.55
Sufficient information provided	4	1	3.50	.55
Information provided was at the appropriate level of understanding	4	2	3.50	.84
Perception of relevance of goals	4	40	4	.00
Preferences respected	4	4	3.33	1.63
Satisfaction with discussion of treatment	4	1	3.83	.41
Perception of shared responsibility	4	2	3.50	.84
Staff explained purpose of goal setting	4	1	3.83	.41

Table 3: Mode, range, mean and standard deviation for staff ratings.

<i>Rating on</i>	<i>Mode</i>	<i>Range</i>	<i>Mean</i>	<i>Standard Deviation</i>
Perception of partnership	3	2	3.58	0.67
Perception of shared responsibility	3	2	3.67	0.65
Ability to provide appropriate information	3	1	3.92	0.29
Involvement in discussion	4	1	3.67	0.49
Provided opportunity to discuss everything	4	1	3.92	0.29
Perception of relevance of goals	4	1	3.83	0.39
Relevance of important matters to goals	4			
Satisfaction with discussion of treatment	4	1	3.83	.39
Satisfaction with patient involvement in treatment	4	3	3.58	.90
Perception of support	4	1	3.92	.29
Satisfactory role taken by patient in the process	3	1	3.92	.29



## **Thematic Analysis of Data from Focus Groups**

A patient centred goal setting tool (Aleksandrowicz, 2016; also see Appendix G) was designed based on existing theories of goal setting, motivation and goal directed behaviour as well as data collected from staff, patients and carers to capture elements that contributed to patient centred care in a neurological rehabilitation unit involving goal setting. Following the introduction of the tool on the ward, focus groups were conducted four months later to obtain preliminary feedback on the experience of goal setting with the use of the tool. Data collected from focus groups conducted with staff, patients and carers can be categorized under three main themes and with several subthemes (see Table 4). The main topic of discussion in all focus groups centred on the facilitation of patient centred goal setting behaviours using the tool. As the discussion continued, the role of the new tool in encouraging these behaviours was discussed and debated at length. These are explored in greater detail below.

### *Theme 1. Benefits of Using the Tool*

Staff, patients and carers identified several benefits of the tool, particularly in using the information disseminated by the tool to think about meaningful goals and plan ahead. This main theme was divided into five subthemes as detailed below:

***Sub-theme 1.1 – Useful resource for information*** - Participants reported the tool was a useful resource that could also be used to communicate relevant information with each other, particularly in instances of severe impairment.

Table 4: Main theme and sub themes from staff, patient and carer perspectives on the experience of using a patient centred goal setting tool.

<i>Themes</i>	<i>Subthemes</i>
<b>1. Benefits to using the tool</b>	1.1. Useful resource for information 1.2. Helpful in setting goals 1.3. Aid in managing expectations 1.4. Enable reflection and monitoring of progress 1.5. A common language
<b>2. Barriers to using the tool</b>	2.1. Overwhelming 2.2. Hard to use with increased impairment 2.3. Time consuming
<b>3. Suggestions</b>	3.1. Within the team and with other staff members 3.2. In introducing the tool to patients 3.3. In using the tool with patients 3.4. In supporting patients and family members to use the tool

*“We can use that in lots of other ways in terms of communicating to families and volunteers and other people that come to see them so I think there’s a lot of value in getting lots of information in that one place that others can use as well.”(Staff group 1)*

*“I think it also helps for the patients that can’t, don’t have the cognitive ability or the language ability to be able to sit down and read through it, it’s nice for then their families to have something that they can refer to.” (Staff group 1)*

*“...had I been given an arrival pack, maybe if you were given an arrival pack and say out loud there’s a formal start and end... I’m sure that would inspire people and explain why they want to get working... its one of the toughest path to follow... so every little bit of help, and really almost as if one is going to nursery school... such a basic thing would be helpful.”(Patient group 1)*

Carers and family members also commented on the helpfulness of a resource that explained the goal setting process and informed them of the various aspects and stages of treatment during the course of admission.

*“It’s definitely useful, because obviously I didn’t know much about the goal setting meetings so it’s nice to have something there before the goal setting meeting, knowing that there is going to be a goal setting meeting, and these are the kind of things which we would discuss and all. So you know, so that way it’s useful. So I had some questions where I might, you know, not have had if I had went straight to the goal setting meeting. At least I knew, I can question about this, yeah...” (Carer group 1)*

**Sub-theme 1.2 – Helpful in setting goals** – Carers observed that using the tool also saved time and provided an opportunity to prepare for the session.

*“Yeah I think it did help, actually, it saved us a lot of time cause we knew what they were going to ask us, cause we wrote it down and he was just asking us and we were just... so it saved a lot of time.”(Carer group 1)*

*“When I explained what each question was to him, it certainly made him think... It made him think, what he needs to try and do and what he aims to achieve later... I think it is quite helpful.”(Carer group 2)*

Staff observed that they had been able to use the tool successfully with ‘tricky’ patients to explore important aspect of their life which could inform goals, and that the tool also helped in breaking down larger goals into smaller ones.

*“...who really has quite poor insight into their problems, and we used this page which is the page on ‘who am I?’ to try to help to pick out some really important aspects so that we could then use them at the goal set, in terms of setting the long term goals and short term goals...”(Staff group 1)*

*“We used it with someone who wanted to go home but we had to think about the steps, you know there’s that page where you kind of break down the long term goals, that was really helpful, you had to work out all the different steps what she would need to do to get there. It makes it clear to them where the records go back to rather than just you saying.” (Staff group 1)*

**Sub-theme 1.3 – Assists in managing expectations** - Staff observed that the tool aided them in managing expectations by validating ‘big’ goals that seemed unattainable and revisiting goals set previously by the patients.

*“Using those steps, it would be a nice way to sort of way to say to them how far they’re going to have to go to get to that goal... but it would be a nice way, to try to think about how they would get back to walking or something, you could break down to the things they need to work on first, how quickly you get to that will*

*show us how realistic we're going to get to where we want to be which is another six steps away from where we are now.”(Staff group 1)*

*“It is actually a confirmation that they have put it (the goals), even if they forget they can actually see there's my writing, I did put it...” (Staff group 2)*

*“I've used it before as well with someone who wanted to go home but we had to think about the steps, you know there's that page where you kind of break down the long term goals, that was really helpful, you had to work out all the different steps what she would need to do to get there. It makes it clear to them where the records go back to rather than just you saying.” (Staff group 1)*

***Sub-theme 1.4 - Enables reflection and monitoring of progress*** - Staff members noted that the tool could be used to enable patients to reflect on their treatment and serve as a reminder for the goals they had agreed upon.

*“using these goal reviews, like what have I achieved so far, which is really helpful to getting them to reflect on you know, where they are, and what their progress is, especially for people who feel they haven't made much progress, you know they kind of haven't done anything and aren't going anywhere, that's a really good exercise...” (Staff group 2)*

Staff members observed that the tool could be potentially helpful in case of low motivation or delay in progress.

*“I think I was just looking at this page and I thought it was quite useful because I can think of situations where the patient may feel like giving up, they're not getting anywhere, they feel really low and upset, it's not working for them, they're not making much progress, but this section's like what have you already got going*

*for you that would help you to work on the goals and what are the barriers to overcome it, I think it's like kind of a reminder to motivate them.” (Staff group 2)*

Carers also stated that the tool helped their relative or patient in thinking about their goals and in monitoring their progress.

*“I discussed that with him and it gives him an idea where he wants to go and also gives him an idea what he did last week... So I think it is quite helpful.”(Carer group 2)*

**Sub-theme 1.5 – A common language** – Staff noted that the tool also provided them with the provision of a common and helpful language that could be used in setting goals.

*“...the language in this is nicer than what we've got, as information to give out that we've got on our database and so on.”(Staff group 1)*

*“Because the benefit of a pack is that it gives us... it gives you some prompts and things and some things you wouldn't have thought about in the session and a common language... so that gives you some nice common language for people...”  
(Staff group 2)*

## *Theme 2. Barriers to using the tool*

Participants also identified some barriers to using the tool which hindered patient centred goal setting (Table 4). This theme was divided into three sub themes.

**Sub-theme 2.1 – Overwhelming** - One of the main barriers related to the presence of a large amount of information in the tool, which was experienced as ‘overwhelming’.

*“The pack, to be honest, I found it’s a lot, especially where patients are concerned...”*

*(Carer group 1)*

*“I think for someone who’s overwhelmed it’s probably not helpful it would just get*

*lost...” (Staff group 1)*

**Sub-theme 2.2 – Hard to use with increased impairment** – Participants noted that the tool was harder for some patients who were more cognitively impaired than others.

*“I mean it’s harder for people that are cognitively impaired and can’t understand it, or have communication difficulties.” (Patient group 1)*

*“I think sometimes getting patients who are quite cognitively impaired to say you only need to do pages this and that and the other and leaving it with them you know just as, that’s just not going to work...” (Staff group 2)*

**Sub-theme 2.3 – Time consuming** - Staff noted that while staffing constrains increased pressure on their time, patients required support from them in using the tool. This was particularly relevant when they were first admitted to the ward.

*“You’ve got to sit down and talk them through it. Some people will be proactive but others would need a lot of, which we do I think I have done that more recently than before but it does take extra time.” (Staff group 1)*

Carers also noted that the tool required additional time which may not be feasible due to reduced staff members.

*“...but I don’t know, with the time limits at the moment, I think, with the shortage of staff, cause I don’t think they’ve gone through the pack together properly, no one’s really sat with her or do they you know, it’s quite rushed. “ (Carer group 1)*

Additionally, absence or unavailability of family members could be experienced strongly by patients who may be overwhelmed by the tool or have extensive cognitive impairment. This would also require additional contribution of time from staff members to introduce and facilitate the tool.

*“And if they don’t have the family or the carers, whoever else around, there’s no one to facilitate the use, it won’t get used unless there’s us (staff) in the sessions sitting down going through things...” (Staff group1).*

### *Theme 3. Suggestions*

Participants recommended a number of suggestions in the group discussion. A majority of these suggestions related to steps that staff could take to facilitate use of the tool on the ward thus enabling patient centred behaviours in goal setting. These are divided into 4 subthemes and listed below list (Table 4).

#### ***Sub-theme 3.1 - Within the team and with other staff members***

- Dedicate more time to embed the tool in the current way of setting goals, for example, by familiarising with the tool.
- Introduce it in the induction phase for new therapists who join the team.
- Remind other members of staff to use the tool, particularly when discussing treatment plans in MDT or review meetings.
- Encourage nursing staff to assist patients in completing exercises in the tool.

#### ***Sub-theme 3.2 - In introducing the tool to patients***

- Streamline use of the tool, in how it is introduced to the patients and family members, for example, in one of the first meetings with the keyworker.



- Provide copies of the tool in advance to patients who are going to be transferred from another ward for treatment, or are admitted to the ward from the community.

### ***Subtheme 3.3 - In using the tool with patients***

- Link the tool to the goals setting process on the ward.
- Use the tool in various sessions such as goal planning, goal review, family meetings etc.
- Introduce discharge meeting using the discharge planning section in the tool to aid in transferring care to the community teams.

### ***Sub-theme 3.4 - In supporting patients and family members to use the tool***

- Remind patients to complete exercises from the tool.
- Add 'read the tool' or 'work on exercises from goal book' to patients' timetables in weekly, 30 minute slots or before goal review sessions so they remember to complete the exercises in the tool, independently or with family members/carers.
- Encourage use of the tool before sessions, for example, by specifying which exercises the patient may find helpful to attempt before their first goal set session.
- Encourage patients to bring the tool to their sessions.
- Ask patients about the experience of answering questions in the tool. Check with them on which exercises were easier to attempt and which parts were harder to understand.

## **Summary of Findings**

Data collected for this study was analysed with the aims of observing patient clinician interactions in the goal setting process, examining the experience of this process,

and identifying factors that could facilitate patient centred goal setting with the help of a goal setting tool.

Data from video recordings was coded into different kinds of goal setting and patient centred behaviours based on a checklist compiled to analyse this data. Video recordings demonstrated a minimum of one instance of all seven subtypes of goal setting behaviours defined in the checklist. In addition to this, goal setting related and generic patient centred behaviours were also coded, as were behaviours that documented goals. A fifth category of behaviours observed from the video recordings was used to code flexibility, normalization and validation, verbal encouragement and conflict management. These were additional behaviours identified from the data itself besides those defined in the checklist.

Data from the rating scales indicated that all staff, patients and carers believed that goals in all the sessions were set in partnership at least some of the time and generally all the time. Patient, carers and staff also reported that goals set were meaningful and relevant to the patient. Patients reported feeling supported in following their treatment plan. Staff and carers also reported that responsibility for the goals was shared. While staff also reported that they felt they were able to involve patients in the process of setting their goals, some responses indicated a lack of support in facilitating involvement of patients in their treatment planning.

Analysis of data from focus groups identified the themes of benefits, barriers and suggestions for using the goal setting tool designed to encourage patient centred goal setting behaviours (Aleksandrowicz, 2016, see also Appendix G). Patients and carers agreed that the tool provided necessary information which enabled them to prepare for sessions in advance and think about relevant areas for setting goals. Staff indicated that

the tool was helpful in managing ‘unrealistic’ or ‘unachievable’ goals. Participants reported that the tool was helpful in documenting progress which was useful in encouraging patients and helped them in reflecting on their development. Staff reported that the tool also provided a common language for setting goals. However, patients and carers also reported feeling overwhelmed and overloaded with information. Participants commented on the difficulty of using an informational tool for patients with severe cognitive impairments. Additionally, staff recognised that using the tool necessitated additional investment of their time, however, they believed this could be a useful investment. A number of suggestions were also made during the focus group discussion to help the patients and carers or family members in using the tool. These suggestions involved staff reminding patients and family members about reading the tool, prompting them to attempt particular tasks in the tool, encouraging use of the tool, reminding patients to bring the tool to their sessions, and asking patients about their experience of using the tool.

## **Discussion**

Studies that examine goal setting processes in practice aid in comprehending characteristic factors that can improve or impede this process (Prescott et al., 2015). Data collected for this study was analysed to gain insight into these complex processes by observing patient clinician interactions and coding them using a checklist of behaviours, examining the experience of the goal setting sessions using session rating scales, and analysing patient, staff and carer perspectives on using a patient centred goal setting tool to facilitate and encourage patient centred goal setting behaviours. Results of the study were divided into three parts to address these three aims.

A significant step in examining clinician-patient involved compiling a checklist of behaviours to code data collected from video recording goal setting sessions as part of quantitative observation. Coding of behaviours defined by the checklist indicated that staff members demonstrated patient centred goal setting behaviours leading to collaborative sessions consistently. The coding of goal setting behaviours into its seven subcategories was structured and well defined with little ambiguity in marking the behaviours as present or absent. In comparison, collaborative behaviours were often coded under several other categories from the checklist with much more ambiguity in marking the presence or absence of the behaviour. Additionally, inconsistencies in the occurrence of behaviours was not coded as the checklist defined and coded the presence of patient centred goal setting behaviours and not partially present behaviours. Recording all instances of each coded behaviour may have addressed these uncertainties in coding.

The quality of the behaviours to be coded was also not defined in the checklist. This contributed to ambiguity in coding the behaviour when it occurred as the checklist lacked explicit definitions on what involved accurate and appropriateness of behaviours when they did occur. These markers of quality would have also addressed the gap in coding contrasting behaviours (such as top down approach and instructive sessions) that were observed but not coded as the checklist did not define these behaviours. As a result of this, no distinction was made between sessions where staff adopted an 'instructive' approach and those sessions where staff adopted a collaborative approach. An instructive approach has been previously identified in literature as clinician or therapist led where topics of discussion are controlled by professionals and change in topic is used to indicate that the discussion is closed (Barnard et al., 2010). Barnard et al. (2010) noted in their study that goals were presented as agreed upon in order to discourage discussion. The checklist did not code these behaviours defined by Barnard et al. (2010).

On the other hand, coded observations of the interactions demonstrated a high amount of flexibility on the part of staff, and this was frequently communicated to the patients. This is important as patient participation can vary depending upon the patient's preferences. Some patients prefer more direction than others, thus, requiring this process to be flexible, in order to accommodate such differences (Lloyd, Roberts & Freeman, 2014). It is worth noting that even patient centred approaches to goal setting may not result in goals that are patient centred, relevant or meaningful (Prescott et al., 2015). However, collaboration supports the delivery of more effective and meaningful treatments by allowing various illness and recovery perspectives to be explored (McClain, 2005).

Data from the rating scales indicated that all participants believed goals were set in partnership in all recorded sessions. However, some responses from staff indicated a lack of support in enabling such a partnership. Patients have reported in other studies that participation could improve if staff were supported in adopting a proactive role while maintaining flexibility in setting goals (Rosewilliam et al., 2011).

Data from focus groups suggested that the goal setting tool was helpful in assisting patients to make collaborative decisions about their goals. Staff also reported that the tool facilitated a shift to patient centred approaches in setting goals. The tool also provided a resource for learning about the process of setting goals and documenting them, a provision which has been previously reported as absent in various rehabilitation settings (Rosewilliam et al., 2011). Staff also noted that the goal setting tool had provided an opportunity to expand the definitions of 'unrealistic' goals, extending the time scale of such goals to include the continuity of recovery beyond hospital admission. This change in the understanding of recovery is an important one as Brown and colleagues (2014)

report that there exist key differences in how clinicians and patients define successful outcomes in rehabilitation, particularly with regard to achievability. While health professionals monitor this through the achievement of specific and short goals, patients view recovery as continuing beyond their hospital admission. Such differences in the understanding of rehabilitation and successful recovery could have also informed the processes observed in the goal setting sessions.

Suggestions to improve patient centred goal setting behaviours included the proposition that staff assume a more proactive role in facilitating, reminding and encouraging use of the tool. Similar suggestions have been made in other studies of goal setting as well but without the use of a tool that facilitates these behaviours. Evidence also suggests that the use of explicit methods of documentation increases patients' awareness of participating in sessions and contributing to treatment planning (Rosewilliam et al., 2011). Thus, using the tool actively may well contribute to better awareness of participation.

Most therapists in neurological rehabilitation rely on a combination of formal and informal approaches to setting goals. The application and measurement of patient centred approaches in neurological rehabilitation is additionally challenging due to cognitive constraints, communication impairment as well as variation in insight into the brain injury and its effect on functioning (Prescott et al., 2015). Clinicians report that often there is insufficient instruction on the process of setting goals for patients (Bright et al., 2012; McClain, 2005; Playford et al., 2009). As a result of this, and variation in interviewing styles, information obtained during assessments can vary widely and lack details related to relevance. Formalizing or specifying the procedures in patient centred goal setting is thus necessary to address this gap. Such goal setting affects treatment delivery and

experience by understanding what recovery and satisfactory outcomes mean to patients who are being treated as opposed to defining this based on a medical diagnosis (McClain, 2005). This also influences long term self-management of illness by enabling independence and autonomy in the patients and empowering them to reconstruct their lives (De Silva, 2014; McClain, 2005), thus ensuring treatment remains applicable even after discharge (McClain, 2005).

### **Strengths and Limitations**

While this is one of the few studies to examine patient clinician interactions in detail, it also has several limitations. One of the key limitations is the small sample size as the study was restricted to collecting data from a single inpatient unit at one hospital. This affects the generalisability of the study to other settings where goal setting practices may vary. Moreover, a substantial number of people were invited to participate in the study, but the exact number of people approached was not recorded. Additionally, the presence of the supervisor as a consultant on the ward may have also influenced discussion during analysis of results.

Goal setting has often been criticized for lacking a cohesive definition which affects how it gets operationalized. This is also the case with measuring patient centred care. This variation in understanding the terminology may also be a limitation of the study and could have played a role in how data was analysed by the researchers, particularly in defining patient centred goal setting behaviours and coding them. In addition, behaviours that were in contrast to the patient centred goal setting behaviours were neither defined nor recorded. Coding these behaviours may have provided the opportunity to explore the clinician-patient interactions in greater detail. Construct validity and inter rater reliability were also not established for the checklist. It is also

likely that the interaction observed in the video recordings was influenced by the ongoing research and focus group discussions on the ward. This may have led to increased awareness of the presence or absence of patient centred behaviours amongst staff.

The rating scales were not tested for validity or reliability. The ratings could not be statistically analysed for differences in experiences of goal setting before and after the implementation of the tool because of a small sample size.

Nevertheless, the study also offers multiple perspectives and direct observation of interactions in furthering the understanding of patient centred goal setting in neurological rehabilitation. Additionally, the inclusion of carers and family members in exploring perspectives on setting goals strengthens the findings of the study. Involving relatives has been known to be valuable and paves the way for designing interventions that involve family members and carers in delivering holistic treatment (Doig et al., 2003). This, in turn, aids them in continuing to care for their relative in the community.

### **Clinical Implications**

Exploring formal and informal approaches to goal setting is the cornerstone in making pertinent recommendations for best practice. Studies such as this one, which explore behaviours and techniques to facilitate patient centred approaches in such settings are crucial in addressing these challenges. Examination of interactions in goal setting sessions aids in identifying barriers and facilitators to the process, enabling it to be modified and improved upon. This was also noted in a review of goal setting approaches in acquired brain injury by Prescott et al. (2015).

The compiled checklist used to identify goal setting behaviours that were patient centred can be developed further to train new staff members in specific behaviours. This



can be further facilitated by the use of the new goal setting tool (Appendix G) that was designed to support a patient centred approach to goal setting (Aleksandrowicz, 2016). Clinicians also agreed that the tool encouraged these behaviours.

The checklist could also be used to monitor goal setting and patient centred behaviours in experienced clinicians. The need for developing such a formal approach and tools to train and monitor goal setting and patient centred approaches in neurological rehabilitation has been previously recognised in literature (McClain, 2005). Lastly, involving carers and families, while considered valuable (Frosch et al., 2012) is practiced inconsistently. Using a tool that encourages their involvement would address this gap and also help in delivering holistic care to individuals with severe cognitive impairments. Both the checklist and tool could be used to train clinicians to adopt a collaborative approach with patients and family members in negotiating goals.

### **Future Research**

A barrier often identified in the literature relates to the requirement of additional time needed to ensure patient participation in treatment planning. Future research that focuses on better understanding and demarcating the processes involved in setting goals would help in making goal setting time and cost effective. Such research would also inform training recommendations for clinicians (McClain, 2005). Examining the efficacy of the goal setting tool as a training aid may, thus, be a useful area of research.

Another relevant area of future research is taxonomy development. This study explored the initial stages of attempting to compile a checklist of behaviours in order to code patient centred goal setting behaviours. A necessary next step would involve establishing construct validity and inter rater reliability for the compiled checklist. Future research may also be able to systematically review existing literature in order to develop a

taxonomy of behaviours associated with a patient centred approach to goal setting. Whyte and Hart (2003) identify descriptive research as the first step towards the creation of such a systematic treatment by categorising ongoing rehabilitation practices. Prescott and colleagues proposed a list of goal setting principles (Appendix H) which could be utilized in developing the checklist further. This would lead to the creation of a more comprehensive checklist that defines behaviours that contrast with patient centred goal setting behaviours.

Furthermore, the newly designed goal setting tool (Aleksandrowicz, 2016) was reported to facilitate a patient centred approach, such as encouraging patient centred goal setting behaviours identified in the checklist. Thus, it may be useful to explore this correlation more explicitly. Future studies that are able to replicate this research and explore the relationship between the checklist and the tool in greater detail may also be helpful in examining how the two could be used jointly to train in and improve patient centred goal setting practice. Such taxonomies would then be able to inform efficacy and effectiveness research (Whyte & Hart, 2003). Pre and post intervention studies using the tool would also be helpful in studying effectiveness of the tool in supporting patient centred care.

## **Conclusions**

Patient centred care has been the subject of considerable discussion in neurological rehabilitation settings. It is often viewed as the foundation of ethical and good clinical practice. However, it is yet to be operationalized effectively, primarily, due to the lack of a unified definition or approach to it (Bright et al, 2012). One way of clarifying this has been by studying the theoretical components that underlie patient centred care, and by

observing clinician patient interactions where these components may be demonstrated or utilised (De Silva, 2014).

Similarly, interventions within rehabilitation, particularly goal setting, have also been subject to various obstacles in defining and operationalizing the processes involved in them. This lack of clarity has contributed to rehabilitation often being described as a ‘black box’. This has meant that research into rehabilitation is necessarily focused on identifying and defining these processes in a systematic manner (Whyte & Hart, 2003). This study was conducted as an initial step in exploring and examining patient clinician interactions and devising tools that could facilitate and improve these interactions, thus contributing towards a clearer understanding of these processes and supporting the development of a patient centred approach. Developing a thorough patient centred approach within rehabilitation settings may require a shift in how rehabilitation is practiced and envisioned. This would necessitate redefining the roles of the clinicians and the patients as well as rethinking how recovery is described and measured. An essential part of this may also include rethinking the notion of ‘unrealistic’ goals (Levack et al., 2011).

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### **PART 3: CRITICAL APPRAISAL**

## **Introduction**

This section offers a critical appraisal of the study outlined in Part 2 which was undertaken to explore processes in setting goals at a neurological rehabilitation unit. This was done to gain an understanding of the current approach to setting goals at this unit. The study also examined the experience of these processes and explored staff, patient and carer perspectives on patient centred goal setting behaviours through the use of a tool designed to increase and encourage these behaviours. This critical appraisal offers a reflexive insight into the progression of this study as action research. It also explores the limits of patient centred approaches and some factors that may contribute to this. The appraisal ends with a reflection on the course of the project and the merits of working jointly when conducting a substantial piece of research in the field.

## **Conceptualising the Research Project**

This study was carried out in partial requirement for completing the Doctorate in Clinical Psychology. Another trainee and I sought an external project to undertake research in the area of neurological rehabilitation as this was a common area of interest for us. Meetings with various practitioners in the field of Neurology and Neuropsychology led us to the hospital where this project was ultimately executed and implemented. The core research team came to be comprised of three people, my research partner, myself, and our supervisor who was also a consultant at the hospital.

In conceptualising this study, several ideas on delivering neurological rehabilitation and setting goals were discussed. My research partner and I were driven by a desire to contribute to existing research and current practice meaningfully in considering these ideas. Initial meetings with our supervisor to understand goal setting practice at the unit soon expanded to include meetings with specialist members of staff at the unit. This

helped in gaining an understanding of the needs and requirements of the unit, thus narrowing down the initial research ideas to perspectives and strategies for setting meaningful goals. Ideas to update practice and supplement treatment also led to the possibility of creating an informational tool or booklet to achieve this.

These ideas were largely informed by dominant notions of treatment delivery in neurological rehabilitation within literature that had acquired popularity in the past two decades. These notions generally outlined an approximate ‘right’ and ‘wrong’ way of setting goals. Early recognition of this bias within the research team paved way for the study to be designed as an exploration into the practice of setting goals and examining staff, patient and carer perspectives in the area of goal setting. Thus, the study evolved into two main parts to address this bias and the initial interest in updating practice.

The first part included the development of a goal setting tool that could facilitate goal setting and supplement treatment. Further meetings with specialist members of staff contributed in conceptualizing the development of the tool which came to be informed by both current theoretical understanding of goal setting, and staff, patient and carer perspectives on the nature of goals set.

The second part of the study, which was written for the purpose of the empirical paper in this thesis, involved recording goal setting sessions to explore the current practice of setting goals on the ward before exploring and recommending techniques and methods for updating this practice. Meetings with the research team and an initial review of literature on working with video recordings suggested the use of a behaviour checklist to manage, organize and make sense of the large amount of data that could often be collected in recording videos. Thus the compilation of the behaviour checklist became a central aspect of the project. The creation of the checklist included several meetings with the

research team to refine the behaviours that had been compiled from other patient centred measures. This part of the study also recorded subjective experiences of the goal setting sessions, and patient, staff and carer perspectives on using the goal setting booklet that had been created in the first part.

Despite early efforts to recognize and address the bias involved in defining a 'right' and 'wrong' way of setting goals, the entire joint research project did have a focus on 'improving' goal setting behaviours. This focus was maintained from the beginning and throughout the other stages of the research. Both the designing of an informational tool meant to improve these behaviours, and the creation of a checklist which helped in observing and coding these behaviours reflected this determined focus on 'improvement'.

### **Challenges in Recruitment and Data Collection**

The recruitment phase of the study was marked by a number of difficulties that contributed to feelings of frustrations within the research team and between myself and the trainee with whom I was jointly working. Difficulties at the initial stages of the project were a result of reluctance of staff members to participate in a study that would impact their current working styles. However, as time elapsed and the goal setting tool was introduced, staff reported finding it helpful in informal feedback, which was offered regularly in addition to data collected in the focus groups.

The latter half of the data collection phase was further delayed due to a shift in the clinical presentation of patients who were being admitted to the unit. Patients were presenting with increased severity in cognitive and communication impairments which affected their capacity to consent or participate in the video recordings and focus group discussions. However, analysis of video recordings collected at this stage, continued to identify patient centred behaviours in goal setting by staff, including those patients who



were more severely impaired. Indeed, in certain difficult sessions when patients were unable to think of goals or did not view their injury as related to their loss of functioning, staff used the tool to direct conversation back to the patient. This was done by discussing what the important aspects of their life were that they wished to return back to, as opposed to debating the specifics of the brain injury and its resulting impact on the patient's brain and body. In other instances, the tool was used to think about pre and post injury identity and roles that were valued by the patient. Rebuilding identity, which had become the focal concept in the conceptualisation and development of the goal setting tool, also came to acquire a central place in treatment delivery and the discussions that ensued in the focus groups.

Several reasons contributed to not reaching saturation in data collection. Firstly, delays in starting data collection meant that a substantial amount of time that had previously been assigned to collecting data was no longer available. Secondly, staff reluctance contributed to ambiguity about conducting the research on the site and additional loss of time and opportunities to collect data. Thirdly, greater severity of impairments in the clinical cohorts contributed to limiting the number of people who were able to use the tool on its dissemination at the unit and participate in focus groups to speak about their experiences. Fourthly, only a handful of interactions could be recorded, dependent upon consent. Staff often spoke about a session that they considered inappropriate for recording as it may not be a 'good' session. This likely contributed to the quality of the data collected and introduced possible bias into the interactions that were ultimately analysed for the study by staff consenting to record what they anticipated to be 'model' sessions of goal setting for data collection. However, this was addressed at later meetings, by clarifying the aims of the study, which were to observe all kinds of interaction within the goal setting sessions, and not simply 'good' sessions. As a result of

these discussion, various staff members consented to recording all sessions. They did not appear as hesitant about recording sessions that were not ‘model’ sessions. This enabled sessions anticipated to be ‘difficult’ to be recorded, a suggestion which had often been met with scepticism previously.

A gradual shift was observed in staffs’ view of the research and its usefulness to their practice and this was evidenced through enthusiasm for using the tool and increased participation in formal and informal discussions about goal setting with us.

The research team also met to discuss the methodology at several stages of recruitment and data collection, particularly when difficulties were experienced. This was done to brainstorm solutions to some of the challenges being faced and to consider alternate methods for collecting data that would enable us to conduct research while continuing to involve staff, patients, and carers. Individual interviews, online surveys and diaries were some of the other methods considered but none of these methods were put into practice after further discussion with staff indicated that they would not be feasible.

### **Data Analysis**

A surprising discovery in data analysis emanated from the observation of staff behaviour in sessions. Staff usually demonstrated a patient centred approach in most sessions, including the ‘difficult’ sessions. This was a surprising finding as initial discussions with senior staff in conceptualising the research had indicated that a patient centred and collaborative approach was poorly practiced. However, it is important to note that the ongoing research contributed to an increased focus on delivering patient centred care, particularly while setting goals. The focus group discussions may have also affected some of these behaviours that were later recorded and observed in the goal setting sessions. Nevertheless, awareness of these biases in conceptualising the study and in the

data collected for analysis were key in setting them aside while analysing data in a systematic manner. It was also important to set aside the difficulty and frustration faced in the recruitment and data collection phase.

Despite the small sample size, a sizeable volume of data was collected for analysis. An initial attempt to code every observed behaviour proved time consuming and laborious. Meetings with the research team helped to define the behaviours compiled in the checklist and to decide on which specific behaviours could be coded based on this checklist. This meant that the checklist only coded collaborative patient centred goal setting behaviours and other approaches, methods or behaviours were neither coded nor discussed. In spite of discussions with the research team, there was sense of loss in not being able to report the various nuances and details observed in each of the recorded sessions. Such tensions in finding a balance are not uncommon when working with such a sizeable amount of data within a qualitative framework (Tufford & Newman, 2012). Striving for balance contributed to the iterative approach that was adopted in carrying out this research.

Discussions with the research team during analysis also helped in addressing blind spots in analysis that could have resulted from preconceived ideas on setting goals and the frustrations associated with collecting data. However, it is possible that the research team as a whole was also somewhat biased due to its position and ideas on goal setting practice, which were difficult to abandon.

While my own personal experiences of working in neuropsychology, both in London and in India informed what ‘good practice’ could look like, care was taken to not make subjective interpretation of data based on these views. Instead, previous theoretical underpinnings and goal setting research in neurological rehabilitation and

neuropsychology were used to guide the process of conception, data collection, analysis and discussion.

### **Conducting Action Research**

This research project can be viewed as action research. Action research is defined as research carried out in a specific context to address a problem and to bring about a change or improvement while addressing the identified problem. This is generally done with the support of the people who form part of the context and participate in the research. It is a continuous process informed by research, action plans, evaluation of plans and process, and reflections on the process (Bennett, 1998; Hart, 1996; Nolan & Grant, 1993). This research was conceptualised from anecdotal accounts of a lag in practising goal setting in a patient centred manner and driven by a desire to rethink how goal setting was approached on the unit and how goals were set ‘for’ patients instead of ‘with’ patients. Awareness and recognition of this position also informed the research question and subsequent methodology of the study. A review of literature guided this process by identifying gaps in literature that could be explored in the context of neurological rehabilitation. Action research occurs as an empowering and collaborative process with participants rather than being conducted on participants (Castle, 1994; Meyer, 1993; Nolan & Grant, 1993) and this was reflected in the study with the involvement of staff, patients and carers in discussing expectations of intervention and what might be helpful in this process. Since action research such as this project involves change in intervention, energy is also focused on facilitating this change. This involvement of the researchers in facilitating the intervention can, at certain times, contribute to difficulty in removing themselves from the research or setting (Meyer, 1993). This was also experienced in this study as data collection was culminated around the same time the new techniques and

tools in delivering patient centred goal setting were starting to gain momentum at the unit. Continued discussion within the research team about the experience of concluding data collection and reflecting on the previous few months supported this transition.

### **Dilemmas in Delivering Patient Centred Care**

The crux of this research is centred on the notion of patient centredness as a form of ‘ethical’ and ‘moral’ practice which acknowledges, empowers and gives dignity and respect to the person behind the illness by allowing them to be active participants in their care instead of passive receivers of treatment (Leplege et al., 2007; Lloyd, Roberts & Freeman, 2014). The approach is often synonymous with good practice and has collaboration and shared decision making as its key principles (de Haes, 2006).

This understanding of patient centred approaches and increasing evidence of its contribution to successful outcomes has galvanised the drive towards patient autonomy and independence, leading to a greater emphasis on long term self-management of care (Robinson & Thomson, 2001). However, a Cochrane review of patient centred approaches in clinical consultations found mixed results for the effect of patient centred approaches on increased satisfaction, change in health behaviours and improvement in health status (Dwamena et al., 2012). Literature also suggests that patients’ preferences vary (Lloyd et al., 2014) and not all patients like to be involved in decision making or take responsibility for decisions made in managing their care. Similarly, some patients like to be informed about their treatment but do not wish to actively participate in making decisions about it (de Haes, 2006; Robinson & Thomson, 2001). Greater impairments in cognitive and executive functioning, including low levels of awareness and insight, are also known to raise the difficulty of practising a patient centred approach to care. This becomes further pronounced due to additional constraints of time, money and resources (de Haes, 2006).

Poor prognosis and age are also known to contribute to a lack of interest in engaging in this approach (de Haes, 2006; Little et al., 2001). Equally, patients may prefer to not share details of their personal lives and goals. Additional factors of differences in culture, language and education could also potentially contribute in varying degrees to a desire to not engage with patient centred approaches (de Haes, 2006).

A dilemma thus presents itself to clinicians as patient centred care also involves respecting the wishes of the patient, including the wish to not participate in decision making (Little et al., 2001). De Haes (2006) explored and identified some of the main factors that could possibly contribute to a desire to not engage in treatment. He proposed that education played a role and that often people were either not aware that they had a choice in making decisions about their treatment or they preferred being a ‘good’ patient. De Haes (2006) further identified the roles of cognition, ethnicity and differences in culture in contributing to underlying assumptions about illness models, treatment and the role of patients and doctors in this interaction, with doctors often being recognized as higher in authority (also in Little et al., 2001). In particular, he noted research which had suggested patients who scored higher on anxiety often preferred a doctor centred approach to treatment. It could also be argued that a degree of flexibility may be key in addressing such predicaments in treatment as the popularity of patient centred approaches continues to grow.

### **Working in a Joint Research Project**

It can, naturally, be difficult to observe current practices or suggest a new model of practising in large institutions with their pre-defined approach to rehabilitation. In the initial stages of this research, a widespread perception amongst staff members was that we were questioning their current practice and skills. Concerns around this were addressed in

later meetings and conversations around goal setting began to shift following these discussions. Working jointly with another trainee helped in this initial stage when the research faced a significant amount of disapproval, resistance and even opposition in some instances, by the staff members. The support of another trainee proved invaluable even as recruitment and data collection challenges continued. Differences in opinions during the analysis stage, particularly when coding behaviours and themes, were discussed in detail to reach a consensus. This enabled both of us to engage with the data in a reflective and curious manner throughout the analysis. Positive experiences with patients also motivated us as most patients who participated in the study described the experience of participating in the focus groups discussions as important and meaningful in thinking about their treatment and how they may be able to influence it.

### **Reflections**

This study was an extensive piece of work which involved a number of challenges and positive experiences in conducting, analysing and writing it. Over the course of the research, joint field notes were maintained and observational comments were documented as two methods of maintaining reflexivity (Tufford & Newman, 2012). However, given the complexity involved in recruitment and the frustration associated with it, it may have been beneficial to maintain separate personal diaries on the process of conducting this research. This would have added valuable contextual information to the reflective process. While working with another trainee was beneficial and helped in being reflective, I wonder if it may have also perpetuated certain biases, particularly as both my research partner and I had a background in neuropsychology. Despite the challenges faced, this study was a valuable experience in conducting field research and exploring, developing

and implementing changes to interventions on a ground or working level, in a large in-patient setting.

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## **APPENDICES**

## Appendix A

**Table1: Joint and individual contribution of each trainee to the project.**

<b>Joint work</b>	<b>Individual work (FS)</b>
Recruitment	Coding of videos (done by both trainees but independently)
Recording of videos	Analysis of rating scales
Facilitation of focus groups	Thematic analysis of focus group data
Design of the goal setting tool	(preliminary coding done by both trainees but independently, before full analysis by FS)
Creation of rating scales, behaviour checklist and interview schedules	Writing of the thesis

## Appendix B

### Ethical Approval



**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





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

#### Confirmation of ethical opinion

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

<i>Document</i>	<i>Version</i>	<i>Date</i>
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

A Research Ethics Committee established by the Health Research Authority

- 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**

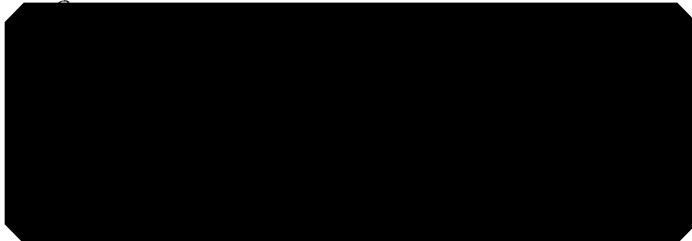
We are pleased to welcome researchers and R&D staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

**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:*







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?**

# Appendix C

## Information Sheets and Consent Forms

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 [redacted] 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 [redacted]. 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 [redacted]

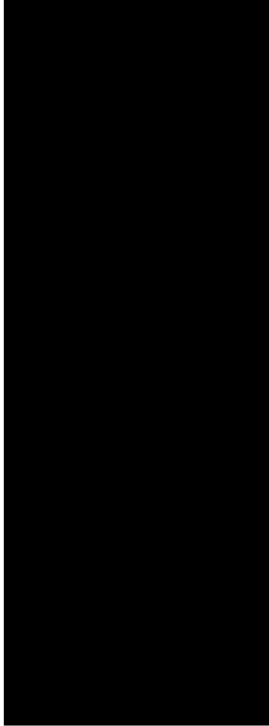
**15. Contact for Further Information**

If you require any further information please contact Dr Diane Playford, [redacted]

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 – 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.

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.

Project ID: 15/LO/0585

### **Information Sheet for Part 2 of the Study – Patients**

This study is divided into two parts. This information sheet is about Part 2 of the study.

#### **1. Title**

Goal Setting in Neurological Rehabilitation – evaluation of a goal setting tool (Part 2).

#### **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 second part of the study. In this part, a new goal setting pack will be distributed to everyone on the ward. After this pack has been distributed, goal setting sessions using the pack will be video recorded. Focus groups will also be conducted to understand the experience of using the new pack.

#### **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 your experience using the new goal setting tool.

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#### **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?**

This is part 2 of the study. 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 experience of using the new goal setting pack. The focus group will last between 1 – 1.5 hours.

If you consent to it, 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.

The videos will be observed to understand what happens during goal setting sessions. 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 evaluation of the goal setting pack.

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 [redacted] for 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?**

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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 National Hospital for Neurology and Neurosurgery. 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 [REDACTED]

**15. Contact for Further Information**

If you require any further information please contact Dr Diane Playford, [REDACTED]

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.

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 Date Signature  
(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/L0/0585  
Participant Identification Number for this trial

**CONSENT FORM - Patients - Part 2**

Title of project: Goal Setting in Neurological Rehabilitation – evaluation of a goal setting tool (Part 2).

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

Please tick all 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.

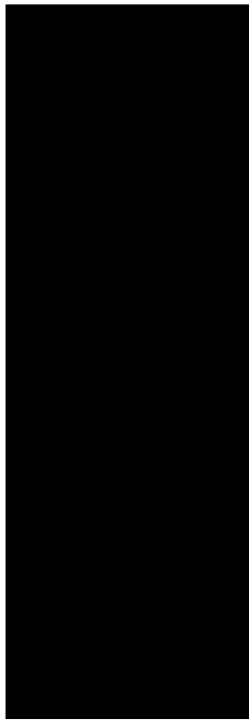
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

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.

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



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

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 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 [redacted] for 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. You will also be asked to talk about the impact of your relatives 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 [REDACTED]. 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 [REDACTED]

**15. Contact for Further Information**

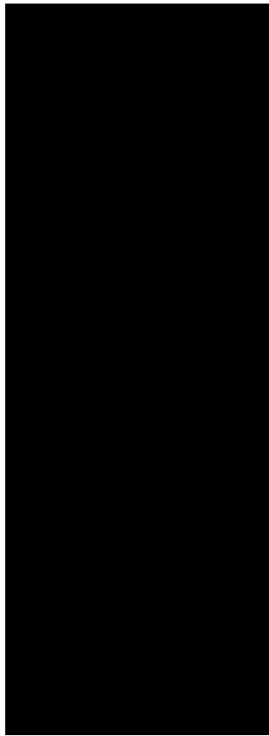
If you require any further information please contact Dr Diane Playford [REDACTED]

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.

- 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 <i>(if different to the person taking consent)</i>	_____	Date	_____	Signature	_____

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



Project ID: 15/L0/0585

### **Information Sheet for Part 2 of the Study – Carers**

This study is divided into two parts. This information sheet is about Part 2 of the study.

#### **1. Title**

Goal Setting in Neurological Rehabilitation – evaluation of a goal setting tool (Part 2).

#### **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 a second part of the study. In this part, a new goal setting pack will be distributed to everyone on the ward. After this pack has been distributed, goal setting sessions using the pack will be video recorded. Focus groups will also be conducted to understand the experience of using the new pack.

#### **4. Why have I been chosen?**

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

1

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.

#### **What will happen to me if I take part and what do I have to do?**

This is part 2 of the study. 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 experience of using the new goal setting pack. The focus group will last between 1 – 1.5 hours.

If you consent to it, 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.

The videos will be observed to understand what happens during goal setting sessions. 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 evaluation the goal setting pack.

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 [redacted] or 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.

#### **6. What are the alternatives for treatment**

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

2

**7. 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.

**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 you and introduce training for staff. There is a possibility of benefiting from sharing experiences within a group.

**9. 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 [REDACTED]

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.

**10. 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.

**11. 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.

**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 [REDACTED]

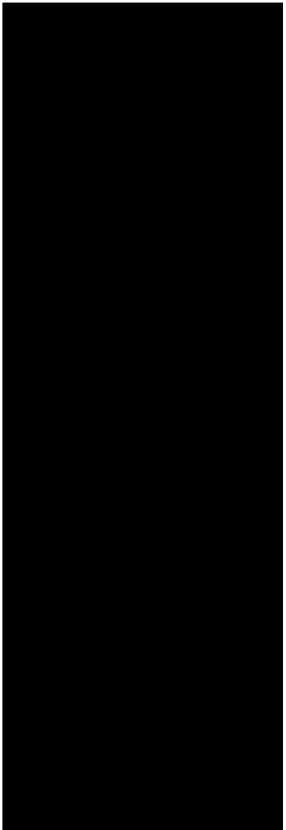
**14. Contact for Further Information**

If you require any further information please contact Dr Diane Playford, [REDACTED]

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 2**

**Title of Project:** Goal Setting in Neurological Rehabilitation – evaluation of a goal setting tool (Part 2).

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

*Please tick all 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.

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.

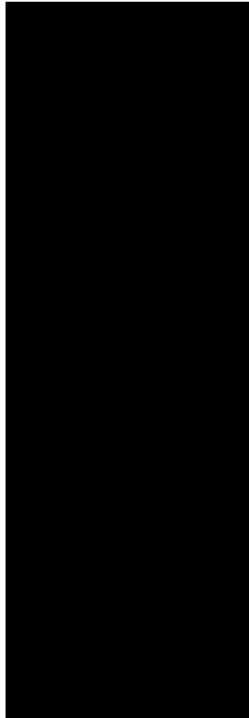
7. I agree to take part in the above study.

Name of Patient/Carer/ Staff Member \_\_\_\_\_ Date \_\_\_\_\_ Signature \_\_\_\_\_

Name of Person taking consent \_\_\_\_\_ Date \_\_\_\_\_ Signature \_\_\_\_\_

Name of Chief Investigator \_\_\_\_\_ 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

**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 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 for 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 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 [REDACTED]. 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 [REDACTED]

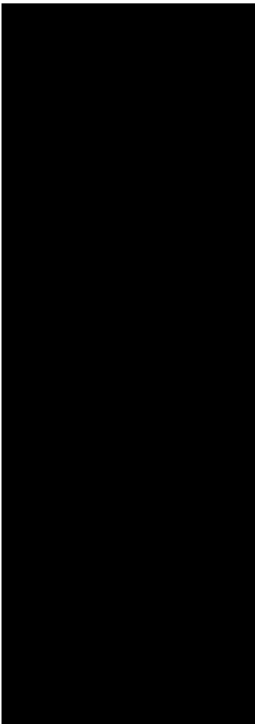
**14. Contact for Further Information**

If you require any further information please contact Dr Diane Playford [REDACTED]

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.



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.

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.

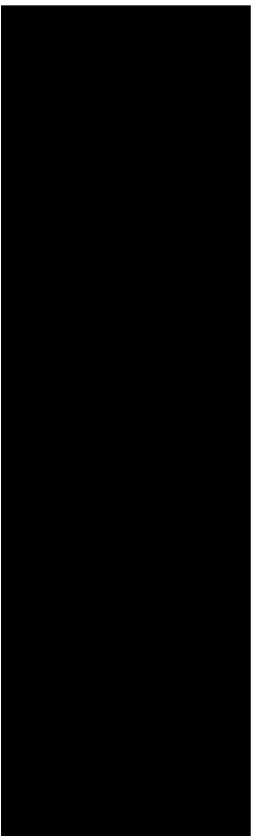
7. I agree to take part in the above study.

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.



Project ID: 15/L/O/0585

### Information Sheet for Part 2 of the Study – Staff

This study is divided into two parts. This information sheet is about Part 2 of the study.

#### 1. Title

Goal Setting in Neurological Rehabilitation – evaluation of a goal setting tool (Part 2).

#### 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 a second part of the study. In this part, a new goal setting pack will be distributed to everyone on the ward. After this pack has been distributed, goal setting sessions using the pack will be video recorded. Focus groups will also be conducted to understand the experience of using the new pack.

#### 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 [REDACTED]. 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.

1

#### 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?

This is part 2 of the study. You will be asked to take part in a 'focus group'. This is a group of 5 to 6 people, where you will be joined by other staff members on the ward. Researchers will ask about your experience of using the new goal setting pack. The focus group will last between 1 – 1.5 hours.

If you consent to it, we will also 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.

The videos will be observed to understand what happens during goal setting sessions. 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 evaluation of the goal setting pack.

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 [REDACTED] for 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 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?

2



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 is based at [REDACTED]

[REDACTED] 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 [REDACTED]

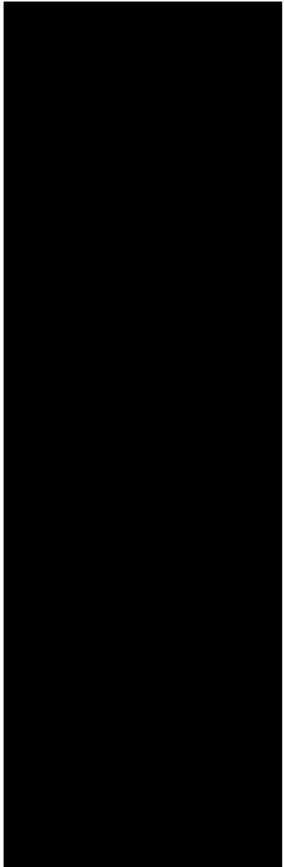
**14. Contact for Further Information**

If you require any further information please contact Dr Diane Playford, [REDACTED]

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.



Project ID: 15/L/O/0585

Participant Identification Number for this trial:

**CONSENT FORM – Staff - Part 2**

**Title of Project:** Goal Setting in Neurological Rehabilitation – evaluation of a goal setting tool (Part 2).

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

*Please tick all 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.
- 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
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Name of Person taking consent	Date	Signature
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Name of Chief Investigator (if different to the person taking consent)	Date	Signature
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When completed: 1 for participant; 1 (original) for researcher site file; 1 to be kept in medical notes.

## Appendix D

### Checklist of Patient Centred and Goal Setting Behaviours

Goal setting
1. <a href="#">Scene setting</a> : Clinician explains the concept and purpose of goal setting on the ward to the patient in the manner that is consistent with their level of understanding.
2. <a href="#">Scene setting</a> : Clinician introduces treatment planning and goal-setting as a collaborative process involving family members/carers, staff and patients. (e.g. making the patient aware that they can participate in decision making, acknowledging the role of a family member in the process)
3. <a href="#">Scene Setting</a> : Clinician explains the difference between short-term (lower order/treatment) goals and long-term (higher order/life) goals.
4. <a href="#">Problem identification</a> : Clinician tries to identify the problem(s) using primarily open-ended questions (asks questions in a way that allows patient to tell own story with minimum of interruptions or closed ended questions).
5. <a href="#">Problem identification</a> : Clinician attempts to determine/shows interest in how the problem is affecting patient's lifestyle (work, family, daily activities).
6. <a href="#">Problem identification</a> : Clinician shows interest in exploring the importance of the problem/goal in patient's life (e.g., asks the patient what it means to him/her, 'What is important to you?', 'How do you want your life to be in the future?')
7. <a href="#">Problem identification</a> : Clinician explores/explains additional goals not identified by patient, but relevant to his/her rehabilitation.

8. <a href="#">Solution finding</a> : Initial assessment findings and their relevance to goals are discussed.
9. <a href="#">Solution finding</a> : Ideas on how to identify goals are discussed with examples. (e.g. discussing what is important to the patient in order to formulate relevant goal).
10. <a href="#">Solution finding</a> : Attention is drawn to discrepancies between a person's current, past and desired abilities when identifying/planning goals.
11. <a href="#">Solution finding</a> : Patient's past roles and abilities are considered in the process of setting goals.
12. <a href="#">Solution finding</a> : Treatment goals are considered in the context of other/life goals. (e.g. "and "What are your hopes and dreams?")."
13. <a href="#">Goal setting</a> : The goals are stated in manner consistent with patient/family member's level of understanding.
14. <a href="#">Goal setting</a> : Goals are stated in patient's own words.
15. <a href="#">Information provisions</a> : Clinician explains the rationale behind stated goals and their relevance to the treatment.
16. <a href="#">Information provision</a> : Steps/activities involved in working towards goals are discussed.
17. <a href="#">Problem Solving</a> : Barriers and/or facilitators in working towards goals are discussed.
18. <a href="#">Problem Solving</a> : Strategies to overcome barriers and/or increase facilitators in working towards goals are generated.
19. <a href="#">Regular monitoring</a> : Arrangements are made to review the goals at a future date.
<b>Goal setting related Patient-Centredness</b>
1. Clinician collaborates with patient/family member to establish goals.

2. Clinician incorporates patient's stated concerns in or during exploration of goals.
3. The acceptability of treatment plan/goals is negotiated between patient/family member and the clinicians (Asking the patient's opinion as to whether or not they agree with the decision)
<b>Generic Patient-Centeredness</b>
1. The clinician encourages the patient to expand in discussing his/her concerns (e.g., using various continuers such as "aha", "tell me more", "go on", clarification questions/statements and open ended questions).
2. There is allowance for small talk to put the patient/family member at ease.
3. Clinician acknowledges patient's feelings (e.g. saying "I can see how this would worry you", "Oh, that must be really difficult").
4. Clinician makes effort to determine whether the patient has understood what has been said (e.g. clinician pauses after giving information to allow the patient to react to and absorb it).
5. Information is stated clearly and jargon is explained to the patient/ family member.
6. Clinician encourages and invites patient's input into the decision making process.
7. There is space and encouragement for patient to ask questions.
8. There is space for allowing family members to express their concerns.
9. The preference to take part in the decision (or not) was respected
10. Clinician summarizes what was discussed throughout the meeting

<b>Documentation</b>
1. Clinician documents the patient's goals.
2. The patient/family member was provided with an opportunity/resource to document their goals (e.g. piece of paper, folder, pack, booklet, etc.).

## Appendix E

### Rating Scales

RATING SCALE - PATIENTS					
1	I felt as though staff and I were partners in the process of setting goals.	None of the time	Some of the time	Most of the time	All of the time
2	Staff encouraged me to voice my concerns and ask questions.	None of the time	Some of the time	Most of the time	All of the time
3	Staff listened carefully and responded to my questions in a way I could understand.	None of the time	Some of the time	Most of the time	All of the time
4	I was satisfied with the role I had in setting my goals.	None of the time	Some of the time	Most of the time	All of the time
5	My preference to take part in a decision (or not) was respected.	None of the time	Some of the time	Most of the time	All of the time
6	Overall, I felt I was treated with respect and dignity.	None of the time	Some of the time	Most of the time	All of the time
7	Effort was made to discuss goals that were relevant and meaningful to me.	None of the time	Some of the time	Most of the time	All of the time
8	I was given opportunity to discuss everything I wanted to or, if not, we agreed to discuss at a later time.	None of the time	Some of the time	Most of the time	All of the time
9	I feel I am supported to follow my rehabilitation plan.	Disagree	Mostly disagree	Mostly agree	Agree
10	I am satisfied with the manner in which my treatment plan has been discussed.	Disagree	Mostly disagree	Mostly agree	Agree
11	I am as involved as I want to be in my treatment planning.	Disagree	Mostly disagree	Mostly agree	Agree
12	Staff explained the purpose of the goals set/decisions made.	Disagree	Mostly disagree	Mostly agree	Agree

### RATING SCALE - CARERS

<b>1</b>	I felt my relative was treated with respect and dignity.	None of the time	Some of the time	Most of the time	All of the time
<b>2</b>	I felt involved in my relative's care.	None of the time	Some of the time	Most of the time	All of the time
<b>3</b>	I felt my relative had the opportunity to talk to staff.	None of the time	Some of the time	Most of the time	All of the time
<b>4</b>	I felt I had opportunity to talk to staff about my concerns and ask questions.	None of the time	Some of the time	Most of the time	All of the time
<b>5</b>	I felt we were provided with enough information needed to help in rehabilitation.	None of the time	Some of the time	Most of the time	All of the time
<b>6</b>	I was provided information in a way I could understand.	None of the time	Some of the time	Most of the time	All of the time
<b>7</b>	I felt the goals discussed were relevant to my relative's care.	None of the time	Some of the time	Most of the time	All of the time
<b>8</b>	My preference to take part or not in a decision was respected.	None of the time	Some of the time	Most of the time	All of the time
<b>9</b>	I am satisfied with the manner in which the treatment plan has been discussed.	Disagree	Mostly disagree	Mostly agree	Agree
<b>10</b>	I feel that we can share responsibility for the goals set in the session.	Disagree	Mostly disagree	Mostly agree	Agree
<b>11</b>	I felt staff explained to us the purpose of the goals set/decisions made.	Disagree	Mostly disagree	Mostly agree	Agree



**RATING SCALE - STAFF**

<b>1</b>	I felt as though patient and I were partners in the process of setting goals.	None of the time	Some of the time	Most of the time	All of the time
<b>2</b>	I feel that the patient can share responsibility for the goals set in the session.	None of the time	Some of the time	Most of the time	All of the time
<b>3</b>	I provided information in a way the patient could understand.	None of the time	Some of the time	Most of the time	All of the time
<b>4</b>	I involved the patient in the discussion.	None of the time	Some of the time	Most of the time	All of the time
<b>5</b>	I gave my patient the opportunity to discuss everything they wanted to or, if not, we agreed to discuss at a later time.	None of the time	Some of the time	Most of the time	All of the time
<b>6</b>	In my opinion, goals discussed were relevant to the patient's care	None of the time	Some of the time	Most of the time	All of the time
<b>7</b>	It was relevant to include what matters most to the patient in choosing what to do next.	None of the time	Some of the time	Most of the time	All of the time
<b>8</b>	I am satisfied with the manner in which the treatment plan has been discussed.	None of the time	Some of the time	Most of the time	All of the time
<b>9</b>	I want the patient to be more involved in their treatment planning.	Disagree	Mostly disagree	Mostly agree	Agree
<b>10</b>	I felt supported to include the patient in setting their goals.	Disagree	Mostly disagree	Mostly agree	Agree
<b>11</b>	The role the patient took in the goal setting process was satisfactory/sufficient.	Disagree	Mostly disagree	Mostly agree	Agree

## **Appendix F**

### **Interview Schedules**

#### **Post Pack Evaluation Focus Group – Patients & Carers**

- What were your experiences in using the patient’s goal setting pack?
- What were the helpful and unhelpful aspects of the goal setting pack in helping to set your/your relative’s goals?
- Did you feel you were given opportunity to fully participate in the formulation of your/your relative’s goals?
- Did you feel this pack provided useful information to you for managing your relative’s care? (Carers)
- Did anything surprising come up during this time, positive or negative?
- What suggestions would you make for using this pack to help in setting goals/providing better treatment?

#### **Post Pack Evaluation Focus Group - STAFF**

- What were your experiences in using the patient’s goal setting pack?
- What were the helpful and unhelpful aspects of the goal setting pack?
- How did you manage the change from one form of goal setting to the other?
- How do you think the new way of goal setting (patients centred) impacts the patients?
- Has using the pack helped with sharing the responsibility when setting “unrealistic” goals?
- What suggestion would you make to help improve this pack and make it more ‘user friendly’ for you and patients/family members?

## **Appendix G**

### **Main Sections of the Goal Setting Tool**

















































## Appendix H

### List of Goal Setting Principles (Prescott et al., 2015)

Principle	Definition
Collaborative	Discussion of goals with client
Client-Centred	Focus on goals relevant and important to the client to promote ownership
Measurable	Describes behaviour when goal is reached at end of therapy from the therapist or client perspective
Realistic	Use of therapist expertise to set achievable goals taking into consideration individual client strengths and limitations
Proximal goals	Goals broken down into defined sub-goals (for example, fortnightly short-term goals)
Feasible	Able to be implemented in clinical practice (for example, able to be completed within appropriate time frames)
Motivational	Focus on increasing motivation and self-efficacy based on factors such as saliency of goals
Therapist-driven	Goals developed based on therapist assessment of the client without the client being involved in the goal setting process
Family involvement	Family members consulted in setting client goals
Domain-specific	Goals set within defined impairment or functional areas relevant to the service
Linked to therapy	Establishment of a clear link between therapeutic intervention and goals set
Education	Education about goal setting provided (for example detailed written information re the purpose and process of goal setting)
Metacognitive	Use of intervention techniques to enable the client to independently set goals and monitor progress in relation to goals
Flexible	The ability to modify goals with changing client priorities/needs
Experiential learning	Client involvement in the goal -setting process enables the client to learn about the rehabilitation process

